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TRANSCRIPT OF PROCEEDINGS

O/N H-985234

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

10.11 AM, THURSDAY, 21 FEBRUARY 2019

Continued from 20.2.19

DAY 8

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: Please open the Commission. Yes, Ms Hill.

MS HILL: If the Commission pleases, I call Gerard Hayes.

<GERARD JOHN HAYES, SWORN [10.11 am]

<EXAMINATION-IN-CHIEF BY MS HILL

MS HILL: Mr Hayes, could you please state your full name.

MR HAYES: Gerard John Hayes.

MS HILL: And what is your role, Mr Hayes.

MR HAYES: I'm the national president of the Health Services Union as well as the New South Wales secretary of the Health Services Union.

MS HILL: Before you were in that role what were you doing for work?

MR HAYES: I was an intensive care paramedic with the New South Wales ambulance service.

MS HILL: And you've prepared a statement date 1 February 2019.

MR HAYES: That's correct.

MS HILL: Operator, could you please display document ID WIT.00019.0001.0001. Is that the statement you prepared in front of you on the monitor?

MR HAYES: That's correct.

MS HILL: And is that statement true and correct?

MR HAYES: That statement is true and correct.

MS HILL: To the best of your knowledge and belief?

MR HAYES: Indeed, yes.

MS HILL: And are there any amendments you would seek to make to that statement?

MR HAYES: Not at this time.

MS HILL: Commissioners, I seek to tender that bearing in mind that the statement that's displayed before Mr Hayes is a redacted copy. For your reference, that redaction is at paragraph 47.

COMMISSIONER TRACEY: Are you able to indicate – well, the copy we have doesn't appear to have been redacted at paragraph 49.

MS HILL: 47, Commissioner.

COMMISSIONER TRACEY: 47?

MS HILL: 47 and a corresponding footnote.

COMMISSIONER TRACEY: I beg your pardon. And is there a reason for the redaction?

MS HILL: It may be that that paragraph canvasses material which is raised at a later hearing, but not this hearing, Commissioner.

COMMISSIONER TRACEY: Yes. All right. Well, you tender the redacted version?

MS HILL: I do, Commissioner.

COMMISSIONER TRACEY: Yes. All right. The witness statement of Gerard John Hayes dated 1 February 2019 as redacted in paragraph 47 and the associated footnote will be exhibit 1-60.

EXHIBIT #1-60 WITNESS STATEMENT OF GERARD JOHN HAYES DATED 01/02/2019 AS REDACTED IN PARAGRAPH 47 AND ASSOCIATED FOOTNOTE (WIT.00019.0001.0001)

MS HILL: As the Commission pleases.

Mr Hayes, could you please tell the Commission what the Health Services Union is.

MR HAYES: The Health Services Union is a national union as well as – it has branches in most States of Australia. It looks after people within the public health sector, the aged care sector, the ambulance service and private health areas.

MS HILL: And how many of your members are working in aged care?

MR HAYES: Approximately 20,000 members in aged care.

MS HILL: And out of the total membership of the HSU?

MR HAYES: That would be reflected at about 20 per cent and I would add that it's a rapidly growing area, too, which I think is significant at this point in time of the industry.

MS HILL: What is the nature of the work being done by the members of yours that are in the aged care sector?

MR HAYES: Predominantly, many of our members are carers in the aged care sector. We also have people who work as administrative people, managers, also a necessary component and an increasingly necessary component is the allied – allied health workers in aged care who clearly are not utilised enough in this industry.

MS HILL: Who are those allied health workers that you're referring to?

MR HAYES: So people such as psychologists, physiotherapists, social workers. I can only imagine that, you know, waking up in aged care every day when you're in your older area of life that it would be very helpful to have someone to be able to speak to if you're feel as though you may be suffering from depression and so forth. The – the allied health members as we see them are seen as more of a luxury item than a necessity and clearly they are a necessity.

MS HILL: When you describe carers as being within the cohort of membership, what role or roles do those carers have?

