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**TRANSCRIPT OF PROCEEDINGS**

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O/N H-985236

**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**

**ADELAIDE**

**10.00 AM, MONDAY, 18 MARCH 2019**

**Continued from 22.2.19**

**DAY 10**

**MR P. GRAY QC, Counsel Assisting, appears with DR T. McEVOY QC, MR P.  
BOLSTER, MS E. BERGIN, MS B. HUTCHINS and MS E. HILL**

COMMISSIONER TRACEY: Yes, Dr McEvoy.

DR McEVOY: Commissioners, this hearing is about care and supports delivered to older people in their own homes. It's scheduled to run for five days this week.

5 During this time, we propose to call more than 20 witnesses, some of whom will be called together, including in a panel format. We may invite the Royal Commission to make findings at the end of this hearing and it's my intention to make a closing address on Friday afternoon. But first it is important to provide some context. This morning, I will outline some of the key features of the current arrangements under  
10 which some people can receive care and support in their home, as they get older.

In particular, I will describe the main programs available for in-home support and care, explain how those programs can be accessed, describe at a relatively high level the available services and funding arrangements and identify some issues relevant to  
15 the quality and safety of home care. I will also draw your attention to some of the issues we will explore over the course of the week. However, first, I should make some observations regarding home care arising from the evidence already before the Royal Commission. The evidence indicates that most people want to remain in their own homes as they age, and this is consistent with common experience. In our last  
20 hearing, Mr Paul Versteeg of the Combined Pensioners and Superannuants Association – the CPSA – told the Royal Commission that a CPSA survey conducted in 2015 indicated that 95 per cent of people wanted to receive care in their own home.

25 Professor John McCallum of National Seniors Australia gave evidence to a similar effect. People generally want to receive any care or support required in their homes and not in a residential facility. The Royal Commission also heard evidence in February about significant unmet demand for home care packages. You were told that demand for in-home care was growing at a faster rate than the demand for  
30 residential care. Ms Janet Anderson, the new Commissioner of the Australian Aged Care Quality & Safety Commission told you that one of the most important issues for regulation of the quality and safety of the aged care system over the next 20 years will be the increased demand for home services.

35 In any consideration of aged care services provided in a person's home, it is necessary to acknowledge the significant contribution made by informal carers. These are partners, children, very often daughters, grandchildren, nieces, nephews, neighbours and friends, all caring and supporting older Australians. In 2015 you will recall that Deloitte estimated that 1.9 billion hours were provided by informal carers.  
40 The replacement value for these services, as estimated by Deloitte, would be \$60.3 billion. That is to say approximately 3.8 per cent of Australian GDP.

Ms Sue Elderton of Carers Australia told you in February that aged care comprises a substantial portion of that \$60.3 billion. Ms Elderton also predicted that we are  
45 approaching a tipping point where there are more people needing care than are available to provide informal care of this kind. There is evidence to suggest that

responsibility for aged care is historically more likely to have fallen on women. This may also be thought to accord with common experience. Ms Justine Boland of the Australian Bureau of Statistics told the Royal Commission at the February hearing that, in the 64 to 74 age range, approximately 17.5 per cent of all females are  
5 providing unpaid assistance to a person with a disability, age-related problem or a health condition. The significant contribution of women to aged care in the home is also reflected in statistics relating to personal care workers. Ms Melissa Coad from United Voice told you that the average care worker is a woman in her 50s.

10 Over the last few weeks, the Royal Commission has held roundtables with a number of individuals to talk in a less formal setting about issues in the delivery of home care and dementia services. Commissioners, you have also held community forums in Bankstown and Wollongong in New South Wales and Bendigo in Victoria to hear  
15 directly from members of the community about their concerns. Those forums have been enormously helpful to our preparations and we thank those communities for their support and their willingness to contribute even when the topics are so confronting and deeply personal. You have also undertaken site visits in a number of locations in New South Wales and Victoria and you have met directly with workers,  
20 with families and with those in receipt of care. We know you will continue to take opportunities to engage with the broader community over the course of this year. This will not be the only hearing dealing with care and supports delivered in the home.

25 Later hearings will deal with particular challenges for groups in our community in this respect, including care for Aboriginal and Torres Strait Islander people and those living in rural and remote areas as well as broader issues of funding and innovation. But before we can consider the future of aged care in the home and think about how that might and should look, we need to examine and understand how aged care services are currently being provided and delivered in the home. In this hearing, we  
30 intend to explore the perspective and experience of people in home care, including people seeking or receiving aged care services in their home or their family members, people who work as personal care workers in various places and circumstances, a home care provider, a witness offering valuable insights on home care from the perspective of people with culturally and linguistically diverse  
35 backgrounds living and working in aged care, those with academic and policy perspectives and also witnesses from the Commonwealth Department of Health.

Through these witnesses, a range of issues relating to health care in the home will be canvassed. These issues will include accessibility, quality and safety, the interface  
40 between aged care in the home and other care, challenges in service provision, administration fees, dignity and respect, the regulatory framework as it applies to aged care in the home, and how some aspects of the aged care system are administered by the Commonwealth. We expect you will hear evidence that highlights aspects of the quality of care provided by many home care providers. You  
45 will also hear evidence about lesser quality care and the resulting distress and trauma

for recipients and their families. It is a full program and we may seek your indulgence to extend sitting hours slightly if that becomes necessary.

5 Before turning to the key features of the current arrangements for the delivery of home care, I should provide a quick update on the public submissions that have been received by the Royal Commission to date. We have now received 1704 public submissions. We invite others to come forward. This can be done through the Royal Commission's website, by letter or by telephone. All of the relevant details are on the Royal Commission's website. Submissions can be made anonymously should  
10 people wish to do so. We have received voluntary submissions from 99 of the top 100 approved providers and have taken steps to obtain information from the remaining provider in that group. Submissions continue to be received from the smaller providers.

15 Can I turn now, Commissioners, to the main programs for in-home care. Commonwealth-funded home care is mainly comprised of two mainstream programs: the Commonwealth Home Support Program, often referred to as CHSP, and home care packages often referred to as HCP. There are also two veterans programs which we will cover in later hearings. The Commonwealth Home Support  
20 Program is an entry level program, intended to provide ongoing or short term care and support services such as help with housework, personal care, meals, and food preparation, transport, shopping, allied health, social support and planned respite. As the first tier in the continuum of aged care services, the CHSP is designed to help people stay in their homes as long as they can and wish to do so, maximising  
25 independence and social connectedness and enhancing wellbeing and quality of life.

Home support is largely based on a home and community care program which dates back to the mid-1980s. Its operation had been to some extent governed by the Home and Community Care Act 1985 of the Commonwealth. The CHSP commenced in  
30 July 2015 and combined four former community aged care programs which included the home and community care program, often referred to as the HACC, which had previously been managed by State and Territory governments, and a number of other programs providing respite for carers, day therapy services and assistance for older homeless people, managed by the Commonwealth.

35 HACC services in Victoria and Western Australia joined the program later than other jurisdictions; Victoria, in July 2016 and Western Australia in July 2018. In 2017/18 the CHSP provided support to 783,043 people. In Western Australia, an additional 75,116 people received services through the jointly funded home and community  
40 care program of whom 64,491 were aged 65 years and over, or 50 years and over in the case of Aboriginal and Torres Strait Islander people. That means a total of 847,534 older people were supported by CHSP in 2017/18. Approximately 43 per cent of those receiving CHSP services are aged over 85 years, and approximately 20 per cent are from culturally and linguistically diverse backgrounds. In the 2017/2018  
45 year this program was funded by more than \$2 billion.

The CHSP is a grants program administered under the *Public Governance, Performance and Accountability Act 2013* of the Commonwealth. Its operation is guided by a program manual, grants guidelines and a standard suite of Commonwealth contractual arrangements. The Royal Commission will hear  
5 evidence this week about the monitoring of the CHSP. If I can turn to Commonwealth home care packages. These packages are the second tier in the aged care continuum, positioned between the CHSP and residential aged care. HCPs are designed to meet more complex care needs at home, and to assist people who would be otherwise eligible for residential aged care to remain living in the community.  
10 Home care developed in the 1990s as an alternative to residential care. Delivering many similar services to home support, the program allows for a package of care to be tailored to the person receiving care.

There are now four levels of packages which can include personal care, support  
15 services, and nursing and allied health clinical services. This program is more comprehensive and tailored than the CHSP. At 30 June 2018, 91,847 people had services provided under a home care package. That is, about 10 per cent of the number of people accessing services under the CHSP. In 2011 the Productivity  
20 Commission recommended reforms to replace the discrete packages of aged care that then existed across residential and community aged care with a flexible and integrated system of care entitlements to be known as the aged care system. In partial response, in 2013 the Commonwealth Government moved from what was essentially a three level care program comprising the community aged care package, referred to as the CACP, which is the needs equivalent to new level 2, and extended  
25 aged care at home, often referred to as EACH, which is the needs equivalent to current level 4.

Each included a second component which provided a supplement for living with  
30 dementia or cognition challenges. That was known as EACHD and was also for needs equivalent to current level 4. At the same time, the government introduced a new philosophy of care referred to as Consumer Directed Care. In 2015, the government announced that from July 2018 the CHSP and home care packages would be combined to create a single program offering care and support in the home. That has not occurred and implementation of a combined program has been deferred  
35 until at least 2020. From 20 February 2017 all packages have been assigned to the person receiving care, enabling that person to select their own provider and change providers if they choose to do so. People with a package receive a budget and are enabled to make decisions on how package funding can be expended.

40 Commissioners, you heard evidence in February about some problems with home care packages. Just to recap some of that evidence briefly, a number of witnesses, including Mr Yates of COTA Australia thinks that there is an absence of quality information to help guide decisions on how package fundings can be expended. Dr Bartone of the AMA told you that too many Australians are waiting for a package.  
45 Even if more packages were assigned tomorrow, there may not be enough providers to meet demand. Craig Gear from OPAN told you that OPAN receives 230 to 240 calls a week. Callers are telling OPAN that wait times are just too long, or the level

of support that they're getting is not meeting their needs. OPAN says that it is equating to 18 to 24 months waiting time. Claerwen Little of Uniting Care Australia told you that HCP funds available to people in remote communities are often consumed by transport due to the distance, leaving less funds for direct service provision.

Maree McCabe of Dementia Australia told you that people often get an inappropriate assessment for a HCP which leads to their care being compromised, resulting in premature entry into residential care and increased presentations to hospitals. Sue Elderton of Carers Australia told you of complaints about fees and charges. Nicolas Mersiades of Catholic Health Australia told you that the policy which allows consumers to spend their HCP budget has led to the practical problem of thousands of taxpayer dollars being left in the custody of service providers not being spent. Questions were also raised about access to respite care to support the work of unpaid carers.

Commissioners, let me turn to access issues in relation to CHSP and HCP. Access to the CHSP requires assessment by a Regional Assessment Service which is generally arranged through My Aged Care. The assessment is usually undertaken on a face-to-face basis. The Regional Assessment Service uses a national screening and assessment form to determine a person's care needs. The process of assessment involves developing a My Aged Care support plan and referral to a list of service providers. There are almost 1500 providers across Australia. The target population for the CHSP is people aged 65 years and older, or 50 years and older for Aboriginal and Torres Strait Islander people, and people aged 50 years and older or 45 years and older for Aboriginal and Torres Strait Islander people who are prematurely aged, on a low income and homeless or at risk of homelessness. The CHSP is not means-tested but some financial contribution from that person being supported may be required.

Turning to access to home care packages, this access requires assessment by an Aged Care Assessment Team, sometimes called an ACAT, known in Victoria as an Aged Care Assessment Service or an ACAS. That assessment is typically organised through My Aged Care. You have already heard evidence about concerns with My Aged Care. The Royal Commission has also heard complaints about My Aged Care through public submissions, roundtables and community forums. These complaints focus on issues about the fitness for purpose of aspects of My Aged Care, such as its centralised allocation system and remote management relying largely on digital platforms.

ACAT assessors are funded by the Commonwealth but coordinated by the individual states and territories. The assessment aims to determine what level of care is required against the four levels currently available and to determine what priority they should be given: medium or high. Level 1 being for people with lower care needs through to level 4 which supports people with high care needs. Individuals approved for a package are placed on a national queue until a package becomes available and is assigned to them. The number of packages offered at each of the

four levels is capped by the government. Services are currently delivered by almost 900 approved providers, providers who are approved under the *Aged Care Act*.

5 In the 2017/2018 financial year, a participant would receive \$8271 for a level 1  
package, \$15,045 for a level 2 package, \$33,076 for a level 3 package and \$50,286  
for a level 4 package. Fees and charges can be payable by those receiving a home  
care package including a basic daily fee and these can increase the total package  
funding available. Unlike the CHSP, an income test determines the care fee that can  
10 apply. In addition to the cap on the number of places, the proportion of packages by  
level is also set. As at June 2018, five per cent of all packages were at level 1. 56  
per cent were at level 2. 14 per cent at level 3, and 25 per cent at level 4. Around  
175 packages are released a week. While there were 91,847 people accessing  
packages at 30 June 2018, the Royal Commission will hear that as at 28 February  
15 2019, there were 128,495 people who were not receiving any home care packages or  
the package level of care they had been approved for.

The average waiting time for level 4 care in 2017/18 financial year was 22 months.  
Data released last week suggests that the number of people accessing packages fell  
20 between June and September 2018. There were 1201 fewer people accessing  
packages at 30 September 2018. The aim of the national prioritization queue is that  
there be a consistent national approach to prioritization of access to services. The  
Commonwealth's guide to priority for home care services that medium priority  
should apply to the majority of clients approved for home care, and that high priority  
should only apply to a small number of clients, for example, when they have a carer  
25 at risk or a crisis point.

Current Department of Health data suggests that a person will be waiting for 12-plus  
months for a level 2, 3 or 4 package. It is not clear what 12-plus months means. The  
30 Royal Commission has received public submissions that suggest 12-plus months  
might mean up to 24 months. Commissioners, you will recall the evidence in  
February from Ms Warrenner whose husband waited approximately 15 months to be  
offered a level 2 package, which was less than the level 3 package he had been  
approved for. At the time Ms Warrenner gave evidence, despite being told in 2017  
that the wait would be about three months, her husband was still waiting to receive  
35 the level of care he was assessed as needing.

The Department of Health, through My Aged Care, did not communicate with Ms  
Warrenner that this timeframe would not be met. The data suggests that this  
experience is not uncommon. As at 30 June 2018, there were 1465 people waiting  
40 for a level 1 package. There were 33,265 people waiting for a level 2 package.  
There were 41,937 people waiting for a level 3 package, and there were 50,065  
people waiting for a level 4 package. To put that in perspective, there are more than  
twice as many people waiting for a level 4 package than are actually receiving one.  
This issue was identified by Mr Tune, AO PSM, in his 2017 Legislated Review of  
45 Aged Care. Mr Tune made a number of recommendations associated with  
addressing the disproportionate wait times and demand, especially increasing access  
to high level home care packages.

Since the announcement of this Royal Commission, and since the publication of those figures, the Commonwealth Government has announced an additional 20,000 HCPs. On 17 December 2018, the Minister for health, the Honourable Greg Hunt MP announced the release of 5000 level 3 packages and 5000 level 4 packages which were to be rolled out in early January 2019. On 10 February 2019, the government, that is the Prime Minister, Mr Hunt, and the Minister for Aged Care, the Honourable Ken Wyatt, AM MP, announced a further \$282.4 million described as funding a further 10,000 packages across all four levels of HCP. At the February hearing of the Royal Commission, Mr Ian Yates of COTA Australia suggested that approximately 30,000 high-level HCP places are required if home care packages are to be allocated in three months or less, and that such an increase would cost several billion dollars, a proposition that the Secretary for the Department of Health accepted as being in the ballpark in her evidence to the Royal Commission.

That may be a conservative estimate given at 30 June 2018, 92,002 people were waiting for a level 3 or 4 package. I should note that in his written submission, after the February hearing, that Mr Yates clarified that his view is that 30,000 additional high level home care packages will not clear the current queues and has suggested that the more critical issue is that people should not have to wait more than three months for a package. He directed our attention to his oral evidence where he said that, “The experts don’t know how many packages you have to put into the system to meet that three months target”. At the same hearing Professor John McCallum from National Seniors Australia referred to a study which showed that home care can reduce the risk of preventable death and preventable hospital admission. That study shows that if you spend six months waiting for an HCP you are 10 times more likely to go into residential care.

While many people are able to access interim funding either by the CHSP or by the offer of a lower level of HCP that support will often need to be supplemented by private funds or by family members, or both. During this week, you will hear direct evidence about the impact of wait times. Mr Tune recommended that a level 5 package be introduced to allow people with higher care needs to stay at home longer. It is a recommendation which was repeated by Craig Gear of OPAN last month. This recommendation has not been implemented. However, even if higher level packages are introduced, or more packages are released, the question remains whether there are sufficient providers and staff to meet the demand.

Ms Patricia Sparrow from Aged and Community Services Australia gave evidence that her members have the capacity to take on more HCPs but that there is certainly no funding. Dr Bartone of the AMA was concerned providers would not be able to meet increased demand. The Royal Commission may wish to consider the capacity of providers in due course. Commissioners, that may be a convenient time to move on to services and funding. As at 30 June 2018, in-home care services were provided by 1456 CHSP-funded organisations, and 873 approved providers of home care. These providers are spread around Australia. For example, there are 29 in the Australian Capital Territory and 783 in New South Wales. The number of providers increased by 17 per cent between 30 September 2017 and 30 September 2018. Let

me deal with the mechanism for approval to be a home care provider. Division 8 of the *Aged Care Act* sets out the approval process for a home care provider applicant.

5 In summary, to be approved as a provider an organisation must be incorporated and be able to demonstrate it is suitable to provide aged care services. The department is required to consider the following matters in relation to each applicant: experience in providing aged care or other relevant forms of care, demonstrated understanding of its responsibilities as a provider, the systems the applicant has or proposes to have in place to meet its responsibilities as a provider, a record of financial management and the methods that the applicant uses or proposes to use in order to ensure sound financial management, where applicable, previous conduct as a provider, and any other matters specified in the approved provider principles.

15 The same requirements do not apply to those providers delivering home support services. They do not go through an approval process. Let me deal with the subsidies in relation to home care packages. The home care subsidy is a payment under the *Aged Care Act* and the Subsidy Principles 2014 to approved providers for providing home care to people that are home care recipients. It is not paid to the person receiving the care. It can only be paid once a person enters into a home care agreement with a provider. The amount of the home care subsidy includes the basic subsidy for the package level, plus any supplement for oxygen, veterans, enteral feeding, dementia and cognition, viability, hardship or a top-up supplement, less any reductions based on the person's means test.

25 Any unspent home care amount, which may include a home care subsidy and fees paid by a person who is a care recipient, must be dealt with by an approved provider in accordance with the User Rights Principles 2014. Where the person changes providers the unspent amount is to be transferred to the new provider within 70 calendar days. Where the person leaves care or dies, the unspent amount paid by the person must be returned to them or their estate and the unspent subsidy will be deducted from future claims. Part 4 of the Accountability Principles 2014 set out the reporting requirements for approved requirements for providers of home care under the *Aged Care Act*. There is no performance reporting required for home care packages although providers are obligated to participate in the aged care workforce census.

35 Providers are instead required to deliver a range of documents to the person receiving care in accordance with the User Rights Principles. These include a home care agreement. This must be offered to each person with a package. The agreement records the administrative details of the service delivery relationship. They must also have a written care plan. This must be provided to the person within 14 calendar days of entering into a home care agreement, and it should set out the day-to-day services that will be provided and how they will be delivered. There must also be an individualised budget. This must be provided to the person with the care plan and it should record the funds available in their package including government subsidies and supplements, and fees or contributions paid by them and how they will be used.

If the person requests a review, or their care needs change, the budget must be reviewed. There must also be a monthly statement. It must be provided to the person each month, outlining the available funds and expenditure for the package in the relevant month. The Royal Commission will hear evidence that the approval regime for home care approved provider applicants is under-resourced and that it may not be sufficiently robust to protect people receiving care and their families. Significant public funds are provided to approved providers and the community expects both high standards of conduct in return, and a robust approval and audit system.

Turning to Commonwealth Home Support Program funding. As mentioned earlier, CHSP is funded by grants. The grants provide for block funding of services and are paid to providers quarterly in advance of services being delivered. The funding agreement sets out the requirements for how funds are spent, including the service types or subprograms that are to be delivered by hour or unit and reporting. There are two main types of reports. An annual financial acquittal report in which the provider is required to make a financial declaration that funds have been spent in accordance with the funding agreement. The second type of report is a bi-annual performance report which covers the actual services delivered by a person and any fees collected.

A client contribution framework outlines the principles service providers should adopt in settling and implementing their own client contribution policy. The intention is that those who can afford to contribute do so, while protecting the most vulnerable. In 2016/17 people receiving home support services contributed \$204 million. This increased to approximately \$220 million in 2017/18 with contributions made by around two-thirds of CHSP clients. Let me deal with fees and charges and the transparency and comparability of these. The level of fees charged by providers for case management and administration fees for home care packages is a recurring complaint among the people contacting the Commission. You will hear evidence of case management and administration fees being charged at varying rates, and some at more than 50 per cent of the package value.