MR HAYES: We've done surveys which – carers will outline their – their role as virtually everything from a friend to a person who will hold someone's hand as they're dying to someone who will undertake cleaning, who will do laundry services, ironing services, assist with medication. Virtually a confidant of the resident on a daily basis. The person who builds up an interpersonal relationship, not a – it's not seen as a job to many of the carers that we have.

MS HILL: And what kind of qualifications do you see in your membership of those carers?

MR HAYES: Generally there's a certificate III in aged care and also a certificate IV in aged care. There's no absolute legal necessity for people to come into aged care to actually have those certificates. Many times people will come into aged care and those – that form of training will be gained on the job and also through TAFE or some other private kind of institute that will pass on that level of training.

MS HILL: At paragraph 44 of your statement you describe the majority of your membership working in aged care are qualified. How are you aware of that?

MR HAYES: Through the surveys that we undertake. That's one of the areas that we think is incredibly important that people will be qualified, not only having the experience which is vitally important but qualifications in terms of mental health,

palliative care, de-escalation of issues and the sort of normal day-to-day caring for people and understanding what those requirements are is vital to this industry.

MS HILL: What are your members telling you about their training needs?

MR HAYES: They're certainly inferior. Some people are undertaking training through TAFE which may take six months, which is thorough and it's open to scrutiny. Others are doing training online which may take six weeks which ultimately is a tick-a-box, that it won't necessarily give the required outcome that is going to be required on a day-to-day basis to do the job thoroughly and be open to scrutiny.

MS HILL: And what's the impact of that training model on the aged care sector, in your experience?

MR HAYES: I think it just promotes an inferior area of aged care. We're trying to promote aged care as a really important and actually a moral situation for people in Australia. I can only imagine that people who have built this country who then get into their older years and don't have the quality that can be there because sometimes things that are out of sight are out of mind and I think the more that we can put into training and supporting the people who look after – who are looking after people who are our senior citizens who actually got us to where we are today, I think is doing the right thing by them.

MS HILL: Is an accreditation scheme appropriate for personal care workers, in your view?

MR HAYES: Look, I think some form of accreditation is. I notice in areas such as in health there are some people who are accredited and registered. There are other people who work in health who are not. I think this is something that needs to be examined. I think it also needs for examined also that when you have people who are on $20 an hour and if a registration is going to be $600 a year, we may see people going to work at Woolworths or Coles for $20 an hour than try to find the money to be able to register themselves. So we've got to be really mindful – I think any form of accreditation is a good thing but we've got to make sure that we're dealing with the demographic that we have. These are people struggling on a day-to-day basis, not a week-to-week basis, a day-to-day basis to make ends meet, at the same time giving of themselves from an emotional basis and then trying to find a way to facilitate that opportunity is something that really needs to be thought through in the longer term.

MS HILL: How does the Health Services Union engage with its members in the aged care sector?

MR HAYES: We have developed – in New South Wales, for example, we've developed an aged care division of our union. So a union that makes up of 38,000 members, 10,000 of those members are in the aged care area. We've developed that

into a specific area of our organisation now. We have an aged care council that directs the union in terms of its activities in relation to aged care. We have organisers who visit our members on a daily basis and then we conduct surveys and throughout the process of enterprise agreements we consistently engage with the membership to make sure what we can be doing is driven by the membership. And I think to some degree the Royal Commission that we're currently in, which is a great process, is something that our membership have been calling for for some time.

MS HILL: Throughout your statement you provide, of various members – and Commissioners, those are in italics within the statement. Where do those accounts come from, Mr Hayes?

MR HAYES: So we've undertaken several surveys. Every time we undertake any kind of enterprise bargaining agreement we put a survey out of our members.

MS HILL: How do you conduct those surveys, Mr Hayes?

MR HAYES: Those surveys are done two ways: one by electronic means through email and the website. Mindful again, many of our members won't have access to email and the website due to financial situations that they may well be in. So we also have hard copies so when our organisers are visiting workplaces that the hard copy of the survey is given out. And then the data is taken once it's brought back into the union offices, the data is then directed.

MS HILL: When was the most recent survey conducted, Mr Hayes?