Why administrative charges can be so high requires further examination. At the February hearing, the Aged Care Complaints and Quality Commissioner gave evidence that the five most common categories of complaints in relation to home care for the 2017/18 year were fees and charges, lack of consultation or communication, communications about fees and charges, financial statements and consistent client care and coordination. Commissioners, you will note that three of the top five categories of complaints relate to fees and charges. The need for transparency and comparability of case management and administration fees was supported in the Tune report. You will hear evidence from a recipient of aged care who has battled to navigate and understand the fees, charges and invoices from a number of providers over a period of eight years. You will also hear evidence about how where a person lives or a person's language may affect the fees charged to them.

A new pricing transparency regime is due to commence between April and July 2019. Providers will be required to publish pricing information in a standard format. We will explore that with witnesses. You will recall that the Secretary of the Department of Health told you in February that only 70 per cent of providers were  
5 compliant as at January 2019 with the current requirement to publish their prices on My Aged Care. Ms Beauchamp said they were following up the 38 per cent, and we will propose to seek further details about that follow-up. At the February hearing you heard evidence from Nicolas Mersiades from Catholic Health Australia to the effect that policy which allows consumers to spend their HCP budget has led to the  
10 practical problem of thousands of taxpayer dollars being in the custody of a service provider but not being spent.

People on average are under-spending approximately \$6,000 a year. This money, which is approaching \$400 million, sits with providers and effectively lays idle. This  
15 may be an unhelpful consequence of person-centred care that is impacting on the provision of care. In this hearing, Commissioners, you will hear further evidence about the underspend in home care packages and what happens to the interest earned from that money. You will also hear evidence of under-spending in CHSP. Let me say something about the distribution of resources. Currently, 67 per cent of  
20 Australians receiving aged care services receive Commonwealth-funded aged care in their home. That is about one million people. Despite servicing two-thirds of people receiving aged care, only 27 per cent of Commonwealth funding is allocated to home care.

25 While home care is where most people want to be, and where most people who require aged care services and supports actually are, home care is not where the majority of Commonwealth funding is going. Is there a better approach, one might ask. Let me turn finally to address quality and safety in home care. The first issue is one of transparency of quality of care and client satisfaction. In the first Adelaide  
30 hearing, the Aged Care Quality and Complaints Commissioner, Janet Anderson, gave evidence that consumer experience reports which are currently conducted in residential care facilities, will be expanded to include the home care environment.

There are significantly lower numbers of complaints to the Commissioner in relation  
35 to home care than residential care. In 2017/18 there were 4315 complaints made to the Aged Care Complaint Commissioner in relation to residential care. In the same year, there were 1464 complaints to the Commissioner about home and community care. The number of complaints needs to be seen in the context that there are about five times more people being supported in home and the community than in  
40 residential facilities. Is this because people are happier with home care than residential care? Is it because the quality of care is better in home care than in residential care, or is it perhaps because there is more scope for complaints to be managed and received by a provider, instead of being escalated to the Commissioner?

45 Or is it because recipients feel more vulnerable and exposed in their own homes in making a complaint? Or is it simply that people do not know who to complain to? We will ask these questions of witnesses from a variety of backgrounds during the

week ahead. We will continue to analyse and compare data from a variety of sources about complaint numbers and management. Commissioners, you will remember Professor Parker's evidence in February about a pilot program for quality indicators for use in Australian home care package services that identify two tools. They are  
5 the Adult Social Care Outcomes Toolkit, a four level, self-completion tool, ASCOT-SCT4 and goal attainment scaling, GAS.

Professor Parker said that no further action had been taken following the pilot. The Australian College of Nursing recommended that a minimum national quality  
10 indicators program for residential aged care and home care packages services should be available to enable the public to be better informed about provider performance. Let me deal with regulation. During the February hearing, the Commission heard conflicting evidence of what exactly is monitored in the provision of home care services. Mr Versteegen, from the CPSA, claimed that the CHSP is not monitored for  
15 safety although HCPs are. Ms Sparrow said that CHSP does not fall within the *Aged Care Act*, and that different processes apply for compliance.

The Aged Care Quality and Complaints Commissioner accepted that in her view the current oversight of quality and safety in home care is inadequate. The current  
20 system for registration and regulation for home care package services includes the following steps. First, approval to be a provider. Secondly, an initial review, possibly in conjunction with a self-assessment against the home care standards. Three, quality reviews conducted at least every three years for most providers. The Aged Care Quality and Safety Commission Rules 2018 require the Commissioner to  
25 give written notice specifying the day or days on which the site visits to the provider is to be conducted. And fourthly, an assessment contact with or without notice.

Janet Anderson gave evidence in February that the standards most commonly found not met by approved providers in the 2017/2018 financial year were regulatory  
30 compliance, service user reassessment, care plan development and delivery, risk management, information management systems. It is interesting to compare this list to the equivalent list for residential aged care where failure of clinical care was number 2 and 3 of the top five areas found to be non-compliant. By contrast, the standards not met by home care providers appear to relate largely to administration  
35 and record-keeping and not direct care. It might fairly be asked why that is so. It is entirely appropriate that the regulatory framework includes record-keeping. However, given the number of people receiving home care services, the question must be asked: how well is the quality and safety of care in the home being monitored and reviewed or, indeed, is the quality and safety of care in the home  
40 being monitored and reviewed?

Under the current system there is no requirement for personal care workers providing services under the CHSP or the HCP to be registered and workers are not externally regulated. The only direct safety measure relating to the selection of personal care  
45 workers is that the *Aged Care Act* 1997 requires approved providers to ensure staff have a national police certificate in compliance with the Accountability Principles 2014. There is no requirement to specify personal care workers or any staff when

applying to become an approved provider. Like CHSP, HCP police checks are subject to review every three years.

5 Is this appropriate and adequate protection for vulnerable members of our  
community, one might ask. There is no doubt that regulation of quality and safety in  
the home presents immediate challenges. People receiving care are not congregated  
in the one place as with residential care. The services they may be receiving range  
from routine non-clinical care services such as gardening or cleaning to complex  
10 nursing care. The workforce who delivers these services have a wide range of  
qualifications and skills, however, it may become clear to you by the end of the week  
that more could be done in this regard. Let me say something about providers who  
have been sanctioned. Only five home care providers have ever been sanctioned by  
the regulator, which is currently the Department of Health.

15 Commissioners, you will hear evidence from two of these five providers. However,  
you will not hear stories of substandard clinical care for recipients of home care, nor  
even stories of systemic complaints by consumers. Instead, you will hear that in both  
instances, small home care providers both run by registered nurses with a stated  
passion for aged care were approved to provide home care services by the  
20 department. Shortly afterwards, sanctions were imposed for reasons relating to  
administration and record-keeping. In both cases, the providers, as part of the  
sanction process, were required to appoint private administrators and advisors at  
significant costs to the providers. You will hear about the absence of regulation of  
administrators and advisors in this context.

25 We do not suggest the administration and record-keeping are not appropriate features  
of any aged care system. Bad record-keeping can lead to bad clinical care. For  
example, if it impedes continuity of care, or frustrates delivery of coordinated and  
planned care. However, we will be asking whether the regulatory approach is  
30 sufficiently directed to client care and if the community can have confidence that  
regulation is effective and does safeguard vulnerable members of our community.  
Commissioners, challenges for the aged care workforce was a consistent and  
pervasive theme during the February hearing. That is the final issue I wish to  
address this morning.

35 In terms of workforce issues, you have heard evidence about the high turnover of  
staff in home care, the lack of a mandated training regime for personal care workers  
with no clear career pathways, and how personal care workers' wages do not amount  
very often to a living wages, and that registered nurses are paid less in aged care than  
40 their colleagues in the acute sector. In the week ahead you will hear directly from  
personal care workers. They will tell the Royal Commission of the issues that  
concern them, including the continuity and stability of work, working in isolation,  
including training and support, concerns about work, health and safety, and other  
such matters.

45 Commissioners, as I said earlier, we have a full program for this week. Unless you  
have further questions, Ms Bergin will call the first witness.

COMMISSIONER TRACEY: Thank you, Dr McEvoy. Yes, Ms Bergin.

MS BERGIN: I call Lynda Henderson.

5

<LYNDA HENDERSON, AFFIRMED

[10.51 am]

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<EXAMINATION-IN-CHIEF BY MS BERGIN

MS BERGIN: Would you please bring up document WIT.0072.0001.0001. Ms Henderson, you should have a copy of a statement in front of you. If you could review that statement and advise whether you are content with its contents.

15

MS HENDERSON: I would like to inform the court, thank you counsel, that I have made an error in the number of years that my – the person I support has been receiving a package. I prepared this submission at very short notice, and I am a full-time care partner of this person who has fairly advancing dementia and it was only when I noticed the reply of one of the providers that I realised I had made that error, so - - -

20

MS BERGIN: Thank you, Ms Henderson. Was there a particular edit you wanted to make to a paragraph of your statement?

25

MS HENDERSON: Yes, indeed. Just one moment, please. This applies particularly to paragraph 43 because the implications of the costs changed considerably, if it's a matter of four and a half years, rather than three. The other paragraphs that are incorrect, I'm sorry, are number 31. That should read "late in 2013." Paragraph 34, at the end of the first line, it should read, "This was five years ago", not four. Paragraph 41, in April 2014, not '15. In paragraph 43, perhaps I can come back to that, but the total there would be roughly \$80,000 rather than 58,000 of which 11,000 would have been from Veda's pension and about 47,000 on case management. Paragraph 44 should read at the end instead of April 2015, it should read 2014. Paragraph 47, her symptoms started to change in 2014, not '15. Paragraph 56, in four years. Paragraph 60, halfway through the paragraph, after three years, not two. Paragraph 62, it took me four years to be able to visit the facility, not three. Paragraph 65, another two years rather than after another year. Paragraph 69 - - -

30

35

MS BERGIN: Could I just pause you there, please, Ms Henderson.

MS HENDERSON: Yes.

40

MS BERGIN: Paragraph 65, what was the edit to that paragraph?

MS HENDERSON: Sorry. “After another two years”, rather than “after another year”.

MS BERGIN: Thank you.

5

MS HENDERSON: And paragraph 69, an excellent team for much of the four and a half years at home, rather than three. And that is all, with my apologies. Sorry, yes, that’s all.

10 MS BERGIN: Thank you, Ms Henderson. So subject to those edits, are the contents true and correct to the best of your knowledge and belief?

MS HENDERSON: Yes, they are.

15 MS BERGIN: I tender the statement of Lynda Henderson document WIT.0072.0001.0001 as amended orally by Ms Henderson this morning.

COMMISSIONER TRACEY: The statement of Lynda Henderson dated 14 March 2019 will be exhibit 2.01.

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**EXHIBIT #2.01 STATEMENT OF LYNDA HENDERSON DATED 14/03/2019  
(WIT.0072.0001.0001)**

25

MS BERGIN: Now, Ms Henderson, what is your current role in the aged care sector?

30 MS HENDERSON: My current role is mainly as an informal care partner to someone with whom I have lived for 13 years. I am also an advocate for Dementia Australia, and my partner is a member of Dementia Alliance International which is a global organisation of people living with dementia, advocating for their rights, and I’m a supporter of that organisation.

35 MS BERGIN: And are you also a recipient?

MS HENDERSON: I am also a recipient – a recent recipient of the Commonwealth Home Support Program. I live with a spinal disability and have for 28 years, and I’m finding that I need to do that, get some support for myself.

40

MS BERGIN: You mentioned you are an informal carer to Ms Meneghetti.

MS HENDERSON: Yes.

45 MS BERGIN: Have long have you known Ms Meneghetti?

MS HENDERSON: 13 years.

MS BERGIN: When was Ms Meneghetti first diagnosed with dementia?

MS HENDERSON: In 2012, in September.

5 MS BERGIN: What type of dementia was Ms Meneghetti diagnosed with?

MS HENDERSON: Veda has a rare form of frontotemporal dementia. It's one of the three variants – language variations of frontotemporal dementia, and hers is called the logopenic variant, and the consequence of that is that she is losing verbal, written language and some comprehension, and cannot read any longer either.

10

MS BERGIN: So I think you used the technical terms in your statement. What are the technical terms for her diagnosis?

15 MS HENDERSON: Frontotemporal dementia/primary progressive aphasia/logopenic variant, to make it short, PPA-L.

MS BERGIN: How was it that Ms Meneghetti was first diagnosed with dementia?

20 MS HENDERSON: The actual occurrence was when I noticed that she was saying the opposite of what she meant, which to me was quite significant. A previous partner of mine had had a series of TIAs, small bleeds on the brain, and at one point she started speaking backwards. So I was probably more alert to these things than many other people. However, with hindsight, both myself, friends who have known her for much longer than me and her family can see that there were signs a long time before that.

25

MS BERGIN: So when you say there was – you observed that what she was saying wasn't quite what she meant - - -

30

MS HENDERSON: Yes.

MS BERGIN: Could you give the Commission some additional examples?

35 MS HENDERSON: Yes, certainly. This particular occasion, it was a winter's day and Veda said "It's getting hot, isn't it". And we looked, and then the same thing happened again later and the same thing happened again the next day. So she was starting to say literally the opposite of what she meant and that caused a bit of confusion when people would say, "Would you like this?" "No", and then, "Yes I want it." So that was a very obvious sign. Her speech had been more and more hesitant over time. Her short-term memory was being affected. That was also obvious. But we weren't certain whether it was a language issue or a psychological issue.

40

45 MS BERGIN: So when you mentioned Veda – do you mind if he call her Veda?

MS HENDERSON: No, please do.

MS BERGIN: When you mentioned that Veda – her technical diagnosis was primary and progressive aphasia, is a difficulty with communication one of the symptoms?

5 MS HENDERSON: Absolutely. It's one of the key symptoms.

MS BERGIN: How did you and Veda come to terms with her diagnosis?

10 MS HENDERSON: With great difficulty. And I think we still have difficulty in coming to terms with it. I think for anybody who is diagnosed with a terminal condition – and all dementias other than the one associated with alcoholism, which may be reversed, are all terminal, and to have that diagnosis when you're young and looking forward to retiring and, in my case, at the height of my career, it's the end of life, as you know it, until you get to the point where you can see that life does go on  
15 in the meantime and we're all going to die anyway. So I hope that answers your question.

MS BERGIN: How have you observed Veda's condition change over time since she was first diagnosed?  
20

MS HENDERSON: We have a number of friends who live with dementia. We have made a lot of good friends over these last six years. I think that every person that we have met has gone through the deepest and darkest depression at some point. In Veda's case, her reaction was very matter of fact, "Well, at least I know what's  
25 wrong now". And I think for many people living with dementia, it is finally a relief to know what's happening, "I'm not going crazy. I'm not having a nervous breakdown. I don't have a brain tumour." That's – that's a relief. There's an explanation for symptoms that often are very confusing to people, and in Veda's case, she took it on the chin, and basically said to me, "Just don't lock me up in an  
30 place with old people. I couldn't stand that."

She loves older people but she has a very different lifestyle. She's a retired rock musician, and she is very fit physically and very lively, normally. And she also said, though, "You don't have to come and visit me if I no longer recognise you". So I  
35 think that this was immediately after her diagnosis, her very first diagnosis of PPA before she knew exactly what variant. And I think that sums up how she approaches it. However, as time goes on, and Veda has been diagnosed now for six years, she retains a lot of insight into what's happening with her, and it's very painful and tragic in that she is well aware of things that she can't do, that she used to be able to do,  
40 and she grieves greatly. And I suppose from my point of view, there are so many moments where you see a change and you know that that's going to become the norm in maybe a month, three months, a year, maybe even next week, that these little signs of things that are changing.

45 And so I think most of us live with what psychologists term anticipatory grief. But in the meantime we have to keep on living and doing what we need to do.

MS BERGIN: So you mentioned that one of the first signs was a misuse of certain words such as it's getting warm, isn't it, during winter. That was at the start of Veda's diagnosis - - -

5 MS HENDERSON: Yes.

MS BERGIN: - - - from what you said about 13 years ago.

MS HENDERSON: Yes, that's right.

10

MS BERGIN: And how old was she at that time?

MS HENDERSON: 61.

15 MS BERGIN: So at the current time how old is Veda?

MS HENDERSON: 68.

MS BERGIN: 68. Okay. So what messages do you want to give the community and the Royal Commission about how dementia changes over time?

20

MS HENDERSON: The first point I would like to make is that we believe that the incidence of Alzheimer's disease is over-estimated worldwide. We don't have firm data nationally or internationally that gives us any kind of comparable or reliable breakdown on the incidences of different types of dementia. But nonetheless, it's very clear that the rarer forms of dementia are much more prevalent in younger people, and Veda's situation is what we talk about as young onset dementia and that's dementia where the symptoms appear before the age of 65. In Australian and British legislation, that has changed somewhat to a diagnosis occurring before the age of 65 but medically it's a bit different.

25

30

And those rarer dementias have incredibly varied symptoms. Their progress is much less predictable. It is not about the stereotype that most of us have in our heads of gradually getting more and more forgetful and the person fading away, etcetera. It's not at all like that. It's a situation of changing abilities, disabilities, compensation; when people lose one ability they might be able to extend another. The brain is very plastic – neuroplasticity exists – but the disease does what the disease does. And which way it's going to go, which part of the brain it's going to affect next, no one can know. An individual's diagnoses change during their lifetime as well.

35

40

MS BERGIN: Ms Henderson, I'm going to move to a different topic, which is the selection of approved provider. And you mentioned in your statement that the woman that you care for is a lesbian woman.

45 MS HENDERSON: Yes.

MS BERGIN: Is there a role for LGBTI-specific home care services?

MS HENDERSON: Not necessarily. It's the same sort of discussion that we've had in our community – I'm also a lesbian woman – about the necessity for LGBTI residential services. The issue for most of us is not about segregation; on the contrary, it's about inclusion. Both Veda and I have participated in work that led to a publication for professional development of staff called "We are still gay". And that work, mainly coming from Victoria but adopted nationally, allows providers to go through a process of education of their staff on cultural diversity generally but particularly on the needs of LGBTI people. And providers can get what's called a rainbow tick. And that would make me and other people quite happy to see more providers wanting to do that. I must add here that this is incredibly important in the case of dementia because a number of people, as their dementia progresses, become more true to what they had always wanted to be.

And I was contacted recently by an extremely conservative Catholic woman whose husband has revealed himself as a cross-dresser, and the consequences for her and him on their social life and her support have been disastrous. And this is not uncommon. So it's very important for staff, both in home care and in residential care, to respect the person the way they wish to express themselves.

MS BERGIN: So how have you researched which approved provider would be appropriate to service Veda's needs?

MS HENDERSON: That was very difficult at the time because when Veda was first assessed and first had her ACAT, this was pre-CDC so at that time the allocation of home care packages was by local government area. Some providers won tenders to offer higher level packages but many providers kept applying for those tender opportunities and didn't win them. And I noticed in our region – I live in the Illawarra of New South Wales, so a couple of hours south of Sydney – that it seemed to be the large, mostly faith organisations that were winning the higher level packages. So we had very little choice in the first place, in that we had to – Veda had to have her ACAT assessment and then wait for providers to contact her, and that was a series of phone calls with everybody trying to convince her or me, if she couldn't understand, to go with them rather than someone else.

MS BERGIN: So when you say Veda and you were contacted by a number of different providers, was this some time ago?

MS HENDERSON: Yes, that was. That was back in – wait till I get this right now, that was back in the beginning of 2014.

MS BERGIN: Okay. I think you observe in your statement that things have changed since then.

MS HENDERSON: Greatly. Greatly. The provider that we went with that Veda was contracted to was quite early in getting ready for CDC. I think their systems were ready in early April and I think it had to come into play in May or June, I can't – or July, I can't quite recall the dates. So they had already modified their reporting

processes, etcetera. But they, like many other providers, were a traditional faith provider. And there's an attitude behind that that says that we know what's best for you. And it was very difficult, I think, for many providers to understand that the difference with CDC was turning it the other way. The client works out what the client needs and then goes shopping, basically. And we didn't have that opportunity because we couldn't go shopping to make it clear.

MS BERGIN: Okay. Now, Ms Henderson, I'm going to turn to the topic of the delivery of the home care package to Veda.

MS HENDERSON: Yes.

MS BERGIN: What level of home care package is Veda currently on.

MS HENDERSON: She's on level 4 and has been for four years, and her provider receives the dementia supplement as well.

MS BERGIN: And what home care package did Veda start on?

MS HENDERSON: Level 2.

MS BERGIN: How long did it take for the home care package to arrive after Veda was advised that she had been assessed as eligible for a level 2 package?

MS HENDERSON: Not long, in those days.

MS BERGIN: Was this back in - - -

MS HENDERSON: A month perhaps, that's all.

MS BERGIN: So that was back in 2013?

MS HENDERSON: Yes. That's right. Yes.

MS BERGIN: How has the delivery of the home care package met or not met Veda's needs?

MS HENDERSON: It changed her life entirely, because she was no longer free to live her life as she wished to, and - - -

MS BERGIN: When you say she was no longer free, that was by reason of her diagnosis.

MS HENDERSON: No, by reason of the provider's decisions about how that funding support could be used. Veda was not - Veda very early - I think it took her about six months to really digest it all and then she decided that because she was a musician, because she had some star power, that she was quite prepared to stand up

and talk about it and hope that that might make a difference to what people understood about dementia. If you remember, a guitarist from ACDC, Malcolm Young did similarly, and David Campbell, a number of musicians and other people have wanted to stand up and say, “Yes I have dementia, and I’m not ashamed to talk about it.” So I’m sorry, I lost track of your question, there.