MR HAYES: The most recent survey was done within the last 12 months and that is – I think it was probably we had somewhere in the vicinity of about 370 responses to that. It was a very interesting survey that a lot of the things that the union and other organisations have been talking about. The message is very clear coming from our members in terms of staffing, training, resourcing, cutting corners. It's – the message just over and over is repeated throughout these surveys.

MS HILL: At page 7 of your statement you set out what the pay of your members looks like in aged care. What are the pay and conditions of your members?

MR HAYES: So the members are currently on about $21 an hour. There is a – the modern award which they may default to is probably about a dollar less than that. So even in an enterprise agreement which you would think you have some ability to use leverage or negotiate there is very little movement, somewhere between .5 and a 2.5 per cent difference between the modern award and the enterprise agreement.

MS HILL: And why is that, Mr Hayes?

MR HAYES: The bottom line is that it's funded by government funding or lack thereof. So when any kind of employer group or individual employer is funded by the Commonwealth to that degree they have very limited opportunity to be able to

utilise any kind of real bargaining strategy in terms of wages for the workers who take up a large amount of their outlay.

MS HILL: When your union gets involved in those negotiations does have that have a broader reach than the individual or group of individuals that you're concerned with?

MR HAYES: It has got a reasonably limited reach. So there's a couple of ways we undertake our enterprise bargaining that ultimately there is two main employer groups that we can deal with, but getting into each of the respective aged care groups, aged care facilities is very difficult. There's, in New South Wales alone, approximately 800 different aged care groups, so trying to be able to facilitate those opportunities right the way through is difficult. So a lot of times that we're dealing with sort of major employer groups.

MS HILL: Why does the pay of aged care workers compare unfavourably to other sectors?

MR HAYES: Because I think, to be quite honest, out of sight is out of mind. The morality of this country needs to be tested at this point in time. Is it good enough to say that the people who went through the war years of the thirties and the forties and the consequent years of rebuilding this country are good enough to say, well, we don't notice them every day so it must be okay. I think this Royal Commission is going to see some staggering things that will come out because people just haven't shone a light on it. We need to be able to make sure that workers in the area – in the industry are able to go to work and be able to look after people.

I just sort of make this point at the moment. Many of us who turn up to work with a passion every day is really important. Not many of us go to work every day knowing that somebody who has been a friend of theirs for the last year or two years is going to die today and die tomorrow and die next month and die next year, because that's what happens to these people. So it's not a job that people can sit there and say, "I'm just going to clock on and clock off". This is a job where people want to look after individuals who become – not residents, they don't become some kind of client; they become friends. They become family members and they know that they are going to die because it's the part of life they're in. I think we need to be actually focusing on the workers and certainly on the residents and on the industry to make sure that Australia can stand up and say that we respect the people who actually got us to where we are today. It's a different industry than anybody else that I am aware of and I've been in a few different areas.

MS HILL: At paragraph 38 of your statement you describe income insecurity as an issue facing workers in aged care. What do you mean by this, Mr Hayes?

MR HAYES: So in many areas of aged care – in home care it's not uncommon to have people on minimum hours contracts. So they may be on contracts of eight hours a fortnight. They're generally working above that so they may be working 30

hours a week or 35 hours a week. We see people in residential care who are generally on 25 to 30 hours a week. Generally they could be working just short of full-time hours and we've been made aware that there are employers out there that will work people on contracts of 37 and a half hours a week to make sure that we are not actually full-time employees. This gives an opportunity to employers to actually, one, if they need to cost shift so if they've got an emergency situation that has come up from a capital base, they are able to actually contract hours so they can transfer money into what capital needs they may have which falls back on the care of a resident.

Or the second issue that we have is that if people are prepared to stand up in aged care facilities – and I would qualify this comment that there are many good aged care employers – but there are people out there, who if people do put their hands up, who would be whistleblowers, whether it's an industrial matter or a safety matter or, indeed, an elder abuse matter, they could be going from what they generally work, 35 hours a week, down to their contracted hours of 20 hours a week. Now, bearing in mind a lot of these people need to do two jobs on a part-time basis because predominantly people are engaged part time to be able to make ends meet. So it really does have a broad spectrum focus about transparency within the allied health setting.