MS BERGIN: It was quite an open-ended question.

MS HENDERSON: Sorry, I’m very tired.

MS BERGIN: I was just asking how the delivery of the home care package has either helped Veda or not helped Veda.

MS HENDERSON: Well, it didn’t help her at all in that in fact she – she almost opposed it, so I think this is a quite common thing with a number of people who are newly diagnosed with dementia. The first thing that people, particularly people a generation older than us, think is no one must know. It’s shame. It’s stigma. It’s running away from everything, closing the door. I can’t come to terms with it. What will the neighbours think, etcetera. Now, that is obviously not the case for our generation, at least not for Veda and myself. But it is unfortunately a reality that the stigma attached to dementia is enormous, and most people’s immediate idea of dementia is so far from the truth, it’s – it’s – it’s worrying.

What was difficult for Veda is that because she is a very independent person who has always made her own decisions, has had a most unusual life, travelling, etcetera, to be told that, “You can’t do this and you can’t do that. No, you can’t have your friend come and do the cleaning any more and no, you can’t have another friend come and do the gardening and a bit of maintenance around the house.” That immediately meant two key people who were regularly in our lives disappeared, and there was nothing we could do about it because the money that we had been using to pay those people was now going – part of it to pay Veda’s daily care fee to her new provider.

MS BERGIN: The cleaner and the gardener that you mentioned were obviously not staff members of an approved provider?

MS HENDERSON: No, they were independent sole traders registered with their ABN, with their usual public liability insurance as most people are who work for themselves.

MS BERGIN: They were very much part of your home life.

MS HENDERSON: Yes, had been for years. And they were personal friends as well.

MS BERGIN: Okay. So once Veda was on a home care package, to what extent did you have different people attend in the home?

MS HENDERSON: A lot, initially. And people who had no concept at all about dementia, let alone any idea about supporting people with disabilities, let alone any idea about how to cope with someone who was losing language; people who had no senior first aid, no training, in my opinion, absolutely inadequate knowledge of manual handling, occupational health and safety, etcetera. And Veda resented that, and I did, too. What are you doing, sending us in people who know nothing at all?

MS BERGIN: You talked earlier in your evidence about the importance of professional development of staff.

MS HENDERSON: Yes.

MS BERGIN: Is this one of the topics that in your view further training is needed on?

MS HENDERSON: Absolutely essential. I completely support Maree McCabe's submission earlier in the hearings. We badly need to look at a review of the national qualifications. This is something that is my professional background, and we badly need to look very closely at career pathways for people working with people with dementia, as most staff in aged care will be doing.

MS BERGIN: Turning back to the structure of the home care package system, at the moment Veda is a level 4 with a dementia supplement.

MS HENDERSON: That's right.

MS BERGIN: Do you think there's room for the home care package system to be changed?

MS HENDERSON: Absolutely. The reality of the home care package system at the moment, even though Veda has changed providers to a very innovative provider and by doing so, she has saved 20 per cent of her Federal budget. So one must ask, where did that 20 per cent go? Where was the value added and, in our opinion, particularly in my opinion, there was zero case management, and I thought that was inexcusable. The reality of dementia is that people will need increasing support. And because we're lesbian women and we live in a regional part of New South Wales, most of our friends are in Sydney. Veda's family is in Adelaide. My family is all around the place and a number of our friends have moved to different areas as well. That means that we do not have the assumed support system of family, or even friends because a number of our friends, being younger, are still working. And it's not easy to get out of Sydney and come down for a weekend or even a night.

So the consequences of that is that we lose income, we lose careers, we lose friendship. We lose social networks, and we lose practical support. Where, for example, Veda and I have both been involved in providing regular support to people going through treatment for cancer, and being part of a group that organises dinners and transport, doesn't happen with dementia, believe you me. If you are not in an

environment where everyone is still around you, the first thing that happens is that everybody walks away. So given that, I can tell you that during the six months when Veda was waiting on a level 4 package, because her ACAT had had to be reviewed within four months, her symptoms had progressed so fast and so wildly, I really think I'm still getting over post-traumatic stress from that six months because I was – I was the only person supporting her for 20 hours a day for six months.

And when someone is incredibly distressed – and I really don't want to go into her private medical history, I don't think that's necessary or appropriate, but let me just say that every symptom of anxiety and fear that you could imagine hit her, and every morning, for example, she had two hour long panic attacks, which were terrifying. I have done my senior first aid and I'm also a qualified Pilates instructor, and I've done yoga for years and all of that but those panic attacks were unbelievable, and to see someone going through that and not being able to help is devastating. And she was not able to sleep through the night. She was just constantly agitated and distressed. It took three months for her neurologists and her GPs to find medication that would assist her and it has since. But I'm just using that as an example for people to understand that it is not a slow, gradual process. And sometimes what's required is that one single person does 18, 20 hour shifts nonstop for months until that support arrives. Many people break.

MS BERGIN: Just to conclude the topic of the selection of approved providers and delivery of the home care package, when did you become aware that you could, or Veda could choose her own provider?

MS HENDERSON: When the legislation changed in February 2017. Because of my background, I'm aware of policy changes and things that are about to come about. So I knew at the time that that was possible.

MS BERGIN: So Veda has had two providers in the course of her time on her home care package. So turning to the topic of fees which you've mentioned already, what fees were taken by each provider from Veda's home care package?

MS HENDERSON: Basically, the admin fees are often common across all providers, although as Mr Judd pointed out, some providers amalgamate them but it basically works out to about 11 per cent across the board for most providers and that's their role in receiving the funds from the Federal Government, monitoring spending, reporting, that sort of business. So that was the same for both providers. The difference, however, with Veda's new provider is that they have a sliding scale of fees. So that as someone's needs increase, they take less in management costs. So at the moment, Veda's provider takes an additional 14 per cent for management, whereas her previous provider took 34 per cent. And that's a big difference.

MS BERGIN: You mentioned a statement of Dr Judd.

MS HENDERSON: Yes.

MS BERGIN: Is that a statement of Dr Judd from HammondCare?

MS HENDERSON: Yes. That's correct. Yes.

5 MS BERGIN: Could a I tender that statement. It's RCD.0011.0012.0001.

COMMISSIONER TRACEY: Yes. The statement of Mr Judd will be exhibit 2.02.

10 **EXHIBIT #2.02 STATEMENT OF MR JUDD (RCD.0011.0012.0001)**

MS BERGIN: Thank you Commissioners.

15 How was Veda's package managed by the first provider, HammondCare?

MS HENDERSON: Disappointingly. I was aware of HammondCare's reputation, both as a registered training organisation, because that's my background as well, and also I was aware of some of their excellent work carried out through their dementia  
20 centre. I was looking for a provider who did understand young onset dementia and the more complicated varieties of that, who would provide us with some clinical case management, and I thought that's what that 34 per cent was for, or 24 per cent, I'm sorry, was for. What I found was an organisation that, in our region, had zero capacity to provide that. They were unable to keep their RN staff and at one point a  
25 particular RN for whom I felt a lot of sympathy had 120 cases to manage.

So the reality was I didn't get any advice from HammondCare at all on how to proceed and I ended up doing the case management myself with our GP, two  
30 neurologists and a close friend who was a retired RN, director of facility, etcetera. That made me extremely angry.

MS BERGIN: I understand you had some criticisms of HammondCare.

MS HENDERSON: Yes.  
35

MS BERGIN: They've been provided, as you know, with an opportunity to respond to your statement and that statement has now been tendered.

MS HENDERSON: Yes.  
40

MS BERGIN: And as I understand it, you might agree to disagree on some matters.

MS HENDERSON: Not many.

45 MS BERGIN: But not many.

MS HENDERSON: Not many. I think the historical context is very fair and very true.

5 MS BERGIN: Okay. And how was Veda's package managed by the second provider, Home - - -

10 MS HENDERSON: That's extremely interesting because the base cost of 14 per cent in addition to the usual admin business really covers continuity of care by a team. That team is supported by the organisation. They work as a team. They have case conferences. At any crisis point, the owner herself and Veda's case manager have phoned and/or visited at our convenience. I feel that we have a responsive, innovative provider, and in terms of case management, or clinical nursing care or advice, for example, that is separately costed so that makes sense to me as well. If we think that we need an hour face-to-face with someone, a health professional of any particular variety, we can have that charged separately.

20 And so you're not paying an amalgamation of costs where you don't know where it's going. If you need nursing, you can ask for it. If you need advice on case management or whatever it may be, you can ask for it, and that's separately costed and you get your quote and it's clear.

MS BERGIN: Now moving to the topic of community and connection, you and Veda, Ms Henderson, have made a video featuring Veda.

25 MS HENDERSON: Yes.

MS BERGIN: When was that put together?

30 MS HENDERSON: That was put together in 2015. We've done about another three since.

MS BERGIN: Operator, can I ask you to play the video LHE.0001.0001.0001.

35 **VIDEO SHOWN**

40 MS BERGIN: Commissioners, I tender the video of Lynda Henderson and Veda Meneghetti made in 2015.

COMMISSIONER TRACEY: Yes. The video will be exhibit 2.03.

45 **EXHIBIT #2.03 VIDEO OF LYNDA HENDERSON AND VEDA MENEGHETTI MADE IN 2015 (LHE.0001.0001.0001)**

MS BERGIN: Ms Henderson, if I might ask you a couple of questions about the video. What is the Southern DAGs group featured in the video?

5 MS HENDERSON: Right. Because we have realised that most people, even of our generation, are so horrified when they learn that they have a dementia diagnosis, that they run away and hide, and because we ourselves have been supported by other people living with or alongside dementia, we had the opportunity in Kiama to become a pilot project of Dementia Australia, it was then Alzheimer's Australia. We have an excellent council in Kiama, and we have a wonderful university, the  
10 University of Wollongong. So the project was set up in 2014. It was launched in July. Veda and I helped launch it. And it has been going very strong ever since.

Our approach is to try and make it a lot more than being about dementia-friendly, but about being dementia inclusive and aligned with the UNCDRP and Australian  
15 legislation about anti-discrimination, Disability Discrimination Act, etcetera. We do regular community education workshops within the local government area. We spread around and offer those to people for free. We have also designed those workshops ourselves. We facilitate them ourselves. And the Southern DAGs group is really a social group that came out of that project where we realised that people  
20 needed to meet others in an informal environment. So we meet up about fortnightly, either for coffee or often at someone's place, own house because it's less threatening. We might go out for coffee, we might go out for lunch and about once a month we go on a picnic.

25 We live in a beautiful area of the South Coast in nature, and for a lot of people with dementia, even if they're older, even if they're in a wheelchair, wherever we go is accessible, and it's a nice outing for a couple of hours. And we find that that peer support is absolutely critical. And we intend to keep on going as well as creating a lot of things that simply aren't there that we all need.

30 MS BERGIN: The video shows that you and Veda are both adept at using technology. How do you and Veda use technology to connect with your communities?

35 MS HENDERSON: That has changed over the last number of years. I have noticed that most communities now have a community Facebook page so I've been using that to advertise the fact that we are doing workshops or whatever happens to be going on. Veda doesn't manipulate the technology herself. She is not capable of doing that with her literacy issues, and she worked professionally in the pre-digital  
40 age. So for her digital literacy is exciting; it's an opportunity to learn and to do new things. So I have learnt on the run, really, to – about multimedia and I've enjoyed doing it, and both Veda and I are both keen to be involved in production. She loves cameras and happy to do anything that needs to be done in terms of media. So the work that our project has done has been covered by the local media, both TV and  
45 press. And some of what we've done recently has been in the national media, both TV and press again.

MS BERGIN: So how do you, Ms Henderson, and Veda learn to use the technology that you prefer to use to connect with your community, such as social media, I think you mentioned Facebook?

5 MS HENDERSON: I think that's because of my own background as a senior manager in TAFE and along with many other people who have worked in TAFE. We all learnt about inclusive web design. We learnt about eLearning. We learnt to play with Twitter, etcetera. So that has always been something that I have done in any case. But I soon realised that that electronic media and the immediacy of  
10 contacting people has expanded enormously and so Twitter is a very common medium for our dementia community.

MS BERGIN: So what were the challenges associated with using technology for someone living with dementia such as Veda?

15 MS HENDERSON: For Veda it's difficult because she can no longer read, and she can't type. And because she can't speak fluently, she can't use voice to text, for example. I don't know if people are aware, but a number of the technologies that we use now were developed by, and with, or for, people with disabilities a long time  
20 ago. And I've been aware of those because of my work in TAFE. For Veda, it's a challenge. And I will give you an example. As her language started changing, and she found it harder to understand people on the phone and to make herself understood, she has moved to using video calling, and that works for her because she can read people's expressions and they can read hers, and I think she does a bit of lip  
25 reading as well while she's at it. That's just a concrete example.

But, in fact, we're faced with the challenge now of really using what's called AAC, augmentative assistive communication, because Veda is getting to the point where it is getting very difficult for her to express herself in a way that most other people  
30 would understand. And it's very important that she be able to continue to say what she wants, what she needs, what she doesn't want, how she feels.

MS BERGIN: So when you refer to augmented assisted communication, what does that mean?

35 MS HENDERSON: In most cases, it – it can mean these days an app, a communication app. A lot of apps exist for people with aphasia but many of them are designed for people who have had strokes where there's an expectation of, sometimes, full recovery, which is not the expectation in dementia. And some of  
40 those apps have been developed for children with developmental disabilities, people on the spectrum, on the autism spectrum, etcetera. There are a number of things out there. I don't think you want to know all the details of those.

MS BERGIN: All right. Thank you, Ms Henderson. Commissioners, that  
45 concludes my questioning.

COMMISSIONER BRIGGS: Ms Henderson, might I ask, what are the differences, if you're aware of them, between the services that you've been able to get through the home care program and those that might be available were Veda younger, and she might be eligible for the National Disability Insurance Scheme?

5

MS HENDERSON: Excellent question. Thank you. The NDIS rolled out, as you are aware, in different parts of Australia at different times and still is an issue with Western Australia, I believe. In our region, it was not the first region to roll out and Veda was, I think, a year too old to be eligible at the time. Similarly, for me, with my spinal disability. We're both on the disability support pension, by the way. We haven't changed to aged care just because we turned 65, and that's an in-principle silly thing of ours, I suppose. It is cruel, it is really difficult because a number of our friends are eligible for the NDIS and we know of people who have packages of \$150,000 per annum and they're just starting. And Veda's is capped at 50-something for the rest of her life. So in terms of support, hours of support, support for me, it's huge and it's unfair.

COMMISSIONER TRACEY: Thank you very much indeed for sharing those many deeply personal insights with us. They have been most helpful in our understanding of the difficulties that people do confront in caring for friends and relatives who are suffering from dementia. We're most grateful to you for your evidence.

MS HENDERSON: Thank you for this opportunity.

COMMISSIONER TRACEY: The Commission will adjourn until midday.

**ADJOURNED** [11.40 am]

30

**RESUMED** [12.06 pm]

COMMISSIONER TRACEY: Yes, Ms Hill.

35

MS HILL: Commissioners, before I call the next witness, Mr Henry, SC, seeks to address you.

COMMISSIONER TRACEY: Yes.

40

MR HENRY SC: May it please the Commission, my name is Henry. I appear for Opal Specialist Aged Care pursuant to a grant of leave that was afforded on Friday last, instructed by Arnold Bloch Leibler. And, Commissioners, I don't want to do anything out of sequence here. My client has provided a response late Friday which I understand has been received by the Commission electronically. If it's convenient, I could tender that at this point or I could wait until Ms Ellis has provided her evidence.

45

COMMISSIONER TRACEY: I'm sorry, I missed that last bit.

MR HENRY: I'm just raising as a matter of sequencing, whether it would be convenient for me to tender the response of my client that was provided  
5 electronically on Friday.

COMMISSIONER TRACEY: Yes, we do have it and perhaps the best time to do that would be after the evidence is given.

10 MR HENRY: Thank you, Commissioner.

COMMISSIONER TRACEY: Yes. Thank you very much. Yes, Ms Hill.

MS HILL: I call Raelene Ellis  
15

**<RAELENE ANN ELLIS, AFFIRMED** [12.07 pm]

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

MS HILL: Thank you, Ms Ellis. Could I ask you to state your full name.

25 MS ELLIS: Raelene Ann Ellis.

MS HILL: And how old are you, Ms Ellis?

MS ELLIS: I'm 44.  
30

MS HILL: What is your occupation?

MS ELLIS: I'm a lawyer.

35 MS HILL: And whereabouts do you live

MS ELLIS: I live in Caloundra, Queensland.

MS HILL: Have you prepared a statement dated 12 March 2019?  
40

MS ELLIS: I did.

MS HILL: Operator could you please display document ID WIT.0083.0001.0001.  
Ms Ellis, do you see a copy of your statement on the monitor there before you?  
45

MS ELLIS: I do.

MS HILL: You have identified a number of typographical errors to your statement. Beyond those typographical errors, do you have any changes that you would seek to make to your statement?

5 MS ELLIS: I don't.

MS HILL: To the best of your knowledge are the contents of that statement true and correct?

10 MS ELLIS: They are.

MS HILL: I tender that, Commissioners.

15 COMMISSIONER TRACEY: Yes. The statement of Raelene Ann Ellis dated 12 March 2019 will be exhibit 2.04.

**EXHIBIT #2.04 STATEMENT OF RAELENE ANN ELLIS DATED 12/03/2019**

20

MS HILL: Thank you, Commissioners.

Ms, Ellis, on what basis have you prepared your statement to the Royal Commission?

25 MS ELLIS: So I'm – my mother has dementia. She is 78 years of age. I acted as her carer for the last two and a half years. For a period of that time, she lived independently but I lived close by and provided her with a lot of care.

30 MS HILL: What's your mother's name, Ms Ellis?

MS ELLIS: Therese Ellis.

35 MS HILL: And at paragraphs 16 to 34 of your statement, you've documented a section of your statement called My Mum. Could I ask you to please tell the Commissioners about your mum.

40 MS ELLIS: Yes, so mum was born in 1940, out of wedlock, and as a result of that initially she was placed in an orphanage for the first 18 months of her life. After – at the age of 18 months her grandfather had gone to visit her and noticed that – or he visited regularly but at that point he noticed that she was underfed and the children were often ill-treated. At that point in time he took her home that day. We have heard the story over the years many times from different members of the family, that mum went home that day and they fed her Weet-Bix, which she ate a lot of with a guarded arm, like this, which was demonstrative of the fact that from a very early age  
45 she had to fight for survival and I think that strength has really come through in her entire life.

She was then placed as the younger of a sibling group with her – it was a big Irish family – with her aunts and uncles, only a couple – some of them only a couple of years older than her. And she believed she was part of that family until one day her step-grandmother, who she called mum, announced to her that “I’m not your  
5 mother”. She said that she always felt different in that family group and that it made sense to her but, obviously, really hurt. And she was shortly thereafter shipped off to boarding school. And at boarding school, she was cared for by nuns who were often abusive, and she eventually ran away from there.

10 She eventually found her way living back with her mother who by that stage had married an alcoholic who was very domestically violent. Again, you know, the story has been told many times over the years with a joke which is demonstrative of my mum’s ability to look at the instances of difficulty in her life with a smile on her face, and, you know, trying to, you know, enjoy – or not enjoy, that’s the wrong  
15 word, but just making a joke, being able to make a joke of herself. And she said that at around the age of 14 she brought home a boy who had a motorbike, and her drunk stepfather came out abusive and threatening and kicked over the motorbike. And mum called the police on him and said – told the police that she didn’t know who he was. And as a result of that, he was taken into custody overnight.

20 The next day my – her stepfather gave my grandmother an ultimatum and that was that it was mum or him and she chose him. So at the age of 14, possibly 15, mum spent the night at Kings Cross and, you know, her life could have gone into so many ways but she was such a strong person that she picked herself up and she moved in  
25 with an older person, being a 17 year old, and they would have a hot breakfast every day, a cup of coffee and a cigarette because that’s all that money could buy. She worked menial jobs, got married at the age of 20, had a child at 21, and then he was also, unfortunately, domestically violent and she left that relationship very shortly after. She had a child on her own and the social security system back then was not  
30 what it is today, and she would tell the story of how she would take – boil eggs for my older sister and hope that she left some food for mum to eat and mum would just leave – eat whatever was left over and sometimes there was none left over.

Mum would make the joke that as a result of that, she had a really good figure.  
35 Again, you know, always happy to try and look on the brighter side of bad instances in her life. She then met my dad, who was – owned a delicatessen, and would give her free food. He was actually 23 years older than mum, and, you know, accepted both mum and my sister. They then adopted two children and then fell pregnant with me. Mum – dad was a real estate agent after we moved to Queensland. She was  
40 born in New South Wales. And real estate back then, dad would bring in sometimes months without any money. And mum would work, sometimes, three jobs during our life to put us – all four children through private education, and made sure that we had everything we needed.

45 There was never any instance where we didn’t have food in the cupboard or anything like that, despite the fact that we were very, very poor and I don’t think I even appreciated how poor we were until I got my dad’s Department of Vet Affairs

records last year, and realised how significantly poor we were. And that was – she protected us from that. Then we all moved – we grew up and all four of us have gone to university, and mum and dad have both enabled us to be able to do that. And then – my grandmother then died in 1999, and I think my mum really felt the loss of having never been accepted by her mum. And my dad died the same year.

MS HILL: Can I take you to 2007, between 2007 and 2014, what was happening in your and your mum's life at that time?

MS ELLIS: So 2007 to 2014 were a really wonderful period of time for my mum and I, I think, and I am so glad to have had that. I had just moved back from Brisbane after working in Gympie for a period of time and I lived very close to mum. I would sometimes go around to her house on a Saturday morning and not leave until Sunday night and we were best of friends. During that period of time, in 2011, we also travelled to Italy.

MS HILL: And paragraph 31 of your statement, you in fact attach a photograph. If I could ask the operator to please display the document ID, RAE.0001.0001.0001. Is that the photograph that you refer to in your statement?

MS ELLIS: It is. That's mum and I in Italy laughing at how little the coffees were over there.

MS HILL: When was that taken, Ms Ellis?

MS ELLIS: That was taken in 2011.

MS HILL: After 2014, what then happened with your mum?

MS ELLIS: So I think, you know – and with dementia, it's difficult to really pinpoint a point in time. I say 2014 she really sort of – she started going downhill. It may, on retrospect have been earlier, but you know, I think that's one of the things with dementia you start to notice change – or you don't really even quite notice changes, and then all of a sudden you realise that your parent is not the parent that they used to be, and sometimes I feel like I missed that opportunity to have those last moments with her before she was gone. So 2014 I had my daughter, and at that period of time I really noticed mum developing agoraphobia, anxiety, she had difficulty driving. I just really noticed a significant decline.

Then in 2015, she fell over trying to turn off a water tap thingy in her backyard and she broke her neck at the T2 or C2, at the very top vertebrae and ended up in hospital for a significant period of time. And that's when we first tried to access the aged care system.

MS HILL: How did you do that, Ms Ellis?

MS ELLIS: So after mum spent a period of time in hospital she was moved over to a transition care, and the transition care people had her assessed and they assessed her for a level 2 – level 1-2. At that point in time, they were grouped together as 1-2 and 3-4. She accessed a level 1-2 package. And that was relatively painless. She  
5 was released from hospital – or from the transition care in December, and it was relatively easy to get a level 1-2 package. But, of course, that only equated to four hours a week. By that stage, I had really noticed a significant decline in mum’s abilities. You know, she was suffering a lot of pain with her neck. She was on warfarin. She had had a heart valve replacement in 2005 or 2006 so she was on  
10 warfarin, and will be for the rest of her life as a result of that which requires specific medication every day or it can be very dangerous.

She wasn’t eating properly, and as a result of that, her INR levels were fluctuating. And QML, who were managing her warfarin, Queensland Medical Laboratories, they  
15 take the blood, and they were unable to regulate her dose of warfarin because of her eating, and other factors were just completely unlablising it. She was unable to take – get the medication out of the Webster packing that we had got for her. There were just numerous signs that she was very quickly becoming quite unable to manage her own needs at that point in time.

20

MS HILL: So what did you do, Ms Ellis?

MS ELLIS: So then I think it was May 2016, I got a further assessment for ACAT – ACAT assessment to have her assessed for a higher level package.  
25

25

MS HILL: And was she assessed for a higher level package?

MS ELLIS: She was, and she was approved for a level 3-4 package in May 2016. But despite being approved for a level 3-4 package in May 2016, we were unable to  
30 find a provider for that package.

30

MS HILL: What was your experience of finding a provider for that package, Ms Ellis?

35 MS ELLIS: So we accessed the My Aged Care website.

MS HILL: When you say “we” who are you referring to?

MS ELLIS: I’m actually really referring to me, sorry. I’m sort of “we” as in me and  
40 mum but it was really just me but mum didn’t do anything. I kind of described that, you know, rather than me helping mum out, it was really mum following me along the process of her dementia because I did everything. In fact, you know, the previous witness said that, you know, with dementia there was some relief in the diagnosis and, in fact, I found the opposite, and I think that shows the individuality  
45 of a dementia diagnosis. Mum was disbelieving. There was nothing wrong with her. She was fine and even to this day she says, “I can walk. I can walk”, even though she is bedridden. Sorry to get off point then.

So I accessed the My Aged Care website and it would say that there were level 3-4 packages available from certain providers but you would ring those providers and they would have no packages available. And I said to them, “Well, the My Aged Care website says you had some”, and then you would ring – they would say, “Well,  
5 My Aged Care are wrong.” You would ring My Aged Care and they would say, well, we get the information from the providers. So both people were just blaming each other about the incorrect nature of the information that was on the My Aged Care website, and it was really useless, that information, because it just – that was not the only occasion that the My Aged Care website had incorrect information.

10 But in addition to that, at that point in time the individual providers managed their own lists; it was not a national list. And we were told by COASIT, who we were working with at the time, that mum was next on the list. And I find that really uncouth that in a civilised society you’re essentially waiting for someone to die  
15 before you can get services. We have enough money in our society to be able to care for everyone. Someone shouldn’t have to be told when the next person dies, you can get help, but until then, tough bickies, you can’t. It just seems extremely not what our society should be about. So, yes, so we stayed on that – we were next on the wait list, apparently to get a level 4 package with COASIT. Then the system  
20 changed in late 2016 or 2017 and the list become nationalised.

We were then – whilst I agree that that is, from a societal point of view, better that the list is nationalised, it creates equality from everyone. From my personal view, like experience, it was very frustrating to go from knowing that my mum was next on  
25 the list to receive a level 4 package, to then all of a sudden having completely no idea where on the list mum was, how long we would be waiting for this extra help. And in the meantime mum’s health was rapidly deteriorating. She lost significant amounts of weight at that point in time. We had to employ a dietician – or go and see a dietitian and get weight – some weight management – calorie-dense juices so  
30 that mum could put on weight and that was very costly. Those juices are about \$5 each.

MS HILL: Were you ultimately able to receive the care for your mum that she  
35 needed?

MS ELLIS: I don’t think that we ever really received the care that she needed. We did eventually get a level 4 package.

MS HILL: How did that come about, Ms Ellis?  
40

MS ELLIS: So in July 2017, mum went to hospital with atrial fibrillation. Sorry, I’m not very good at saying that. That brings me also to, you know, the aged care system is happening in the backdrop, really, of people’s significant health decline. This is a system that is being provided to people that are already in crisis. They’re  
45 going through health declines, they’re going through hospital appointments. You know, arranging health – health care, etcetera. And the aged care system is happening in the background of a family that is already in crisis. So mum went into

hospital in June and, you know, I had significant problems, which I won't go into, as outlined in my statement, with the hospital at that point in time.

5 I believe mum had a stroke while she was in hospital. They deny it quite obviously because they did nothing about it. And mum got out of hospital at that point in time and was still unable initially to get a level 4 package. I employed every resource I could. I had her reassessed for an ACAT to try and get her priority.

10 MS HILL: Could you get your mum a higher package at any point during this time?

MS ELLIS: I did. So around the end of July or mid to end of July we finally got approved for a level 4 package. And, you know, I was over the moon. I remember the phone call when the care provider rang me and said, "We've got the level 4 package, we've got it" and I was like over – it was like this sense of relief that finally  
15 mum was going to get the care that she needed. But, unfortunately, what came out about that – with that is that it equated to only nine hours a week. And it was – the funding for it, I set out the specific figures in my statement, but it's \$49,000 or thereabouts that the government provides for a level 4 package. And then mum – I had mum assessed for the dementia supplement slightly later which was another  
20 1000-odd or something. So it was over \$50,000 that the government was paying for a level 4 package, and yet it equated to just nine hours of support a week. And the reason for that is because that the care providers were charging 38 per cent of that figure in their admin fee - - -

25 MS HILL: I apologise, Ms Ellis. In your statement at paragraph 63 you refer to an attachment of a statement from COASIT Community Services and, in fact, there's a typographical error, that's paragraph – I understand that that date should read 31 August 2017. Is that correct, Ms Ellis?

30 MS ELLIS: That's right.

MS HILL: Operator, if I could please ask you to display document ID, RAE.0001.0001.0002. In fact, Operator, if you could please display the document ID that ends in .0003. Ms Ellis, is that an example of a statement that you had  
35 received? On the monitor before you.

MS ELLIS: The budget. That's a statement of the budget that we received, and that is for 11 hours but, as you can see, that includes a contribution by my mum of a bit over four, \$4000. So, essentially, what that provides is that their admin or  
40 coordination fee of 38 per cent equated to \$18,845.17 a year, just straight out for their management of it. And then on top of that – and this is why I say they are paid twice, because then they charge, as you can see, support for Mondays to Friday is \$49 an hour. So out of the package is \$49 an hour for the person that comes and provides you with that care. I can guarantee you that that carer is probably only  
45 getting \$25 an hour. So they're getting another \$25 an hour for the care on top.

Then, of course, mum was getting podiatry and gardening services, which I should say it's great that, you know, you can have things such as gardening for old people that can no longer do their gardening themselves so I certainly think that that is wonderful that we can include that. But on top of that, the gardening services which  
5 were outsourced and the podiatry which were outsourced, they then charged a \$25 handling fee for each instance of booking that. So for – so, essentially they're getting paid twice. Now, I equated it to, I think, just over \$20,000 that was going just for their administration, which left about \$30,000 for the actual care of the individual, which is being charged at \$49 an hour, \$73 for a Saturday and \$98 for a  
10 Sunday.

So it's a lot of money that seems like we could really provide care for these people. But it's just – it seems to me like it's being wasted away into profits or, you know, for the not-for-profits, then what are the CEOs getting paid. Where is the money  
15 going? Because \$50,000 should not translate to just nine hours of care.

MS HILL: Could I take you, then, to the document and ask the operator to display document ID that is ending in the numbers .0001. I apologise, .0002. Ms Ellis, could I ask you to identify that document for the Commissioners.  
20

MS ELLIS: Yes, so that's the statement that we would receive at the end of the month.

MS HILL: How does that relate to the earlier statement that you were taking the  
25 Commissioners to?

MS ELLIS: So, the income there is the income that I think mum was putting in. The expenses were the payments out from that previous budget. The estimated government funding awaiting confirmation – that, on my understanding, is in fact  
30 because the government, I'm told, is paid – pays the funding for aged care every, say, three months or in block amounts every few months. And what that means is that these organisations are then – doing work with no funding, at least initially and are waiting for the government to pay that funding at a later time. And I just – I say in my statement I just don't know why it's not like child care where, you know, you put  
35 your child into child care and the child care benefit is paid a week later or a week and a half later, you know, the government kicks in their share and you pay the rest. I just don't know why it's not done instantaneous, which would enable providers to just have more surety and be able to provide better and certain care because they know how much money they've actually got.  
40

MS HILL: Commissioners, if I could take the opportunity to tender both the document on the monitor presently and the earlier document.

COMMISSIONER TRACEY: I will take the one that's on the monitor immediately  
45 and then I will get the operator to go back to the other one so I've got its correct title. The Home Care Package statement for Therese Ellis, as at 31 August 2017 will be exhibit 2.05.

**EXHIBIT #2.05 HOME CARE PACKAGE STATEMENT FOR THERESE ELLIS AS AT 31 AUGUST 2017 (RAE.0001.0001.0002)**

5 COMMISSIONER TRACEY: And if the operator would please go back to the preceding statement. And the Home Care Package Budget level 4 for Therese Ellis dated 8 August 2017 will be exhibit 2.06.

10 **EXHIBIT #2.06 HOME CARE PACKAGE BUDGET LEVEL 4 FOR THERESE ELLIS DATED 08/08/2017 (RAE.0001.0001.0003)**

MS HILL: May I also take the opportunity to formally tender the photograph, 15 which is the document with ID number concluding in 0001.

COMMISSIONER TRACEY: Photograph of Ms Ellis and her mother will be exhibit 2.07.

20

**EXHIBIT #2.07 PHOTOGRAPH OF MS ELLIS AND HER MOTHER (RAE.0001.0001.0001)**

25 MS HILL: As the Commission please. Ms Ellis, you've touched on your concerns around the use of the dementia supplement and the client contribution and, indeed, you raise those in your statement. Could I ask you to take the Commissioners to those concerns.

30 MS ELLIS: Yes. So, in relation to accessing the dementia supplement, we were told that that required an assessment that despite mum already having a formal diagnosis of dementia, she required an assessment, a RUDAS assessment, to access that dementia supplement. That RUDAS assessment was going to cost \$80 and, you know, like I'm not aware of any other – maybe there is but I'm not aware of any 35 other government funding that requires a person who is applying for it to actually, you know, pay to have an assessment done to qualify for a government funding. I disputed the need to do that and I – mum was in hospital at one point around that point in time and so I spoke with one of the nurses at the hospital and managed to get mum assessed for free.

40

But, you know, I wonder whether there are other people out there who are just not applying for the dementia supplement because they don't want to have to pay that, that \$80. But in addition to that, in fact no one ever told us about the dementia supplement. I stumbled across a reference to the dementia supplement on the 45 internet. So we have these service providers that, you know, are providing us with care that are supposed to sort of, you know, be experts in their field, had never mentioned a dementia supplement to me. It was simply me googling or looking

around at what other support was available but I stumbled across it and approached them about that dementia supplement.

5 MS HILL: Can I take you to what was happening in your life during this time whilst you were caring for your mother.

10 MS ELLIS: Yes, at this point in time, like I said, this is – the aged care system is really something that's happening behind a family in crisis. So I had a toddler during this time, she was between one to four years of age, and I had just returned to work, part-time, three days a week. So, you know, in between work and caring for my one/two/three, as she got older, I was having to drag her along to doctors' appointments, and, you know, I would leave a doctor's appointment with mum with 15 five or six jobs that the doctor had left me to do. So I was juggling just multiple commitments left, right and centre, as well as trying to access the system for mum, and figure out how to best support her.

It was a period of time that put a lot of pressure on me, on my partner. My daughter probably loved it. She still, today, talks about enjoying going to doctors' surgeries. So I'm at least grateful that she enjoyed running the halls of the hospital and the 20 doctors' surgeries, but it certainly put a lot of pressure, and created difficulty with me listening to doctors with my two/three year old running around. It was never easy. You're juggling multiple balls when you're doing these sorts of things for another individual.

25 MS HILL: Did you get any assistance whilst you were juggling these various balls, as you've described?

MS ELLIS: Initially, I didn't get any financial assistance.

30 MS HILL: I'm referring to really financial, and more generally within the community.

35 MS ELLIS: I don't think that I really did get any assistance and, you know, I say in my statement that I think that more needs to be done for your informal care network. We don't need that measly \$75 a week that is paid in a carer's allowance, well, at least I guess I don't. What we need is a real support network because it's hard. You know, you're going through the emotional difficulties of watching your loved one essentially move towards death. You're juggling all of these balls and there's just nothing for the informal care network out there. And, you know, I probably haven't 40 offered a lot of ideas but I think that there just needs to be more recognition because the longer a person stays in the community, number one, it's better for them, but number two, it's also cheaper on the government to have people stay in the community being cared for by the informal care network, than to go into a nursing home which is much more expensive.

45 So it seems like a win-win situation to provide better care and, of course, for me, that's what I wanted. I wanted mum to stay not in a nursing home but with me or in

the community. I didn't want to put her in there. But all of these things were just acting to be straws on a camel's back to just make it so difficult. Now, I don't know, I'm not really 100 per cent sure what it would look like. You know, I sort of talk about better options for some day care facilities for older people, that would give you  
5 a bit of a break and allow you to recharge. And, you know, there's, I'm sure, many other ideas that people could come up with. But being a carer, an informal carer is hard. And I think that there just needs to be a reflection of that in the system as well.

10 MS HILL: What were the consequences for you and your family in not receiving that type of support that you've described within the community?

MS ELLIS: You know, I think – I think in the end, you know, the consequences were that I had to – I had to essentially give up on mum. I couldn't keep doing it, you know. It became so difficult that – and mum's care was increasing, that you  
15 know it just – it got to the point where I was unable to keep doing it, I think. And my partner certainly drew the line and said I just couldn't keep doing this any more. He was being the primary carer for my child during periods where I was, you know – where I would leave her with him, and take mum to doctors by myself, etcetera. He was a shoulder to cry on. It was a lot of – you know, there was a lot of pressure on  
20 all of us.

MS HILL: Ms Ellis, could I ask you to tell the Commissioners about your decision to put your mum into residential care.

25 MS ELLIS: Yes. So, we had mum in respite care at Opal Aged Care in November, late October, early November and at that point in time, mum was having a lot of falls. And the saddest thing I think about this is that one of the reasons why I put mum – I decided to start moving her towards permanency was because she would just walk, up and down the house, all day. And it was a constant falls risk. She had  
30 significant anxiety. She didn't really – she thought she needed to go back to Sydney where her mum/step-grandmother lived and that they would be wondering where she was and she was just constantly anxious and walking up and down the house all day. I went over, on a cruise for 10 days and so, and I started talking to Opal about having mum there permanently, and I think respite care is also something that's really  
35 important to ensure that your carers are really recharged.

So during that period of time and I go into, I guess, a lot of detail in my statement about that but mum got sick at one point in time. She was diagnosed with – eventually diagnosed with pneumonia. And I saw her on one night and she had just  
40 started getting sick and because she was down at North Lakes, which was about an hour away, I didn't see her again for about five days, and by five days later, she had – she was significantly ill, very, very ill. And apparently she was on antibiotics but, I mean, my partner actually took my four year old out of the room because mum looked so significantly ill at that point in time. She was lying on sheets that were  
45 stained with urine.

When I told them to get mum out of bed, and I had asked them – I had spoken to them about, you know, why an ambulance hadn't been called. In any event, I took on board that maybe she had had her night-time tablets and that's why she was looking so bad, and I asked my sister to – and brother to drop in and see her the next day. So my sister went there the next day and she was even worse. And we insisted that mum had to go to hospital. Of course, what happened once mum went to hospital is that the respite arrangement ceases under the current legislation. Someone is not allowed any leave from a respite situation, unlike if they're in permanent care where you're allowed, I think, 63 days leave a year, or something like that. Under respite you're not allowed any leave. Now, as a result of that, they basically – I go through in detail in my statement – but they basically terminated her respite arrangement.

Now, there has been a lot of back and forths about whether contractually – because we did have a contract – they were able to, in fact, terminate her respite agreement but effectively they refused to have her back once she was discharged from hospital. She was in hospital on IV antibiotics which she reacted really well to and she was actually only in hospital for a period of 40 hours. She went to hospital on Monday night. She was due to be discharged by Wednesday morning; they started arranging the discharge, and then I received a phone call from Opal Aged Care, essentially refusing to have her back. Now, you know, I appreciate that I had been talking to them about permanency, and there were number of factors why I couldn't enter into a permanent arrangement at that time, one of them being the emotional difficulty of giving up on my mum.

There's one thing, you know, having a rational brain knowing that you're mum needs to go into a nursing home, and letting your heart take that next step. And if these people are providing that care, they need to have an understanding of that because it's not a decision that I want to make for my mum. And all I'm doing is the best I can to make sure I make the right decision for her. But, as I appreciate, that was probably really frustrating for them that I was just, you know, umming and arring, and I understand that but I'm sure that most families have an element of that. But in addition to that we had not yet received an assessment from Centrelink as to what mum's contribution towards aged care would be.

Mum still owns a home, and I was unsure whether that would be treated as her primary place of residence because she had moved up with me, or whether it would be treated as another asset and however it was treated could have made quite a dramatic difference on the contribution. I had these conversations with them. And, you know, this is a significant contract you're entering into for another person under a power of attorney. I felt it my – the right thing to do, to get some financial advice, to wait for that Centrelink assessment so we actually knew what sort of contract we were entering into. And so they knew all of this that I was going through and that I was thinking about when, you know, they refused to have mum back after just 40 hours worth of leave unless I signed a permanency agreement then and there.

You know, I think that that was probably the hardest thing I have ever gone through in my entire life, because – and I should say because I felt blackmailed I also was like – and their focus was so on money, I felt that that was not the place I wanted my mum to be. But the result of that decision was that mum then became homeless.

5 That month after that was probably the hardest period of my life apart from when my father died, where I think I entered a state of depression and I would just randomly cry for periods of time. And I remember one morning when I got up and my partner was still in bed and I was getting my four year old breakfast I just started bawling my eyes out and she's just looking at me going, "Mummy, what's wrong?" And I just  
10 couldn't quite talk, and she took me by the hand to my partner and said, "You tell daddy what's wrong and he will give you a hug."

So this emotion that I was feeling as a result of that decision affected everyone in my family. And you know, I say in my statement I understand that this is a peculiar set  
15 of circumstances. You know, I've heard that from, you know, my local member of Parliament, from everyone else I've complained to, you know, is this really a big deal because, you know, how often is this situation going to come up. But this could translate into the everyday situation of – you know, what if someone is over in  
20 Europe and they're having a well-deserved break, because we need breaks as carers, and all of a sudden, you know, their person that they've put into respite back in Australia has gotten sick and gone to hospital, and is all of a sudden homeless.

And amazingly when I mentioned that to my local member of Parliament or his secretary, his secretary said to me, "Well, wouldn't you jump on a plane back from  
25 Europe?" I mean that's just crazy. That's not possible. There just simply needs to be an ability to have breaks from respite to go into hospital. That should not terminate the respite arrangement. I should say that mum actually did go to hospital when she was on respite at the centre that she is now living in, not once – and she was there for, she was in hospital at that time for a week and a half. Not once did  
30 they ever ring me to mention to me, "We are now no longer getting paid so you need to find other arrangements." Not once. Mum was in a double room at that place. It was kept open for her. We paid not a cent to have that room kept open.