MS HILL: Is it fair to say that your statement focuses predominantly on residential care and workers within that environment?

MR HAYES: Indeed. Yes. So we work collaboratively with the Nurses and Midwives Association and United Voice. They have predominantly different groups of workers that they look after. We predominantly look after people in residential aged care, whereas United Voice predominantly work with members in home care.

MS HILL: At paragraph 41 of your statement, you discuss whistleblowers and you describe that there's a disincentive for whistleblowers in the aged care sector. What do you say the consequences of this are for your members?

MR HAYES: Look, again, it's an area where there's a lot of people working in aged care who are on visas, there's student visas while people are being trained into other areas of employment. So if you are a whistleblower and you are either on a minimum hours contract or you are in a precarious situation of being on a visa of some sort you need to think very carefully before actually you raise your hand. Now, we all should stand hand on heart to say we are not going to put up with elder abuse or anything along those lines when someone's livelihood – or bare livelihood – on a daily basis may be a consideration. That is a concern.

So what we advocate is that there should be protections for whistleblowers; that they can actually make a notification, whether it's an industrial notification or a notification in relation to any form of abuse. It's interesting to note that in the Fair Work Act that if people do raise issues and then action is taken against that individual from an industrial perspective there are protections there. So we would

like to see that making sure that any kind of concern, whether it be a safety matter or any other kind of abuse matter that people could do so freely without any threat of any kind of action taken against them.

MS HILL: What are the consequences of that environment for the person receiving aged care services?

MR HAYES: It underpins everything. So any kind of roadblock that's put in the way, any kind of bump in the road – so I think if we look at the – there's a funding model and that funding model underpins everything that we – that is within aged care. So, you know, if the resources aren't there, if the – if there's intimidation within an organisation, if people don't feel as though that they can actually transparently identify issues, the person who loses all the time is the resident. It's the person that we are all there for is the person who will ultimately suffer, irrespective of if it's a resource issue, it's an issue of lack of transparency, it's a funding issue; it is always the resident who will suffer at the end of the day. And sometimes and in many times I think will suffer in silence because they don't have that ability to make sure that their concerns have been ventilated.

MS HILL: If there's a continued expansion in the need for aged care places in this country, why does the Health Services Union say that there's no guarantee for workers in aged care to get the hours that they need to provide that consistent standard of living?

MR HAYES: That's an interesting thing. It's – you know, it's not like some industries that are declining. This is an industry – we can see there's a tsunami off the coast and it's coming in, in the next 10 to 15 years. We have got a major issue ahead of us. It's not a matter that we're guessing and yet there's a lack of funding that is actually dealing with the aged care matter as we see it today, let alone as the aged care matter that we see in the next five to 10 to 15 years. So there needs to be an absolute commitment to the consistency of what we see and the expanding consistency of what we see. We're seeing some manufacturing industries close in terms of the car industry. Isn't this the opportunity to actually transition people into the growing industry and the respectful industry and the industry that should be giving dignity to people in their ageing, their life, as opposed to, well, we will just sort of see where we're at at the moment. So there is an absolute consistency, there is just an absolute lack of resourcing and commitment from a range of levels to be able to address it.

MS HILL: What do you see the role of the Health Services Union in that circumstance?

MR HAYES: Our role is to clearly stand up for our members and their communities and the residents of these facilities. One goes hand in glove with the other. This is not an industrial matter, from our perspective. This is a community matter. And we want to play our part with the community and all the other organisations who have been making contributions to this fine Commission. This is something that we can

make significant change to collectively. We can tell our side of the story from what our members see on a daily basis. This is a systemic issue. This is not an individual issue. I think it's going to be very easy to say that there are certain problems here and here and here. No, there's not. There are systemic problems that we all need to take our level of responsibility for and I think if we do that well we are going to make sure that people in Australia can age with dignity as opposed to we're just going to look the other way.

MS HILL: At paragraph 24 of your statement you describe that the number one issue for your members is short staffing. What is short staffing, Mr Hayes?