So, you know, they could have done it if they wanted to but there was a priority of  
35 money over my mum. But the solution is that there just needs to be a legislative change to allow someone to take leave from respite for hospital admissions. I mean, obviously if someone is going to be in hospital for, you know, the rest of the respite time, that might be a different thing but conversations can be had with family, "Look, your mum is likely to be in hospital for another two weeks so why don't we just  
40 terminate the respite agreement now". You know, conversations can be had around that but it should not be the case that simply because you're in hospital the respite terminates.

45 MS HILL: How is your mum going now?

MS ELLIS: Look, now mum has – mum lost a lot of weight as a result of that hospital admission. She's now a two-assist.

MS HILL: What does that mean, Ms Ellis?

MS ELLIS: Two-assist means she has to have two people at any time to move her at all. And she is not allowed to be moved with just one person helping her up and  
5 down. And so she has got to be hoisted out of bed. She can't walk. And she's – she's around 50 kilos at the moment. So she has lost significant amounts of weight. There has been some – there was some assessment or some suggestion that maybe that was a further decline in her dementia, that she couldn't walk. But I actually had her assessed when she was in hospital the second time, I said "Look I want to make  
10 sure there was no further stroke or stuff like that", and the conclusion that they came to was that it was muscle, muscle dystrophy, is that the word, where your muscles – and that was the reason for her inability to walk.

We have really tried to work with the physio to get her walking back but it just hasn't  
15 worked because it's only happening once a week, and it's just not enough to get that back and she's still now very much struggling to eat sufficiently in order to put on weight. So she has put on a little bit of weight but not enough to really repair that. And I think that that's, you know, a thing of dementia as well, that they no longer want to eat and they no longer recognise some foods that they used to like and their  
20 appetites deteriorate. And so it's always a real struggle to try and get them to maintain weight and it's something we had to do the whole time mum was with us.

MS HILL: Can I take you to the present day, March 2019. How are you and how is your family?  
25

MS ELLIS: Look, I think, you know, I think we're still really struggling to this day. Mum now lives over an hour from me. She lives closer to my sister but to tell you the truth, I'm exhausted. I travel up and down that highway several times a week to visit her because the reason she came to live with me was because my brother and  
30 sister are hopeless. Maybe I shouldn't have said that on the record but, you know – and I was the one that did everything for her. And they've picked up a bit but not enough so I'm driving up and down that highway. I saw her four times last week and my brother saw her once, and my sister saw her twice. So she's living over an hour from me, really close to them and you, know, I'm exhausted.

35 And, of course, she's not there any more. You know, like I said to her, just a couple of days ago because she was always really proud that, you know, I was a lawyer and you know, wow, you coming from her humble beginnings and I've got a daughter that's a lawyer. I said to her the other day, "Mum, do you know what I do for a  
40 living?", and she looked at me and said "No". I said, "Do you know what anyone else does, what Jane does?" "No." "Do you know what Stephen does?" "No". She wasn't even interested to ask. So, you know you're being there for her in circumstances where she's not even really there any more. She's not interested in what I do. I should say that we're really lucky that mum remembers all of us, every  
45 single one of us, and I know that's really unusual with dementia but she knows exactly who we are when we walk in. And I'm grateful for that because, you know, I

hear the stories where, you know, they're not recognisable by their mum and how hard that is.

5 My mum might not know what I do for a living or where I am in my life. Sometimes she forgets that I'm partnered even. But she always remembers me and she always remembers my daughter, and usually remembers my partner when she sees him face-to-face. May forget him if he's not in front of her. So we're really lucky to have that. But it's exhausting and, you know, even having her in care in a nursing home, I'm not sure that it's actually easier because, you know, I'm running around even  
10 more so than when she was right next door. I'm worried that they are not feeding her enough so I take her food every single time I go there, and you know, I'm still making my own appointments for the GP to go and see – the GP that's now attending upon her at the nursing home. So I'm still running around doing everything for her. It just creates real difficulty.

15 I also, I talked about in my statement one of the things for carers, you know, I had to contact Centrelink and I had to contact the Department of Vet Affairs and Medicare and all of that, and each time I did those sorts of things, you were met with barriers and it was several hours to contact Centrelink. It was several hours. I even tried to  
20 contact Centrelink just the other day, and for two days their phone number was engaged. So you know there's these constant barriers that are within the department of whatever it's called these days, that my life could just be made easier. I'm not ringing Medicare to change my mum's address for me. I'm doing it because it's the right thing to do and I just don't know why those little things that could change in the  
25 system don't happen to make our lives that bit easier because while I'm spending an hour at the Centrelink office, while I'm spending an hour at the Medicare office, while I'm doing those things, it's time away from my family, it's time away from my four year old, it's time that my partner is being the primary carer and it's time away from mum.

30 So, you know, there's just such, those little things could just go such a long way to preserve my sanity, to make my life easier so I can focus on being a carer instead of focusing on the administrative stuff, you know. And, you know, it just – there's constant barriers that just come up within the system that makes it all so much  
35 difficult.

MS HILL: Thank you Ms Ellis. Commissioners, that concludes my examination of this witness.

40 COMMISSIONER TRACEY: Thank you. Ms Ellis, when you were giving your evidence earlier, you referred to the transitioning arrangements that occurred in relation to your mother in 2017 where she moved from being on the top of the list to somewhere in a national list. Did you ever get any correspondence from My Aged Care that explained that change and what was involved in the transition?  
45

MS ELLIS: Not that I recall. I mean, I may have – I mean, I knew – I certainly knew that those changes were happening but there was certainly never any – any

clear explanation about how the list was going to be managed, and certainly never any certainty of where on the list we were. In fact, when I ring – when I rang My Aged Care to say, “Look, what’s happening? We really, really need this level 4 package”, they would say, We simply can’t tell you where on the list. It’s being  
5 managed and we can’t give you any indication of where on the list you are”.

COMMISSIONER TRACEY: On a different subject, you said that it would have assisted you had some daily respite care been available for your mother. There are some aged care facilities that offer things like a daily drop-in centre where the  
10 dementia sufferer and others can sit around, engage in activities that they want to be involved in; it may be quite simple things. But there are appropriate carers there and that gives a break to the full-time carer. Is that the sort of thing that would have assisted you, had it been available to you at the time?

15 MS ELLIS: Yes, most definitely. And we did – we tried to get mum in. Unfortunately the care providers that we had in Caloundra did not have their own day respite facility. So they had to try to make some arrangements to access the Blue Care day respite facility and I’m not 100 per cent clear on what conversations took  
20 place between mum’s care provider and the day respite centre but it just seemed to be that it never eventuated. We could never get it to occur. There never seemed to be agreement there that mum would go along and the arrangement just never happened. I was told at one point that people that are on a Blue Care package get priority over other people that are with a different provider. I don’t know if that was the part of the problem. I was not really privy to those conversations but certainly we did try to  
25 get mum into one of those facilities but completely without success.

So we then – we then got an extended carer on a Wednesday to stay with mum for five hours on a Wednesday, and to take her to bingo. We thought maybe mum want  
30 to get into bingo. She had kind of gone to bingo a little bit when she was about 60-odd and that just, unfortunately, didn’t work. Mum returned home quite aggressive and, you know, didn’t really know where she was. And it just unfortunately never worked out but a day respite centre, I think would have been great. I’m not sure whether, you know, maybe there’s just not enough spaces in the day respite, whether that’s an issue. But like I said, we were just never privy to why that never happened.  
35 They just couldn’t seem to facilitate it.

COMMISSIONER TRACEY: You said that the first you had heard of the obtaining of a level 4 funding package came from the provider. Did anyone from My Aged Care subsequently advise you of the details of that change?  
40

MS ELLIS: Certainly not – no, I mean, I would have got a letter, you know, at a later point in time but no one ever – ever rung me or - - -

COMMISSIONER TRACEY: So did your provider knew about it before you did?  
45

MS ELLIS: Yes.

COMMISSIONER TRACEY: And on a similar topic, you spoke with feeling about the difficulties you've confronted in dealing with other Commonwealth agencies. My Aged Care was, I think, conceived as a one-stop-shop but your experience is that it isn't. Is that right?

5

MS ELLIS: It's a – it might be a phone directory where you can get telephone numbers for other services. It is by far a one-stop-shop – it is anything but that. All that they can do when you ring them is say hey, why don't you try ringing these people, or try that telephone number, or have a look on our website, that will give you some availability and then ring the service providers. There was never a circumstance that I contacted My Aged Care where it was a one-stop-shop. It was always, "Here is some telephone numbers for you to go off and do your own exploration." In fact, when I – when you started inquiring with them as to the more complicated questions such as when mum was kicked out of Opal, My Aged Care were very cagey in being able to provide any information about how the system was supposed to work and the intricacies of the legislation. My experience with My Aged Care is that it's really just an operator assist type facility. They can direct you to places but really nothing more than that.

20 COMMISSIONER BRIGGS: I think, Commissioner, it may be that a number of these rehabilitation type projects of funded in the short-term, and not the longer term and that may well be part of the reason and I do want to follow up this question of rehabilitation. In the nine or subsequently 11 hours of home care and, indeed, in the facility where your mother is now, are there rehabilitation services in that facility, and were they offered as part of the package, home care package?

MS ELLIS: So we were able to access physiotherapy as part of the package as well. I mean, you know that was once a fortnight and, you know, charged at a higher rate from the package. It – certainly I wouldn't have classed it as going towards, you know, rehabilitation, as such. You know, I think it was more, you know, a bit of pain management, mostly for her broken neck. There just wasn't enough direct time with them. Once a fortnight was not sufficient for it to be a rehabilitation component. And I mean, even now mum is having physiotherapy once a week and that's just not simply enough for rehabilitation. In the home that she's in at the moment, they do have a physiotherapist there but, of course, because mum has been classified as a two-assist, they're doing nothing more than giving her some little exercises while she is in bed.

40 So, again, it's probably management as opposed to any form of rehabilitation. I understand, though, that a physio there – because I hire a physio to go see mum. So the physio that is seeing mum at the moment every week is actually a privately funded one. I understand, I think – so they tell me, the physio sees her maybe once a week but does very little with her, just the in-bed exercises and then an assistant of the physio does kind of go and have a bit more of a chat and how are you feeling today, Terry – they call her Terry for short – and that sort of thing but really doesn't do a lot more than that with her. So it's more, I think, maintenance as opposed to any rehabilitative component, in my view. In fact, one of the reasons why I am

5 paying privately – or mum is paying privately for a physio to come once a week is because I know that’s the only time that mum actually stands up during the week. At no other point does her two feet touch the ground, and she stands upright, because their physio just simply won’t do it because mum as two-assist and I have asked them to do that and they won’t because she is a two-assist.

10 COMMISSIONER BRIGGS: You spoke quite eloquently about the burden that one of several children tends to bear or sometimes bears in watching out for their elderly relative. You didn’t get in your evidence, though, as to how you see stronger support for you as a carer operating, apart from the respite issue. Can you talk to us about what you’re looking for. Is it help with the coordination of the services, or what is it?

15 MS ELLIS: I guess – I guess I’m not really 100 per cent sure. I mean, I think that removing barriers like, you know, being able to change mum’s address with ease. And you know, I mentioned in my statement that literally the Department of Social Services at Caloundra, they all sit in a big open room like this. So Medicare is here and, you know, Centrelink is there, and yet I have to spend an hour, you know, at different occasions to be able to change mum’s address with each of them because  
20 they won’t just share information. So I think it’s about time – it’s about giving me back time that I’m losing with little things like that, I think. And I don’t know – I mean, I think – I did struggle to come up with ideas but, you know, I think that it’s probably something that, you know, a think tank could do. But I guess my point was that I thought it was very important because you care for the carers. The carers are  
25 caring for the elderly. The elderly don’t go into a nursing home. They have a better quality of life and it’s cheaper for the government. So it just seems to be a win-win to provide that flow-on.

30 Because I think that the carers are the best people to care. I know my mum. I know her intimately. I go there to the nursing home and they’re giving her food she doesn’t like and just trying to shove it in her face. Mum doesn’t say, “I don’t like fish”. They’re still shoving it in her face anyway because she doesn’t communicate now. You know, it’s the carers, we know her, we can communicate on her behalf. I  
35 should say also, I had – and it’s probably not for this Commission – but there are a lot of difficulties with Queensland Health as well, and that created barriers in terms of being able to care for mum. And I mean, particularly before mum got really bad, because she could present okay. And so the doctors at times just refused to talk to me and say, “Your mum is fine”. And I’m like, “No, she’s actually not. She doesn’t  
40 remember seeing you an hour ago. She’s not actually okay.” There were just sort systemic barriers, not only within aged care but also within the local health system, and just across the board. So yes, I’m sorry, I can’t help much further.

45 COMMISSIONER BRIGGS: So, that’s all right. We will be considering the health/aged care interface later on, and certainly we might ask the Department of Human Services about the addresses issue because when the department was formed some years ago, facilitating address and other changes was part of the combination of the agencies. So we might follow that up, I think, counsel.

COMMISSIONER TRACEY: Anything arising out of that?

MS HILL: Nothing arising, Commissioner.

5

COMMISSIONER TRACEY: Mr Henry, you have a statement to tender.

10 MR HENRY: Yes, if I may. There's a statement, Commissioners, dated 15 March 2019. It was provided to the Commission in a redacted and unredacted form and I'm informed through Ms Hill that Ms Ellis is content for the redactions to not go in. In other words, that the full document go in unredacted. And Opal Specialist Aged Care is content with that in those circumstances. So I tender that statement. Ms Hill says she has the document identification number which she might read for the benefit of the transcript.

15

MS HILL: The document ID number to which Mr Henry refers is RCD.0011.0014.0001.

20 COMMISSIONER TRACEY: Opal's response to the evidence of Ms Ellis dated 15 March 2019 will be exhibit 2.08.

**EXHIBIT #2.08 OPAL'S RESPONSE TO THE EVIDENCE OF MS ELLIS  
DATED 15/03/2019 (RCD.0011.0014.0001)**

25

COMMISSIONER TRACEY: Mr Henry, in the final paragraph, you reserved your rights in respect of any further submissions. Do you still wish to preserve those rights?

30

MR HENRY: The short answer is if it's not inconvenient, is that something we could communicate with the Commission's staff this afternoon?

35 COMMISSIONER TRACEY: Yes, certainly. I don't think you will find any difficulty about getting leave to file a supplementary statement if there's significant issues that you simply have not yet had the opportunity to deal with.

40 MR HENRY: Thank you. We obviously don't want to burden the Commission unnecessarily but I will take some instructions and perhaps if we can communicate our position through the staff. Thank you.

COMMISSIONER TRACEY: All right. Thank you. The Commission will adjourn until 2 o'clock.

45

**<THE WITNESS WITHDREW**

**[1.15 pm]**

**ADJOURNED**

**[1.15 pm]**

**RESUMED**

**[2.07 pm]**

5

COMMISSIONER TRACEY: Yes, Dr McEvoy.

DR McEVOY: Commissioner, I call witness BE.

10

**<BE, SWORN**

**[2.07 pm]**

15 **<EXAMINATION-IN-CHIEF BY DR McEVOY**

DR McEVOY: Operator, could you please bring up WIT.0087.0001.0001. Now, witness, is this your statement?

20

BE: Yes.

DR McEVOY: Do you wish to make any amendments to that statement?

25

BE: No, I don't.

DR McEVOY: And are its contents true and correct to the best of your knowledge and belief?

30

BE: Yes, they are.

DR McEVOY: Commissioners, I would tender that statement which bears, as I've said, document number WIT.0087.0001.0001.

35

COMMISSIONER TRACEY: The witness statement of BE dated 13 March 2019 will be exhibit 2.09.

**EXHIBIT #2.09 WITNESS STATEMENT OF BE DATED 13/03/2019  
(WIT.0087.0001.0001)**

40

DR McEVOY: Ma'am, I will refer to you during the course of your evidence as "witness", in the circumstances. I mean no disrespect by that, but that may be convenient. Could you indicate to the Commission which department of the Commonwealth for which you work?

45

BE: I work for the Department of Health.

DR McEVOY: And could you indicate also what your APS level is.

5 BE: I am an APS6.

DR McEVOY: And could you give an indication as to what your daily role involves?

10 BE: Including where I work?

DR McEVOY: Yes.

15 BE: My role is an assessor in the Approved Provider Program Section of the department. My team's role and my job is to assess applications from companies that want to become residential home care or flexible care providers under the Aged Care Act 1997, and we assess those companies against criteria in the Act as to whether or not they meet that criteria and are suitable to provide Commonwealth-funded care.

20

DR McEVOY: One of the points you address on paragraph 6 of your statement is the high turnover of staff. Could you perhaps explain a little bit more to the Commission what you mean by that?

25 BE: So what I mean by that is we have what we would call a small FTE or full-time employed staff. We have three permanent roles in the team for APS6 assessors. The rest of the team is made up of contract staff who, as I've said in my statement, we've been fortunate to get some good contract staff. But that money is not departmental money, it's administered funding that my area must bid for once a year to try and  
30 obtain money to get contract staff from recruitment agencies. Now, once that money runs out or – we've recently had some contract staff who didn't want to do the role any more, and sought opportunities elsewhere. So that's what's meant by the high turnover of staff. It's mainly contract staff that come and go.

35 DR McEVOY: In paragraph 7 of your statement, you mention the answers that application forms require to an extensive list of questions and you mention the four criteria: experience, management systems, understanding responsibilities, and financial management or proposed financial management. I wonder if you might briefly indicate to the Commission what each of those criteria is concerned with.

40

BE: So those, the main one being experience, we are looking to see if an applicant has already got some experience providing aged care. That would normally be in the form of the Commonwealth Home Support Program or CHSP, or care in another supported environment. We're looking, really, have they provided government-funded care where they had to – where they're highly regulated, where they've got to  
45 work within a framework in return for the money that they receive, do they understand what it means to work within legislation, what their responsibilities are.

So if there's an experienced applicant with, I guess, reliable or relevant experience, that's taken into account.

5 Where we can verify, say, if a provider might be – sorry, an applicant might be providing services for DVA, either the Veterans' Home Care program or community nursing, then we can have a look at what their standards are. Are they similar to ours? There's not a lot of places where we can verify if they've been successful in meeting particular standards but that's really around their experience and whether or not they're used to dealing with regulation and legislation.

10 DR McEVOY: Anything else in relation to any of those criteria, ma'am?

15 BE: I think – I think if you wanted me to talk to each criteria, I can around their management systems, that's extremely important. We very much look at the governance systems that these companies may have in place, or they don't have in place, or they don't understand what governance is. They don't understand what – I guess I'm speaking because most of what we see; these things aren't in place and they're not evident in the responses in the application forms. We're looking to who the directors are, what – what skill-set they might bring to that board. Are those 20 skills relevant to the provision of aged care? Can they oversight the delivery of aged care? So management systems is really around their governance and whether or not they even understand what that word means. And when assessing the applications, it's fairly clear the ones that do and the many that don't.

25 COMMISSIONER TRACEY: May I interrupt there. I'm sorry to do this, but we've just been advised that sound has fallen off on the webcast and we may need a short adjournment so that the problem can be rectified. The Commission will return as soon as we're advised that the problem has been fixed.

30 BE: Thank you.

**ADJOURNED** [2.17 pm]

35 **RESUMED** [2.27 pm]

40 COMMISSIONER TRACEY: We have been advised that it has not been possible to correct the lack of sound coming out of [the video-link]. The best that can be done is that the transcript of witness BE's evidence will be available on the Commission's website. If in the course of her evidence, the problem is corrected, we will so advise everybody involved. Yes, Dr McEvoy.

45 DR McEVOY: Thank you, Commissioner. Operator, could you please bring up document CTH.0001.1000.3881. I will repeat that, CTH.0001.1000.3881.

Do you recognise that document, ma'am?

BE: I can't see the document.

5 DR McEVOY: I will move on. I want to ask you about the process. Let me know if that document comes up.

BE: Yes.

10 DR McEVOY: Do you see that document?

BE: I absolutely do and, my word, I recognise it.

15 DR McEVOY: Yes, and that document is the application document, in effect, that providers are required to complete; is that correct?

BE: That – that applicant – yes, it is. That's the one.

20 DR McEVOY: Yes. Commissioners, I would seek to tender that application form document, which bears the number CTH.0001.1000.3881.

COMMISSIONER TRACEY: The application form for approval to provide aged care will be exhibit 2.10.

25

**EXHIBIT #2.10 APPLICATION FORM FOR APPROVAL TO PROVIDE AGED CARE (CTH.0001.1000.3881)**

30 DR McEVOY: Operator, could you please also bring up document CTH.0001.1000.3930. Do you need me to read that again, Operator; CTH.0001.1000.3930.

35 Witness, while the operator attempts to bring that document up – here we go. Do you see that document, ma'am?

BE: Yes, I can.

DR McEVOY: And - - -

40

BE: And yes, I recognise that.

DR McEVOY: And that document, is, in effect, a set of guidance notes for - - -

45 BE: That's right.

DR McEVOY: For applicants. Commissioners, I would seek to tender that document as well; guidance notes for applicants, CTH.0001.1000.3930.

5 COMMISSIONER TRACEY: Yes, the document entitled guidance for applicants seeking approval to provide aged care will be exhibit 2.11.

**EXHIBIT #2.11 DOCUMENT ENTITLED GUIDANCE FOR APPLICANTS SEEKING APPROVAL TO PROVIDE AGED CARE (CTH.0001.1000.3930)**

10

DR McEVOY: Thank you, Commissioner.

15 Now, witness, can I ask you about the guidance that officers are given when it comes to the assessment of applications?

20 BE: There's not really a training program for new assessors. There are – there's the three permanent APS6 positions; we've each been there for quite some time. What should happen is the supervisor of the team would ideally have time to sit down with new contract staff and explain to them an overview of the aged care system, because it is so complex, where we fit in, and how an assessment is made, including applying fairness to the applicants, good, bad or otherwise, insofar as the quality of the application – I'm not commenting on whether the people are good or bad, but the quality of the application. What really happens is they're given a copy of the Act, the Aged Care Principles, and given a caseload of assessments to start working on. As I said earlier, we have been lucky to get some contract staff that have been very good. But they still need a lot more help and support than they receive.

30 We try and help them where we can, explain to them the aged care system, what we do, why we do it, and that's really what happens. It's kind of get – the workload builds up so much, it's get these people in quickly and get them working on assessments. And it's not uncommon that they will really work a lot of it out for themselves. Where we can, we give them copies of assessments that we have done. We will show them a copy of "This is a really good application. This is the benchmark." A copy of a very bad application, "This is what a bad application looks like." We will then give them a copy of the assessment that has been made and the recommendation to the delegate, particularly if it's a not-approved assessment. Then it's not easy for them just to come in, really, with often no background or understanding of aged care or the legislation that surrounds the sector and be given the responsibility to recommend whether or not a company should or shouldn't be let into the sector.

45 DR McEVOY: Well, just stopping you there, is it your evidence that, in fact, there's no actual program of training given to assessors?

BE: That's accurate. It's very ad hoc, if I could put it that way.

DR McEVOY: All right. In paragraph 12 of your statement, you deal with, or you start to deal with the way you go about making an assessment. Can you give the Commission an indication of how long it takes to complete an assessment of an approved provider application?

5

BE: So, whether it's an approve or a not-approve, it would take me a week and a half to two weeks to assess an application. That's from the very beginning to when the recommendation is made. That will include reading their application.

10 Sometimes there's just an abundance of information that they provide. It all has to be read through before it's – if we miss something, well, that might be the one thing we miss that is relevant to their application and their suitability. So it all has to be read. Where possible we will verify the statements that they make – or the claims, I should say, that they make in their applications. Then I guess it depends on which assessor it is, and how we work, but there's lots of notes taken around is this going to be a not approved application? Is it a straight up so good that it can be approved, or there's that middle category where they seem to have, you know, good governance in place. They might understand their responsibilities but there could be some questions around financial management or experience. So in those circumstances a request for further information is issued.

20

But that then kind of halts the process there. But if it's from woe to go I will use a not approved because that's mainly what we see; it will take me two weeks, to make sure I've picked up every single, I guess, point where they have – where they've demonstrated they're unsuitable, as well as giving them the benefit of anything positive that's in there, because I was always taught, before a recommendation is put before a delegate, that they must have all information before them, good and bad, so that they can turn their mind to everything and make a fair decision based on the recommendations. That takes a lot of time to craft that properly.

25

30 DR McEVOY: Yes.

BE: It's not just the assessment instrument that has to be filled out, which is extremely laborious. That then has to be translated into their notice of non-approval, which doesn't run in line with the assessment instrument and application form because those four criteria are very distinct. So you've got to take information from the assessment, translate it into a notice, into a way that that applicant will understand where they've been found unsuitable and why, in fairness to them. Well, that's part of our job. But it takes a long time because if it's a not approved, that decision is reviewable within the department, a different assessor, a different delegate and then - - -

35

40

DR McEVOY: So you've said - - -

BE: Sorry, you go.

45

DR McEVOY: So you've said that takes about two weeks, I think, on average.

BE: Yes.

DR McEVOY: How many - - -

5 BE: That's right.

DR McEVOY: How many applications are allocated to each staff member for review, at any one time?

10 BE: So when you say – I will just - - -

DR McEVOY: Well, for assessment.

15 BE: Okay. Thank you. Only because we use the word “review” for the reconsiderations. But – so at the moment, I would have 13 at least. What happens is those - - -

DR McEVOY: Just – so you say you would have 13 at any one time.

20 BE: Yes.

DR McEVOY: And it normally takes you about two weeks to process the 13. So that means that there's, effectively, about 26 weeks work for you at any one time.

25 BE: That's right.

DR McEVOY: And so how many staff carry out the function of assessing these applications for approval?

30 BE: At the moment, in the team there's the three permanent staff, and we have two contract staff, and another APS6 departmental staff member has been pulled in from the section – a team that has a function unrelated to ours, to try and help with the workload. So, effectively, there's six.

35 DR McEVOY: Okay. So in paragraph 14 of your statement, you say there's pressure not to allow any application to go over 90 days.

BE: That's - - -

40 DR McEVOY: That's correct?

BE: That's right.

DR McEVOY: Yes. How many.

45

BE: There's a lot of pressure.

DR McEVOY: How many, if any, applications, would expire? In other words go past the 90 day period?

5 BE: I can't tell you exactly how many at the moment are over 90 days. I can tell you that I would have some going over 90 days, as we speak. I don't know how many of the others have gone over 90 days. I know it was – it's just getting to that critical mass again where they are starting to go over 90 days. That's at the moment. I can speak more historically around last year but at the moment I don't know the exact number, I'm sorry.

10 DR McEVOY: Well, just looking at yourself, is that number on the increase or on the decrease?

15 BE: It's on the increase.

DR McEVOY: In paragraph 16 of your statement, you observe that there are a variety of applicants which include sophisticated providers and what you refer to as "bottom feeder" applicants.

20 COMMISSIONER TRACEY: I think that might be a different paragraph, Dr McEvoy.

DR McEVOY: I'm sorry, Commissioner.

25 Paragraph 15; do you see that?

BE: Yes. Yes, I do. Yes. Yes, they are my words.

30 DR McEVOY: And what do you mean by that exactly?

BE: What I meant by "bottom feeder applicants" is there's a very large cohort of companies that I believe see home care as a business opportunity, and not much more than that. The reason I refer to them as "bottom feeders" is the quality of their applications is so poor, it is so obvious that they have not even taken the time to read the guidance for applicants, which was the document you put on the screen earlier. They don't understand what their responsibilities would be as an approved provider. They are applications that will – and I'm speaking primarily – this is really home care applicants. They will have references in there to legislation which does not exist. They will have references to other government-funded programs such as the NDIS, which has got nothing to do with our application.

45 They – the fact that they spend no time understanding what it means to provide home care, yet think that it's okay to submit an application for what I suspect they think is a tick and flick process, when it isn't, it makes me angry. It makes my team angry that we have to spend extraordinary amounts of time keeping these people out of the sector because, as I've said previously, I believe that they're dangerous. If they can't be bothered to even read the guidance that goes along with the application, if they

don't know what the home care common standards are, if they don't know what the services that have to be delivered under schedule 3 of the Quality of Care Principles are, if they don't know that they have to provide clinical care if someone needs it, then they have no business making an application, because the message that comes through is there is no regard for the care recipient on the other end that they think they will get to take care of. It's frightening to me that there's so many of them out there. So that's what I mean by "bottom feeders", is there's just no regard.

DR McEVOY: Yes, and what proportion of applications that you review, that is to say that you assess, would you regard as falling loosely within that category?

BE: This is not based on my own statistics but I would say eight out of 10 of them. You just – I pick them up and I start reading them and I just – I look and I go, "Here we go again."

DR McEVOY: So you would say eight out of 10 that you look at fall into the bottom feeder category, would you?

BE: Yes, I would.

DR McEVOY: When you say that's not based on your statistics, what do you mean by that qualifying - - -

BE: Like, that's more – that's my – like, they keep statistics on each of the assessors but I would – not colloquially but my guess is eight out of 10 of what I look at is rubbish.

DR McEVOY: Well, just on that subject, ma'am, in paragraph 18 of your statement, you make the observation - - -

BE: Yes.

DR McEVOY: - - - that you find some applications that have the same words in them, at times almost identical, and you make reference to consultants in the sector who you think are available to assist in making applications. Do you see that?

BE: Yes. Yes, I can.

DR McEVOY: To what extent would you say that you find those sorts of, if you like, pre-completed application forms, if that's an expression that you would be prepared to adopt?

BE: Yes, I would adopt that expression. I can't give you a statistic but I would say maybe 40 to 50 per cent will see a spate of the same application come through. The first time, say, that application from that consultant might come through, if it's a good one, then that applicant – and they tick the boxes. Then that applicant will be found suitable, and they will go ahead into the sector. It may not be until two or

three or four or five have come from the same consulting company that we realise, through talking with each other – and that’s an advantage of being a small team, is that some of the things, again, that they write in these applications are ridiculous, and we might say, “Oh my gosh, listen to this.” And then another assessor will say,  
5 “Hang on, I’ve just done one like that” or “I’m reading one that’s got those words in it”. And then we can compare applications and realise that they’ve got a virtual copy and paste, which does not prove suitability in any way whatsoever.

10 DR McEVOY: Can you give the Commission some specific examples or a specific example of the sort of thing you’re talking about?

BE: As in the copy and paste applications?

15 DR McEVOY: Yes, that’s right.

BE: So some things that really stand out, again, with consultants who I would think prey on the bottom feeders, they will have references – in a home care application, they will have references to residential care. They shouldn’t be there. They will have references to what used to be called the Residential Care Standards which is  
20 legislation repealed many years ago. They will talk, again, about legislation or guidelines that don’t exist any more. And that, one, a consultant is prepared to give an applicant that kind of rubbish and the applicant knows so little about home care and what it is they’re applying for, they don’t even pick up where the consultant has made such obvious errors if you understood home care and what it means to provide  
25 home care.

So that’s an example of some of what we see with what the consultants do. And, unfortunately, the applicants, or the directors, the key personnel of these companies, are signing the last page of the application form saying everything is true and correct,  
30 yes, I’ve read the guidelines, yes, I understand everything, and they absolutely don’t.

DR McEVOY: So these sorts of, if you like – I think you’ve accepted my characterisation of what you’ve said is pre-completed application forms – these sorts of applications; would you say they’re routinely refused or routinely approved or  
35 neither or what would you say about that?

BE: No, no. Routinely not approved because, again, I mean one of the criteria – understanding their responsibilities – how can they understand their responsibilities if they think that they need to follow the residential care standards in a home care  
40 application. They’re not hard to kick and then knock out. It just takes a lot of time to do that properly and fairly, as I said, because it’s internally reviewable and, again, can end up at the Administrative Appeals Tribunal.

DR McEVOY: So do these sorts of applications take more time than applications  
45 that don’t feature, if you like, pre-completed information?

BE: Look, they all take a lot of time. Any not approved takes a lot of time, but, yes, there's – there are things that need to be brought to an applicant's attention if they've used a consultant, and that can be – it's common to put in the not-approved notices that we are aware that this information has been received before, it's not reflective of  
5 your policies, your processes, your understanding of home care. So that they are routinely knocked out, yes. But they will come back again for a reconsideration under the Act. I think the consultants - some of them, will get very angry once they realise they've bought a product from a consultant that is of no value to proving suitability under the Act. So – but they still will take up – many of them, not all –  
10 but many of them will take up the option to have the decision not to approve them reconsidered under the Act. So then they have to be assessed again.

DR McEVOY: Can I take you to paragraph 23 of your statement. You make the observation there that in your view:

15 *The home care reforms which effect on February 2017 have had devastating consequences to the quality of care available, particularly once the Aged Care Approvals Round (ACAR) was removed for home care packages.*

20 And you say in particular, in particular, that:

*This created a “free-for-all” attitude amongst provider applicants [and] that [they] began to apply in unmanageable numbers for approval to provide home care.*

25 Can you just elaborate a bit about that and, in particular, what you mean by a “free-for-all attitude” amongst provider applicants?

BE: Yes. So the – prior to the reforms taking place, an approved provider home care or residential but I will just stick with home care, they will have to get an approval from my team and then they would wait for the Aged Care Approvals Round or the ACAR to be announced. They would then have to apply for packages in the ACAR, which is a competitive process, and only the best applicants would be given home care packages. The reforms reviewed home care packages from the  
30 ACAR. It took away a second vetting process. The way it was marketed and, I guess, informed to the general public is all they needed now, these companies, was an approval. So – which again, from my team, and that's where it stops. So they get the approval and then it's up to them as to when they want to start providing home care.

40 They then have a process to go through with My Aged Care and registering their company, their services on My Aged Care through the portal. That's not something my team has anything to do with. But that is what created the free-for-all attitude insofar as – I think it was just seen as a big business opportunity to get in and make  
45 some money. If I could provide an example. Say, there may be somebody on a home care package who has had a gardener coming to do their lawn for however many years, and then the care recipient might say, “I'm getting a home care package now, maybe I could pay you to do my gardening out of my home care package”.

And then the lawn mower might say, “Well, how I get paid from your home care package? I will call My Aged Care”. My Aged Care tells them they have to become an approved provider, which is not the case.

5 So the free-for-all – it was kind of like there’s this big – what I think the public assumed to be a big bucket of money ready there for people who were industrious, who wanted to start businesses. It was, “Let’s get in there and get some of that money” which just opens the floodgates, and as we’ve talked about, brought out a lot of the bottom feeders. And many people who use a lawn mower for an example, he has got no ill-intentions. He just doesn’t understand that he can’t be – well, you can have a go at becoming an approved provider, but he can’t just mow the person’s lawn. He has got to be able to take care of their clinical needs. He has got to have somebody there who is going to do a needs assessment, who is going to care plan, who is going to monitor, who is going to review. Do they have third party arrangements in place to use brokering agencies. How are they going to oversight that? There’s no way somebody who just wants to mow the lawn is going to be an effective approved provider, but they apply anyway.

20 DR McEVOY: Can I take you to paragraph 26 of your statement. You make a reference there to having, in more recent times, got a lot of people we refer to as “scheme hoppers”. What do you mean by the use of that expression, “scheme hoppers”?

25 BE: So what I mean by that is we saw a wave of family day care providers applying from the Melbourne area. They were, I guess, heavily supported by consultants. So they would be registered for family day care. They would then think, “I will register for NDIS as well”, because that – my understanding is that it’s a registration process. I’m not 100 per cent sure but that’s my understanding. And then they would think, “Well, home care, the rules for home care have just been loosened greatly, so let’s have a go at putting home care in our range of services we can offer as well.” But not understanding, I think – and, again, this is just my opinion, but having – because it’s much easier to become a family day care or NDIS provider, I think they approached home care with the same attitude that they just had to put something in an application form and they would be approved and off they would go, ready to provide home care. So that’s what I mean by “scheme hoppers”. They seem to be companies trying to get these three programs in their suite of care and services they think they can offer.

40 DR McEVOY: So in paragraph 28, you talk about how there would have been applicants who slipped through – the words you used “slipped through” – with an approval before you realised, or your section, I take it you mean, realised that the consultants are out there. Why, exactly, would there have been people slipping through, in your view?

45 BE: Well, because the numbers came – well, the applications came in such great numbers but then it really depends on chance, almost, if, as I said before, because we’re a small team, you might read something very inappropriate in a home care

application. and say that out loud to the person next to me, or somebody else might say that. So if you don't know that there's a consultant who has given, you know, X number of applicants the same application, the first time you see that application and if it – if they can demonstrate suitability, then there's no choice but to recommend  
5 that they be approved. To not do so would be unfair. That's what they have to do, is demonstrate suitability under the Act. And unless we – as I said, unless the team – someone says such and such, listen to this, then we don't know that it's a consultant or a copy and paste application.

10 DR McEVOY: In paragraph - - -

BE: There is no one to triage.

15 DR McEVOY: There's no one to triage because, as you say in paragraph 29, your section was not, and still is not, staffed adequately to be able to devote the time needed to assess the volume of applications. Do you see that?

BE: Yes, I can't see it on yours but I've a copy of my statement in front of me. So yes, I can see what - - -

20

DR McEVOY: In paragraph 29.

BE: Yes.

25 DR McEVOY: And what you say in the second sentence of paragraph 29 is you've raised this issue more times than you can count over the years and nothing changes. Can you see that?

BE: That's right. Yes, I do.

30

DR McEVOY: So can you tell me what it is you have done when you have raised this issue, how often have you raised it, to whom have you raised it?

35 BE: So the issue is always raised in section meetings, or our assessor team meetings. That's – it's just a given now. But most recently – and this is, I mean the understaffing has been a problem for quite some time but most recently I raised the issue directly with my branch head in a branch meeting when he wanted to discuss the branch's – what they call in the department, a pulse survey, how is the branch going type thing. There was a decline in some of the results, and he opened the  
40 floor. He's a very decent man. He opened the floor to staff to give their opinion as to why they thought the results had taken a dive. And I said, you know, "Perhaps if we were resourced properly to do the work we need to do and to deliver on these reforms properly, then you wouldn't have staff complaining about workload, stability in the workplace, and things like that, that staff are just burnt out."

45

And so I raised that with him in a very public forum and then I also raised it with him – he wanted to have individual section meetings with each section in the branch

because people can be more likely to speak freely in a smaller group. And I again raised it with him then, and the answer was creating permanent positions is a risk. And I don't know what that means, as to why that would be a risk, but that was the answer I was given. So it has been raised extremely recently, not just over the years.

5

DR McEVOY: Can I ask you to what extent you're aware of whether an approved provider can, in effect, return its approval should it decide not to offer home care services having obtained approval?

10 BE: It – well, it can ask to return its approval, but the branch and the – I'm not sure of the branch name that the aged care compliance team sits under. The only way for them to technically to hand back in their approved provider status is to be revoked under section 10(3) of the Act, which is quite a process to go through. There used to be provisions many years ago in the Act to allow a voluntary, I guess, revocation of  
15 their own status. But, yes, there have been – I can't – I don't know exactly how many but I would describe it as a handful at the moment who are trying to hand back their home care approvals, and my area, and I believe the compliance area that would normally revoke someone's status, I don't – I think there's some discussions going on between them about how they will do that. They have sought legal advice around  
20 how to do that, and I believe been told that it can only be done under section 10(3) of the Act.

DR McEVOY: Commissioners, I have no further questions.

25 COMMISSIONER TRACEY: Just one question from me. I assume from what you have said that it's a lot easier for the assessor to come up with a positive assessment than a negative one because if there is a negative one then it has got to be written up fully as against the possibility of an AAT challenge. Is that right?

30 BE: Commissioner, the time taken to assess either an approve or a not-approve, both – the assessment instrument is the same. There's still a lot of work to be done on an approve for every question in the application form. There's a corresponding question on the assessment instrument. So to give you an example, the one I most recently did and approved for was 7000 words long, and that's not the norm. It  
35 shouldn't take that long to do an approve. The difference in the time taken is the notice that they get. If it's an approve, then there's no need to translate the assessment into all the reasons for why they were not approved, relating all the time back to the Act. So an approve notice is virtually a template where they just change the name and the company's name and the details specific to them.

40

A not-approve is a different thing, because, as I said, that assessment has to be translated into the notice which can eventually – not often, but I think we should always be mindful that any not-approve could end up with the AAT. And that's why I believe they have to be shown fairness in the assessment that's made on them. And  
45 I guess I do go to great lengths to make sure – sometimes it takes a long time to just pick every little thing that they've got wrong and show them, in that notice, this is

why, you do not understand. So, yes, the assessments can take as long but the notice doesn't take nearly as long for an approve.

5 COMMISSIONER TRACEY: A related question is this: given that you, at the moment, have, I think you said, about 13 cases in your docket to be assessed, and  
- - -

BE: Yes.

10 COMMISSIONER TRACEY: - - - you're taking an average of two weeks to deal with each of them, then the one at the bottom of the list is not going to be resolved for roughly six months.

BE: You're exactly right, yes.

15 COMMISSIONER TRACEY: And in the meantime, presumably once you've resolved the case at the top of your list, you get a new one. So you've got this constant burden. And what I want to get a feel for is whether you are typical of the group of six that undertake these assessments, would everybody have roughly the  
20 same workload and take the same amount of time to deal with individual cases?

BE: So most of us take the same amount of time as I do. We do have one member of the team who is quicker than the rest of us. She may take a week, maybe a week and a half at the most. She tends to – she will do a full and thorough assessment but  
25 might not write as much in the assessment instrument or the notice. But she would move through more applications than the other assessors, yes.

COMMISSIONER TRACEY: And does that mean she gets more work allocated to her docket?

30 BE: Yes, it does.

COMMISSIONER TRACEY: Yes, and has the point been reached where allocations stop because each of the six of you are overwhelmed?

35 BE: No. They – as a new bunch comes in and as they're ready to be allocated, they're still allocated because if a question comes from an applicant or if an applicant is getting a bit antsy because it is taking some time and if they go to their local member or make a complaint, then the department likes to be able to say that it has  
40 been allocated to an assessor. In my case, I might not get to read an application until the eleventh hour but they can still say it has been allocated to an assessor, but it doesn't mean it is being worked on.

COMMISSIONER TRACEY: Thank you.

45 COMMISSIONER BRIGGS: Thank you, witness. It is Lynelle Briggs here. I just wanted to ask you, if you feel that the range of providers that are being approved are,

in fact, suitable for approval – improvement. So I'm really trying to understand whether the assessment process is working or is broken.

5 BE: The assessment process is working, and I say that because, as I said in my statement, the team's culture has always been that we work for the care recipient. We don't work for the applicant. We don't work for the provider. So there is no attitude whatsoever amongst the team. And that includes my direct supervisor, my director, my branch head. There is no way that we would purposely let an unsuitable provider into the system because it was quicker or easier to get through the workload. 10 That is just not what we're there for. So the assessment process is working but it's extremely inefficient. And if we were adequately resourced, we could move through the applications in a timely manner. As I've said in my statement, whether the application is good, bad or somewhere in the middle, these companies still have a right to get their answer within the first 90 days.

15 It's not uncommon if we get to an application – or I will speak about myself – get to an application at the eleventh hour. I recently had one. I thought from reading it that they had a lot of good infrastructure and governance in place. There were some questions around responsibilities. That request for further information was sent to 20 them on day 88. Now, that, if that – it's really – it's not good practice but that's the position that we are in sometimes. That it's just what we have to do. So, yes, the assessment process is – it's working but it can work so much better. I mean, my whole point in making this submission is how can we deliver on the home care reforms – and we know there's a wave coming -how can we do that when we've got 25 three permanent staff that are constantly supplemented with contract staff that need training.

They get up to speed, they go, and it starts again. It's – you know, there's a lot of – I guess the team has a lot of heart in what we do. And there's just such – so little 30 support or little understanding, is my perception, of what we do that – and I think that's why we constantly are just expected to keep on keeping on.

35 COMMISSIONER BRIGGS: Thank you. So that, in effect, implies that were the process to, in your words, be more efficient than you suggest and people would be trained properly and more ongoing staff, then there may well – the department may well be better positioned to facilitate the growth in services that may well be imagined would align with the growth in the demographic of people needing care.

40 BE: That is a perfect way to sum that up, Commissioner, yes. Thank you.

COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising out of that, Dr McEvoy?

45 DR McEVOY: No, Commissioner.

COMMISSIONER TRACEY: Yes, Mr Free.

MR S. FREE: Just before the witness is excused. I have an application, I'm Mr Free, I appear for the Commonwealth which has been given leave to appear, and I would seek leave to ask a short number of questions. Sorry, I seek leave to ask a short number of questions of BE.

5

COMMISSIONER TRACEY: On what topic?

MR FREE: A couple of issues that have arisen in her evidence today which aren't in her statement, and otherwise going to the last sentence of paragraph 21 of her statement in which she makes a reference to having a bad feeling about applications. I anticipate it will only be in a matter of five or 10 minutes, Commissioners.

10

COMMISSIONER TRACEY: Yes. Well you have leave.

MR FREE: Thank you, Commissioner.

15

**<CROSS-EXAMINATION BY MR FREE**

**[3.21 pm]**

20

MR FREE: BE, my name is Mr Free. I appear for the Commonwealth. I just have a number of questions for you, beginning with, at the end of paragraph 21 of your statement, you make reference to having a bad feeling on some occasions about particular applications.

25

BE: Yes.

MR FREE: Do you recall that? Now, if you develop - - -

30

BE: Yes.

MR FREE: If you develop a bad feeling in the course of your assessment of an application, you take steps to investigate and assess to try and get to the bottom of whatever you had the bad feeling about?

35

BE: That's right.

MR FREE: And you can discuss that with your supervisor and with the delegate, if need be?

40

BE: If need be, yes.

MR FREE: And one of the options in that scenario is you can call the applicant, for example, if you want to test them verbally to see if they can verify what they might have said in writing?

45

BE: Yes.

MR FREE: And depending on that response, you might issue them a request for information?

BE: Yes, that can happen.

5

MR FREE: Or on some occasions you might go straight to issuing them a request for information if you've got a bad feeling about the application?

10 BE: No, not necessarily. If their application as a whole – are you referring to the not approved applications or the ones where, say, when I say “bad feeling”, I refer to applicants that may have come in – I had one that had come in for its third time, and this time they had demonstrated suitability because they had said, in the application form, I guess what they needed to demonstrate they had systems in place. Now, whether or not that was a consultant, we don't know. But this organisation in  
15 particular were not very nice people to deal with over the phone. They were aggressive. And – which again is not a criteria under the Act but can be an indication of how they deal with people, if they were prepared to deal with the regulatory body in that manner, then how will they deal with a care recipient making a complaint. However, they demonstrated suitability. They have to be approved  
20 regardless of whether or not there's that gut instinct that they shouldn't be in the sector.

MR FREE: So in that scenario, you made an assessment based on the criteria for approval that they satisfied the criteria; is that right?

25

BE: Well, that – yes, that's what we have to do, yes.

MR FREE: Thank you. Now, you're not personally involved in the recruitment of new staff including the hiring of contractors, are you?

30

BE: I was at one point, maybe two years ago, but no, not now.

MR FREE: Thank you. And when a new assessor joins the team, they sit with either the director or the team leader and they're taken through a process of one-on-one training; is that right?

35

BE: If either the director or the team leader have time, yes. That is not common.

MR FREE: Thank you. Nothing further, Commissioners.

40

COMMISSIONER TRACEY: Yes, thank you, Mr Free. Anything arise, Dr McEvoy?

DR McEVOY: Nothing further, Commissioner.

45

COMMISSIONER TRACEY: Ms BE, thank you very much for your evidence. We are most grateful to you for having made the statement and given the evidence today. There will be a short adjournment while the [video-link] is broken.

5 BE: Thank you Commissioner, for the opportunity.

**<THE WITNESS WITHDREW** [3.25 pm]

10 **ADJOURNED** [3.25 pm]

15 **RESUMED** [3.34 pm]

COMMISSIONER TRACEY: Yes, Dr McEvoy.

20 DR McEVOY: Commissioner, I now wish to call Paul Michael Sadler but my learned friend may wish to announce an appearance.

MR D. LLOYD: May it please the Commission, my name is Lloyd. I appear for Mr Sadler. I understand that leave has been granted.

25 COMMISSIONER TRACEY: Yes, it has, Mr Lloyd and thank you for announcing your appearance.

DR McEVOY: Commissioner, I call Paul Michael Sadler.

30 **<PAUL MICHAEL SADLER, SWORN** [3.35 pm]

35 **<EXAMINATION-IN-CHIEF BY DR McEVOY**

DR McEVOY: Operator, could you please call up WIT.0078.0001.0001. Mr Sadler, do you see that statement on the screen?

40 MR SADLER: I do.

DR McEVOY: And is that the statement that you have prepared?

MR SADLER: It is.

45 DR McEVOY: And do you wish to make any amendments to that statement?

MR SADLER: No, I do not.

DR McEVOY: And are its contents true and correct to the best of your knowledge and belief.

5

MR SADLER: They are.

DR McEVOY: Commissioners, I would seek to tender that statement, which bears the number 0078.0001.0001.

10

COMMISSIONER TRACEY: The statement of Paul Michael Sadler, dated 11 March 2019 will be exhibit 2.12.

15 **EXHIBIT #2.12 STATEMENT OF PAUL MICHAEL SADLER DATED 11/03/2019 (WIT.0078.0001.0001)**

DR McEVOY: Thank you, Commissioner.

20

Mr Sadler, could you give the Commission your full name.

MR SADLER: Paul Michael Sadler.

25 DR McEVOY: And your professional qualifications.

MR SADLER: I am currently the CEO of Presbyterian Aged Care, and my professional qualifications include a masters in social work.

30 DR McEVOY: And what experience have you had in the aged care sector, would you say?

MR SADLER: So I've been working in the aged care sector for over 30 years in a range of roles, including as a social worker, including time with an aged care assessment team working for the New South Wales government, including managing the then Home and Community Care program for the New South Wales government; working with Aged and Community Services in a peak body support and lobbying role and now as CEO of an aged care provider.

40 DR McEVOY: And could you give the Commission a little bit of the history of Presbyterian Aged Care.

MR SADLER: So Presbyterian Aged Care has existed since 1942, Commissioners. It was set up by the Presbyterian Church in New South Wales to provide care and accommodation for older people, and we do that with a commitment to excellence inspired by the life and teachings of the Lord Jesus Christ.

45

DR McEVOY: Now, it would be right to say, would it not, that as at the moment, you're providing home care package services to something in the vicinity of 830 people.

5 MR SADLER: Counsel, we are providing home care services, including Commonwealth Home Support to around 500 people, home care packages to about 130 people, and then also private paid services to the balance, and our total number of people receiving home care services is around 830 each week.

10 DR McEVOY: Yes. And could I have you, Operator, please bring up document RCD.0011.0010.0017. Now, do you recognise that document, Mr Sadler?

MR SADLER: I do, that is our current home care package fees schedule.

15 DR McEVOY: Commissioners, I would seek to tender that document.

COMMISSIONER TRACEY: Yes. The Presbyterian Aged Care home care services price list effective on 1 January 2019 will be exhibit 2.13.

20

**EXHIBIT #2.13 PRESBYTERIAN AGED CARE HOME CARE SERVICES  
PRICE LIST EFFECTIVE 01/01/2019 (RCD.0011.0010.0017)**

25 DR McEVOY: I wonder, Mr Sadler, if you might just very briefly walk us through what that statement sets out.

MR SADLER: So, counsel, we show there two aspects. The first is at the top of the page, the fees that are charged for the direct care services that we provide. I say  
30 "fees". This is what is taken out of the home care package funding, which is, of course, as you rightly pointed out earlier today, it's the – a mixture of both the client contribution and the government contribution, with the government contribution being by far the largest component of the funding. So we have there a different rate  
35 or allied health professionals. In the second part, we identify the fees that are charged for case management and for administration costs.

DR McEVOY: Thank you. Can I jump forward a little bit and take you to one of the central issues in your statement, which is concerned with supply and distribution.  
40 And, Operator, if you could go at least to paragraphs 56 to 59 of Mr Sadler's statement. So you see there, in paragraph 56, Mr Sadler, you talk about a gradual but inexorable erosion in the relative purchasing power of both HCP individual budgets, and CHSP grants. Can I ask you in that context what quantum of funding for a level 4 – what quantum of funding for a level 4 would have been delivered in 20 hours,  
45 two decades ago?

MR SADLER: So it would have been in the region of 30 to 35 thousand dollars back then and at that point it was common to provide around 20 hours of direct care.

DR McEVOY: And how has that position changed in substance?

5

MR SADLER: So what you now have is somewhere around half that amount that is actually available to be provided in direct care. So I mention that commonly now a level 4 package might be providing 10 to 12 hours of direct care, and at paragraph 57 I cite information provided to me by StewartBrown where they indicate that there has been a decline between June 2015 and December 2018 across all levels of home care package, in the total staff hours that are available to be purchased by the home care package funding.

10

DR McEVOY: Now, if you go back to about paragraphs 26 to 28 of your statement, so, Operator, you might go back, that's page 6 and page 7. You make the observation that the creation of the national pool of home care packages has highlighted the length of the waiting list for packages and that at 30 September last year, nearly 127,000 people were on the national waiting list. Do you see that?

15

MR SADLER: I do.

20

DR McEVOY: So what do you say about the extent to which recent increases in package numbers might reduce the waiting list?

MR SADLER: I thought it very interesting, counsel, in your opening observations this morning that you pointed to the data which was released after I prepared my witness statement just late last week that showed the total number of active home care packages had actually fallen by 1000 between that date that's in my witness statement of 30 September and the end of December. I think what we're seeing is the government attempting, understandably, to play a level of catch-up here. We've uncovered, with the creation of the national waiting list, evidence that we have 128,000 older people waiting for allocation of either the correct level of package or any level of home care package at all. And there's no question that the two announcements that you referred to this morning of 10,000 additional packages in December and another 10,000 in February will help. But there's also no question that those figures are quite small when you compare to a total waiting list of 128,000.

25

30

35

DR McEVOY: So how many more packages would you say need to be allocated to take up the shortfall?

40

MR SADLER: I think it's arguable because obviously people move through the packages so you don't necessarily need to create 128,000 packages to absorb the majority of that waiting list. But I would argue that you're probably going to be needing somewhere around 40-50,000 packages to actually absorb a waiting list of 128,000. And that, in effect, given we have 90,000 operational at the moment means that you are going to need to increase resources by another 50 per cent.

45

DR McEVOY: And what about high care packages, would you say there's an adequate provision currently of those or not?

5 MR SADLER: No, I would not say that the provision is currently adequate, and I note that in David Tune's legislated review report he also recommended the creation of a home care package level 5, so a level above the current level 4 package. I think there's an argument for that, but it does pose the broader question of how much do we wish to support people to stay in their own home in the aged care system. Currently, our maximum payment is, when you add the contribution from the client plus the dementia or veterans supplement, if you are eligible for it, you might be 10 looking at around 66-70 thousand dollars as a maximum amount of money available to support someone at home in aged care.

15 If you look at the National Disability Insurance Scheme we have packages of over \$300,000 per person to support people to stay at home in the NDIS. So there's a quantum of difference between what is available in aged care and what is available in the disability system. I would argue that we absolutely need a higher level of funding available to help people stay in their own homes, if that's their choice.

20 DR McEVOY: Now, you are familiar, of course, with the Tune Review and the various recommendations. You've referred to several of them in your statement. It might be desirable, Operator, to bring up recommendation 12, if I can give you the reference, RCD.9999.0011.0746. And perhaps if you could scroll down, Operator, to recommendation 12.

25 You might be aware – while that is happening, Mr Sadler, you might be aware that recommendation 12 is that the government should revise the naming and structure of fees to rename the basic daily fee as a basic care fee in home care, to require that providers charge the basic care fee in home care, to require that providers charge the 30 income-tested care fee in home care, to make the value of the basic care fee proportionate to the value of the home care package, retaining an upper limit relating to the value of the single aged pension. You're familiar with that recommendation.

35 MR SADLER: I am, indeed.

DR McEVOY: What would you say would be the impact of mandatory fees on consumers and, for that matter, on sustainability for care in the home?

40 MR SADLER: Counsel, I suspect it would be positive for both the sustainability of the sector but also for older people themselves to make the fees mandatory. As David Tune found in his review, we currently have a situation where not all providers do charge the basic daily fee, and in some instances, not even the income tested fee. And the net effect of that is actually to reduce the available funds for the home care recipient in those circumstances. So they actually have less money 45 available for their care. It's important to note that both David Tune's report and my position would be that you absolutely need to have a strong hardship provision, if you make fees mandatory, because there will be circumstances where, for various

reasons, older people are not in a position to pay the fee or a proportion of it. So you do need to have an appropriately managed mechanism for hardship applications.

5 DR McEVOY: Can I take you to the subject of My Aged Care and the way My Aged Care communicates with older Australians and their carers, and, Operator this is at paragraph 18 of Mr Sadler's statement. Can I get you to indicate how, in your view, if it be so, My Aged Care has improved access to information?

10 MR SADLER: Counsel, I believe that the creation of My Aged Care was absolutely an attempt to improve access to information compared to the previous arrangements that existed under the former Home and Community Care program, and the Commonwealth Carelink Centres, which I refer to in 18 and 19 of my witness statement – paragraphs 18 and 19. What I would say is that it has only been a partially realised improvement, and in paragraph 20 I go through a number of areas of additional improvement to the My Aged Care system which will help it achieve its identified goal of making it a simpler entry system for old people.

20 DR McEVOY: You list a series of things there in paragraph 20. I want to take you to your – at paragraph 20 (b), that is, in relation to the simplification of letters sent to older Australians seeking to access the My Aged Care system. What would your observation be about the letters that are being sent, and what improvements might be made to them?

25 MR SADLER: So, counsel, at the moment, when you are first assessed as eligible for a home care package, you will receive a letter from My Aged Care that advises you that you have been basically approved for care and what level of care you've been approved for. There will then be a subsequent letter that you receive at the time when your care package is actually available for you to take up because you've reached the top of the national prioritization queue. In both cases, the experience that I have, including personal experience with my mother who is on the receiving end of these letters, is that they're written in a very bureaucratic manner and they're actually quite difficult for older people, particularly people who might have English as a second language or might have dementia, to really grasp what they're about.

35 The Department of Health is well aware of this and has certainly conducted consumer surveys, and has been working with the National Aged Care Alliance and others to try and approve the letters that are sent, make them simple to understand, but I think we've still got a way to go to achieve that.

40 DR McEVOY: Perhaps it might be constructive, Mr Sadler, if we look at one of those letters. I'm going to ask you, Operator, to bring up a document. It's KWH.9999.0001.0006.

45 COMMISSIONER TRACEY: While that is being done, was it your intention to tender recommendation 12 with the Tune Review?

DR McEVOY: I think we have already tendered the entirety of the report, Commissioner. The number is RCD.9999.0011.0746, so unless you would like me to - - -

5 COMMISSIONER TRACEY: No, if it is already in evidence, I don't require you to do it again.

DR McEVOY: Thank you, Commissioner.

10 Yes. Now, Mr Sadler, can I direct your attention to the page you see there on the screen. That's a letter dated 6 November 2017 to Mr Leslie Warrener, that is already in evidence before the Royal Commission and, indeed, Mr Warrener's wife has given evidence to the Commission. So can I just ask you to cast your eyes over that first page. That's really the only page I want to take you to on this question of whether  
15 letters are unduly complicated.

MR SADLER: Yes.

DR McEVOY: Do you want to make any observations about whether there might  
20 be room for improvement in that letter and, if so, what that might look like?

MR SADLER: I particularly draw your attention, counsel, and Commissioners, to the very last paragraph on the page, which is the one that we often find people are very confused about which is where it says:  
25

*You will not be able to access Australian Government subsidised home care services until you have been assigned a package.*

30 So this letter is in effect, for home care, the first of those two stage letters I referred to earlier. So it's the one that kind of advises you that you have been approved by the Aged Care Assessment Team but it doesn't assign you a package yet. So what we often find is that people don't understand that difference, what does it mean and even just the language, "assigned" is not necessarily a very straightforward word. What does it mean in the context of an aged care approval? The other thing that is  
35 often the case is that people often get confused when they've been approved for multiple different levels of care, as this person has. So Mr Warrener has actually got three approvals in the one letter which can also cause a level of confusion.

DR McEVOY: If I take you to about point 7 of the page, there's a heading Home  
40 Care.

MR SADLER: Yes.

DR McEVOY: And it's apparent that he has been approved for home package level  
45 3. Can I direct your attention to the diamond point after that:

*Your priority for home care service is medium. You will be placed on the national queue for access to home care and will be notified when a home care package is assigned to you.*

5 Do you see that?

MR SADLER: I do.

10 DR McEVOY: So that is saying, in effect, is it, that as at 6 November 2017, the date of the letter, he is in the queue and he will be informed when he can actually have, that is to say start accessing, the level 3 home care package. Is that right?

MR SADLER: That's correct.

15 DR McEVOY: Operator, can I now ask you to bring up the next letter to Mr Warrener, which is KWH.9999.0001.0004.

20 Could I ask you to take a moment, Mr Sadler, to read that. You will see that that's a letter to Mr Warrener dated 21 March 2018. So it is some four or five months after the 6 November letter that I took you to a moment ago.

MR SADLER: Yes.

25 DR McEVOY: Now, it's apparent from the first paragraph that this letter is saying to Mr Warrener that he has moved up the queue since November, and that it is now expected that he may be assigned his home care package in about three months. So that would be by June 2018.

MR SADLER: Correct.

30

DR McEVOY: Do you want to make any comment about the structure and language of what's communicated to Mr Warrener on that page?

35 MR SADLER: I think it's worth noting that the second paragraph:

*Please tell us if you don't want to receive a package yet so someone else can use it.*

40 It's interesting in the logic that that's the first thing they ask you to consider. So I personally would have thought that's the bottom of the page, not the top of the page, in terms of a piece of information. If a person has applied for a package, you would assume they wish to continue on it unless otherwise informed, but the way the letter is structured, it comes first.

45 DR McEVOY: Can I direct your attention also to the heading at the top of the page, just underneath the address:

*Get ready to receive your Australian Government subsidised home care package.*

MR SADLER: Yes.

5

DR McEVOY: What would you say it might be reasonable for Mr Warrener to expect on the basis of that assertion?

MR SADLER: I would assume he is expecting, when he reads that as the opening  
10 description of the letter, that he is about to commence on the package imminently.

DR McEVOY: Or at least, if he reads further - - -

MR SADLER: Within three months.

15

DR McEVOY: - - - within three months. Operator, I'm going to ask you to bring up the next letter to Mr Warrener. It's KWH.9999.0001.0001. I might ask you to take a moment, Mr Sadler, to read that letter.

20 MR SADLER: Yes.

DR McEVOY: Now, I won't ask you to do this, Operator, but I can tell you, Mr Sadler, that at the end of that letter, on page 3, under the name Secretary, Department of Health, that letter is dated 5 February 2019. So the first observation to be made is  
25 that that has come almost 12 months, about 11 months after the 21 March 2018 letter. Is that uncommon, in your experience?

MR SADLER: Far from it. It's quite common. The other thing that you immediately note is the first paragraph:

30

*You've been assigned a level 2 home care package.*

When he was approved for a level 3. And as we can see from the statistics released by the department last week, that's a very common outcome that people get assigned  
35 a package lower than their actual need was assessed at.

DR McEVOY: Do you wish to make any other observation about that page?

MR SADLER: I think it reinforces a point that I made in my witness statement,  
40 which is once you are up and running in the system, you've been assigned a package, you have 56 days, as it says in the kind of description at the top there, to enter into the agreement. This assumes that people can do this fairly independently. If they're struggling for reasons of language, dementia, other reasons, then obviously family carers are needing to assist. Or alternatively, the person might need specialist help,  
45 albeit from a culturally linguistic – ethnic support group or whatever to actually access. This is an area that the – when the home care national pool was created, there was not an investment immediately in a consumer support structure to actually

support people to navigate through this complex system. And groups like the National Aged Care Alliance have been advocating that there should be such a system put in place and it is encouraging to see that the government has now started some trials of system navigators to support people who will need assistance to actually enter the system.

DR McEVOY: Operator, could I ask you to go to the next page of that letter that you have on the screen, and Mr Sadler, if I can just ask you to scan that page.

10 MR SADLER: Yes.

DR McEVOY: Now, you have, of course, made some observations about the need for simplifying letters. Is there anything on that page that you would wish to emphasise in that respect?

15

MR SADLER: I think one of the key things is there's a lot of information for people to take on board in the letter. You're already up to page 2 of a three-page letter, as you mentioned. The other thing is the referral code, which is blanked out there, two-thirds of the way down the page, that's your key to get into the system, and what we find is often people have not picked up the importance of that code. So they start approaching aged care providers and they don't actually provide that code, and then the provider cannot pick up the information about them from the My Aged Care system. So it can delay the process if people don't realise the importance of that referral code.

25

DR McEVOY: And, Operator, could you please go to the next page, page 3 of the letter. Now, you will see there, as I indicated to you earlier and as you accepted, Mr Sadler, the letter is dated 5 February 2019. There is further information on that page 3. Would you make any comment about that information from the vantage point of simplification?

30

MR SADLER: I think that information, in and of itself is relatively straightforward but it's, I guess, a question of, you know, third page of a letter. Will an older person, again, with a language problem or dementia be able to take it in?

35

DR McEVOY: Well, one of the things you say, Mr Sadler, in paragraph 20 – one of the other things you say in paragraph 20 is that it's necessary to make the online environment, that is to say the My Aged Care online system, I take you to mean, more user-friendly because it can be complex to use. Do you want to just expand a little bit on that and what you think might be done in that respect?

40

MR SADLER: Certainly. That comment refers to two parts. The first is the experience for consumers and families trying to find their way into the aged care system and it's certainly something the Department of Health has been well aware of and has been working to simplify and improve the information available via My Aged Care. However, it is still often difficult for people to work their way around the My Aged Care website to be able to do searches for services. The other aspect is,

45

it's often complex for us as provider organisations to use the system as well. And in order for the system to work well, it's really important that the providers can update their information in a simple manner, have it actually communicating the key issues about their own services. And our experience has been at the provider end as well as  
5 the consumer end that there could be difficulties with that.

DR McEVOY: One of the other points you make is in 20(e) and you may have touched upon this but you talk about the possible improvement of the system by removing all duplication of assessment processes. I wanted to ask you what separate  
10 purposes do RAS and ACAT assessments serve and whether there might be some utility in keeping them separate.

MR SADLER: At the moment, the regional assessment services, RAS, are assessing for Commonwealth Home Support services, and the Aged Care  
15 Assessment Teams assess for home care packages and residential aged care. With the introduction of the My Aged Care system they have moved on to a common platform. So you mentioned this morning, counsel, the national screening assessment form, which is a common form which is used by both the RAS assessors and the ACAT assessors. However, I would argue that at the moment the fact you  
20 have two different assessment teams is in and of itself causing a level of duplication of assessment. So if you're an older person who is receiving a Commonwealth Home Support service – and Mr Warrenner is a classic example of that, on that page 3, that's still up, he is receiving CHSP services while he is being assigned a home care package. That means he has already gone through two assessments. He has  
25 been through an assessment by the Regional Assessment Service and he has been assessed by the Aged Care Assessment Team. It's the intention of the government to look at merging the two workforces, and I would support that intention because I think it will streamline the system even further if older people do not have to go through separate assessment processes.

30 DR McEVOY: Just continuing a bit with the assessment process, and I suppose the funding or the nature of the funding tool, you would agree with me, I think, wouldn't you, that if, say, your needs are somewhere between a level 2 and a level 3, then you either, you have a choice, in effect, of either being underfunded at level 2, or you  
35 have to wait to get reassessed and get the additional amount, I think it's about \$15,000, on level 3. You would agree with that?

MR SADLER: I would agree.

40 DR McEVOY: And does that suggest that the home care package funding tool is too rigid or is it reflective of some other problem, would you say?

MR SADLER: At paragraph 54 of my evidence I actually refer exactly to the issue you're talking about, counsel, which is in that context, Commissioners, it was  
45 referring to the tendency of unspent funds to accumulate as one of the consequences of these rigid four levels. But I point out that we have just been through a process with Wollongong University to look at the creation of a new assessment tool for

residential aged care funding, which is now before the government and the government has agreed to trial the Australian National Aged Care classification. And that is assigning people through the assessment process to a more granular level of funding. So the four bands was actually something that the Wollongong Uni  
5 looked at for residential aged care and found that it was, it created too many gaps, exactly as your question actually posed, and their recommendation was in terms of residential care to look at a system that actually assigned more closely to the needs of the person to match the level of funding that they actually have.

10 I would note that the work that Wollongong University has undertaken was specific to the residential aged care context so they would be, I think, the first to say that an additional piece of work would be required to create a home care classification tool of a similar nature.

15 DR McEVOY: Can I just take you back to something we were talking about a little earlier in connection with the My Aged Care service. You will be aware, I think, that COTA has recently announced sponsorship of system navigators, taking up something from the Tune – one of the Tune recommendations, recommendation 23. Are you aware of what that involves?

20 MR SADLER: I am aware at a general level. I'm not the expert that Ian Yates would have been on that topic.

25 DR McEVOY: Yes, and what do you – what's your understanding about how the current call centre and the website might be improved upon as a part of that initiative?

30 MR SADLER: So my understanding is that the, that trials of system navigators are looking at some different models which will pick up the differences between the different groups that actually have difficulty accessing My Aged Care. So in some instances they're going to be trialling basically place-based support. So actually creating a physical presence in regions where people can access information about how to access services. They're also trialling a model which includes support via particular communities. So that will be particularly the case for Aboriginal and  
35 Torres Strait Islander communities, and also culturally and diverse linguistic groups.

So that could be funding of a support mechanism via a, for example, a CALD-specific service provider. And then the third model they're looking at is actually specialist support worker model which I think is the model that they're particularly  
40 going to use in areas like homelessness.

45 DR McEVOY: Can I turn, then, to the issue of pricing and transparency, which you deal with at about paragraph 27 of your statement. It might be desirable to go to paragraph 27, Operator. Now, of course, recommendations 11 and 17 of the Tune Review are relevant here, Mr Sadler, as you would be aware. Can I ask you what you see as being the impact of the current exercise in pricing transparency for your organisation but also for the sector more generally?

MR SADLER: Certainly. So the government worked with myself and a range of other bodies, both consumer bodies and provider representative bodies, to look at how to set up a new schedule for pricing transparency. So if you take the price list that we looked at earlier for Presbyterian Aged Care, it would capture some of the same components of that but it's going a bit further. So it's attempting to identify five very common types of service, which are provided under a home care package and ask the provider to nominate its price for each of those service types so that you can get a direct comparison of types of service.

10 It's also deconstructing the administration fee. So it's actually removing the concept of an administration fee per se, and asking you to look at what they're calling package administration, which is a different concept and restricts the areas of administration to things like scheduling for the package. But there's also then still a case management component that could be priced and provided separately. One of the implications for providers such as Presbyterian Aged Care is that we will have to go back and by the end of June, we will have had to establish prices linked to those new components of the pricing transparency and make sure they're published by 1 July.

20 DR McEVOY: Can I take you, Mr Sadler, to paragraph 33 of your statement, where you make the observation that in the lead-up to and since the move to create the home care package marketplace in February 2017 the department has roughly doubled the number of approved providers of home care, and you make the observation that:

25 *... the Quality Commission will therefore need to ensure that all providers are complying with the relevant standards.*

30 How effective would you say that the new Commission has been in relation to its compliance activities?

MR SADLER: I guess I would observe, obviously, in defence of the new commission, they've only existed since 1 January this year, so it's a very short time to judge them compared to the previous quality agency arrangements. In terms of where it's up to, my understanding is that the former quality agency and now the Quality and Safety Commission are applying a triage approach to how they look at the new approved providers that are approved by the Department of Health. So, for example, if you're a provider who has no history in aged care provision or in a similar field like the NDIS you would be assessed quite quickly by the Quality and Safety Commission in terms of either a self-assessment or potentially a visit by the Quality and Safety Commission staff.

45 If you're a provider of Commonwealth Home Support and you've applied to become a home care provider, so it's the first time you are being registered under the Aged Care Act, you are probably not as significantly a risk because you've been operating in the home support space already. And if you are a residential aged care provider who is applying for the first time, even though you might not be familiar with

home care standards, you are also deemed less of a risk if there has been a good track record of compliance with the residential care standards over that period of time. So the Quality and Safety Commission is undertaking some triaging, is my understanding. It's also true though that the Quality and Safety Commission is behind in its regime of assessing quality reviews. And that is one of the reasons in paragraph 34 that the government announced additional resources to support both the approved provider registration components through the Department of Health but also the quality review components through the Quality and Safety Commission.

10 DR McEVOY: In paragraph 36 of your statement, Mr Sadler, you refer to the Productivity Commission report, and you make the observation that, referring to that report, that home care and home support services are more likely to fail to meet all home care standards, 12 per cent in '17-18 than their counterparts in residential care where the comparable figure was five per cent. I wanted to ask you why it is, in your view, that home care support services are more likely to fail to that extent than residential care providers.

MR SADLER: I think one of the reasons is that the former Home and Community Care program, which is now part of the Commonwealth Home Support Program had an approach to quality assessment which was very different from the approach that is now taken, for example, by the Quality and Safety Commission in terms of home care standard compliance. Secondly, many of the former Home and Community Care, now CHSP services, are voluntary managed organisations, Meals on Wheels, Neighbour Aid, social support services that are community based but have not necessarily got the level of sophistication in terms of regulatory compliance and bookkeeping.

Counsel, in your opening remarks today, you talked about the fact that the Quality and Safety Commission, when Janet Anderson presented did talk about the fact that regulatory compliance was the number one failing that it has found in the current home care standards, and that is reflective of this issue, that it's often the bookwork and the record-keeping that catches up many of the voluntary managed sector.

DR McEVOY: Can I turn, Mr Sadler, to the issue of mandatory reporting. You deal with your work in relation to elder abuse at paragraph 40. It might be desirable, Operator, to go to paragraph 40 of Mr Sadler's statement. Now, you were the author, you say there of the ACSA elder abuse position statement in November 2016, that's correct.

40 MR SADLER: Co-author, yes.

DR McEVOY: Co-author. Operator, could you please bring up RCD.0011.0010.0001. Is that the ACSA elder abuse position paper?

45 MR SADLER: It is.

DR McEVOY: Commissioners, I seek to tender that document.

COMMISSIONER TRACEY: Yes. The elder abuse ACSA position paper dated November 2016 will be exhibit 2.14.

5 **EXHIBIT #2.14 ELDER ABUSE ACSA POSITION PAPER DATED  
NOVEMBER 2016 (RCD.0011.0010.0001)**

10 DR McEVOY: Thank you Commissioner. Now, in paragraph 42 of your statement, Operator, if you go back to 42 and perhaps have pages 8 and 9 up on the screen, you make the observation that it's important that alleged crimes are reported to the police, including elder abuse that is or may be a crime. Is it your view that there should be some sort of mandatory reporting obligation of elder abuse on personal care attendants and others?

15 MR SADLER: It's my view that if the abuse is being perpetrated by family members, neighbours or so forth, it would not be helpful for mandatory reporting to apply. My reasons for that are stepped out in 43 to 46, and I guess to sum them up, it is that elder abuse captures a wide range of conduct, not all of which is criminal  
20 conduct. Secondly, where there are regulatory levers, they are actually available at the State and Territory level, not at the Commonwealth level. So things like guardianship, policing, criminal justice that apply in cases of physical abuse, sexual assault and the like, are actually held by the States rather than the Commonwealth Government.

25 Thirdly, if we were, which I go to in paragraph 46, to include reporting of elder abuse committed by a family member into the proposed serious incident reporting scheme that the Australian Law Reform Commission has recommended, we would run the risk of providing a lot of additional reports but not to an agency that could  
30 actually deal with them, because the Federal Government – and it's anticipated that the serious incident reporting scheme will be administered by the Aged Care Quality and Safety Commission in the future – it really wouldn't be in a position to investigate what is being perpetrated by family members, or other people who aren't paid staff members or volunteers of a home care service provider.

35 DR McEVOY: Do you have particular views about how that problem might be addressed?

40 MR SADLER: So in terms of the cases where it is family members who might be perpetrating the abuse, I would certainly recommend that aged care service providers have very clear policies and procedures in place and that is now a requirement under the new aged care standards that will come into place on 1 July. As part of that, that should include the staff members reporting to, within the service provider, any  
45 concerns they have about abuse or neglect that they might suspect could be happening in the home. And at that point there's the capacity to link in, for example, with elder abuse help lines that are run by the States and Territories and also, obviously, where there's concerns it's a crime, as per paragraph 42 of my witness

statement, to report that directly to the police. I guess it's the additional reporting burden and bureaucracy of making family-based abuse a mandatory reporting exercise at the Commonwealth level that I can't see that that will help us.

5 DR McEVOY: Can I take you to paragraph 49 of your statement, Mr Sadler, where  
you deal with the issue of interest generated on unspent funds. You recall that I  
touched upon that this morning in my opening remarks, and you say there that  
interest generated on unspent funds is not included in the amounts to be returned to  
the government and consumers when the consumer leaves a home care package.  
10 And you say that your organisation and other not for profit organisations use the  
interest generated to support the provision of aged care services. How is it exactly  
that Presbyterian Aged Care uses that interest to support the provision of aged care  
services?

15 MR SADLER: Certainly. So, we provided some information to the Royal  
Commission, Commissioners, that indicated that the amount of interest based on our  
most recent year of holding the funds on behalf of our home care package consumers  
amounted to about \$21,400 over that year. And that interest amount that we've  
raised from the home care package fees that we're holding, unspent funds, is  
20 basically part of our general interest income, which we use to support all of our aged  
care service operations. So it could include home care, CHSP, it could include  
residential aged care or other services that we're providing as a not-for-profit  
organisation.

25 DR McEVOY: So in paragraph 50, if you go to paragraph 50, Operator, you refer to  
the fact that the Aged Care Financing Authority reported at the end of June 2017 that  
those providers who had submitted their financial reports to the department reported  
unspent funds totalling around \$329 million, and that this equated to holding average  
unspent funds per consumer of about \$4600 which was an increase of about 26 per  
30 cent from the unspent funds balance per consumer in the preceding 12-month period.  
Are you able to indicate why, in your view, there is this level of accumulation?

MR SADLER: Certainly. So, in paragraph 52 I go through what I identify as four  
main contributing factors. The first is, obviously, that there can be a contingency  
35 amount that is being put aside for the proverbial rainy day when the consumer might  
become ill or need additional services for a short period of time on top of their usual  
regular service provision. Secondly, the consumer might be planning a larger  
expense. It could be a period of respite. It could be a period – a need for aids or  
equipment purchase. Thirdly, you've got the situation where the consumer has been  
40 accurately assessed, so their level of service that they've been allocated, level of  
package they have been allocated is correct in terms of their assessed need but for  
whatever reason they choose not to take up the full suite of services.

45 And in my experience, it's not uncommon that is particularly around clinical care  
services like nursing. And the final reason is where the assessed level of home care  
package is actually higher than their needs really are. So for whatever reason there

has been a mismatch between the ACAT assessed level and the level of care that is actually needed by the recipient.

5 DR McEVOY: Does Presbyterian Aged Care encourage its clients or some of its clients to accumulate for a rainy day, as it were?

10 MR SADLER: Look, we do where we believe that will be in the interests of the older person and we absolutely agree that holding a contingency amount or an amount for a planned purchase makes a lot of sense and the flexibility of the individual budget actually supports that.

DR McEVOY: Commissioners, I don't have any further questions for Mr Sadler.

15 COMMISSIONER BRIGGS: Mr Sadler, it's hard, I think, or so we've been told, for elderly people and their families to understand why they're given a lower level of package that doesn't match their assessed need. Do you want to comment on the – what's the word for this – the appropriateness or the signals that provides to elderly people and their families?

20 MR SADLER: I'm happy to comment. I'm not sure I've got an easy solution because it's obviously partly a function of a resource-constrained environment. So the older people are often receiving Commonwealth Home Support services even before they get any level of package but they've had a higher level of need that might have developed over time. And then in our resource-constrained environment we try  
25 and prop them up for as long as possible with CHSP services. Then because the largest number of packages are available at level 2 and that's the history of Commonwealth – the old community aged care packages that were the largest component of the system, basically continuing to be the majority of all of the packages that are available. It often means that the first resource that comes  
30 available for somebody is a level 2 package when in fact they might have a level 3 or a level 4 need, but the number of packages at those higher levels are much lower than the number at level 2.

35 I can see from the point of view of the system as a whole why it's important to get some care to people. It doesn't make sense to have people getting nothing at all, but it does have its own complications. For example, if the person really has quite high level needs, for example, they might need two people to help them with personal care in order to get them out of bed or to shower them or whatever because they've got particularly complex needs, if you can only provide them with a level 2 package or  
40 some CHSP funding for a period of time, we are not meeting those people's needs properly. That is the message that I think is one of the reasons you see the level of concern about the home care package waiting list. People know they're not getting what they need.

45 COMMISSIONER BRIGGS: There has been some discussion before the Royal Commission about how priority is determined in the allocation of spaces through My Aged Care and this national system. And we've heard various suggestions that that

might be according to the fragility of the carer or something like that. To what extent does priority relate to the care needs of the individual?

5 MR SADLER: My understanding is that the intention of the government is, it's kept  
to as few as people as possible that are allocated the high priority by the Aged Care  
Assessment Team. And part of the reason for that is that if you are setting up a  
waiting list process, a queue, you don't want most of the people jumping the queue  
because the queue simply won't work. So the way I've had it explained to me by  
10 people in the department that the queue is meant to operate is effectively like two  
queues; one is moving slightly faster than the other one. The reasons that an Aged  
Care Assessment Team might assess people to actually be on the faster queue, the  
high priority queue, can include where the family carer has had their own health  
crisis or, you know, is otherwise unable to continue to provide the care.

15 And so that person really needs, you know, the care to be assigned very quickly. But  
I do believe that the person's own level of disability which could have been acquired  
suddenly through a stroke or something like that will also be considered as a factor in  
terms of whether they will be on the high priority queue.

20 COMMISSIONER BRIGGS: It's a challenge, isn't it. We have a national system  
but there's not a lot of transparency about how it works.

MR SADLER: I'm all for increasing the transparency and through the witness  
statement I've made comments on a number of points about ways in which we can  
25 improve the transparency of the system, I believe going forward. It's certainly true  
that as a community, we should have an expectation that we understand how the  
system operates, and as an individual consumer, you need to know where you are. It  
simply doesn't work if you receive a letter that says you are about three months from  
receiving service, and in fact it's another nine months or 12 months before you  
30 actually do. Something is not working properly when that happens.

COMMISSIONER BRIGGS: Are you confident that the national system of  
allocating care packages is regionally equitable?

35 MR SADLER: Confident would be too strong a word. The evidence that is coming  
through in the data reports that the, are being released by the Department of Health  
do indicate that there are allocations going to all regions across Australia. It gets a  
little more difficult to know what the impact is at a lower level than the Department  
of Health's planning regions. And so in my witness statement, I've made comments  
40 about the importance of having an alternative approach for really remote service  
provision or into Aboriginal or Torres Strait Islander communities. In those sorts of  
circumstances, you need a confidence that there is a service infrastructure there  
which presumably needs a level of block funding or guaranteed funding to ensure  
that you actually have the service to be provided when that person finally gets on to  
45 the home care package queue or at the end of it.

So, for example, if you are in a really remote area, you might only have one person allocated every two, three, four years into your region. You've got to have the service infrastructure there to actually be able to provide that service. So both myself and people like the National Aged Care Alliance have argued that we need a  
5 different approach for regional and remote Australia and potentially for specialist groups like homeless people, Aboriginal and Torres Strait Islander communities, which looks much more like block funding than the current allocation formula.

10 COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising, Dr McEvoy?

DR McEVOY: Nothing arising, Commissioner.

15 COMMISSIONER TRACEY: Mr Sadler, we're indebted to you for your measured and considered views about the difficulties that are involved in the funding and the application of the system that we're grappling with. And they will be – your views will be of great value to us when we come to write our report. Thank you very  
20 much.

MR SADLER: Thank you Commissioner.

25 <THE WITNESS WITHDREW [4.38 pm]

COMMISSIONER TRACEY: Unless there are any other matters the Commission will adjourn until 10 am tomorrow morning.

30 DR McEVOY: No other matters, Commissioner.

**MATTER ADJOURNED at 4.38 pm UNTIL TUESDAY, 19 MARCH 2019**

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