MR HAYES: Well, short staffing can be one person on a night shift looking after 25 people and having to have the union engaged to get a second person put on with that person. It can be two people looking after 35 people. But if I can put it in this – this is the reality of what short staffing is. You've got one person, you've got 25 people. You've got five people who may want to go to the bathroom at the same time. It's not going to happen. You may have one person at the same time who is suffering a major medical issue. There's no RN on shift that night so the ambulance needs to be called in to address that matter. But still while all those matters are being dealt with, you still have five residents who want to go to the bathroom. Then they have to suffer the indignity of soiling their beds.

And this is the thing that we get to and nobody ultimately talks about or knows about. And it's really an issue that we need to make sure that if people are in a position like that they can actually be assisted because that's what aged care – and that second word care is what it's supposed to be all about; it's not the age indignity network. And this is the thing that people are suffering every day at a whole range of different levels. And, again, it's not the individuals who are creating this; it's the system that's promoting it.

MS HILL: What does that mean for people that are working in residential care?

MR HAYES: It means they go to work tired. They get to work frustrated. They try to do as much as they can knowing what they can do is just not enough because they don't have the resources to be able to do it. They have an issue of higher workers compensation from physical injuries, from mental health injuries. Again, when people are dying, you know, every week that they love and then the next step is that before they're dying they can't get to them to help them to get them to the bathroom on time and things like that. So the incredible stress that gets put onto aged care workers on a daily basis, whether it's an RN, whether it's a carer, whether it's an allied health professional, this is what these people live with every day and we don't talk about it enough.

MS HILL: At paragraph 69(d) of your statement you are evidence is that understaffing ought to be addressed by a minimum staffing standard. What do you mean by that?

MR HAYES: So at the moment I think there's several views that are ventilated and probably will be ventilated throughout the course of this Commission. Ratios are one area of view. We have a view about minimum staffing levels that there should be staffing levels that can't – that organisations can't fall below. Those staffing levels should be holistic staffing levels to be - - -

MS HILL: Do you distinguish between minimum staffing levels and ratio?

MR HAYES: I think the difference is putting a set figure on a ratio in an area where we're growing and consistently growing, I just think it's – I wouldn't suggest for a minute it's short-sighted or anything but I think we need to be a little bit more scientific in where we're trying to get to. So when we're looking at a holistic minimum staffing level we're talking about RNs; we're talking about allied health professionals; we're talking about carers. It's a collective workforce that works together. When you don't have an RN on night shift there are places who will say, well, we do but they're on call so if there's a problem you ring and the RN on call will deal with it. But I think it's grossly unfair to the residents. It's also grossly unfair to the nurse who has got that level of responsibility to make a decision not on-site.

That also reflects then onto the ambulance service who will ultimately be called in to be able to address the matter. So I think it's something that we need to consider: what does a aged care workforce look like going forward. I think where it has been in the last 20 years to where it's going to need to be in the next 20 years is a matter for an open consultation and discussion. One issue that we are very interested in is a shared service in relation to allied health professionals.

MS HILL: What do you mean by a shared service?

MR HAYES: So at the moment, let's take for a regional area. Let's take Canberra, for instance. So you might have 40 aged care facilities there and some are private, some are public; there's a range of them. Some of those facilities won't have the ability to actually engage a psychologist or a social worker, but I can guarantee everyone – well, not everyone but there will be a percentage of people in all of those facilities who will wake up with depression every day. They will just want to talk to someone. They will actually want to be able to deal with how they are feeling like the rest of us do on a day-to-day basis and we have that ability. So a shared service along those lines might be instead of a facility trying to employ an OT or a speech therapist or a physiotherapist or a social worker or a psychologist, there could be a regional hub that each of those facilities can draw on on a regular basis.

One, it will actually get people in those allied health areas regional jobs but, two, they will have a facility where each of the residents or each of the aged care facilities will be able to buy into which would actually be good for the resident at the end of the day and I think workable for a whole range of reasons.

MS HILL: Why in the current setting aren't more staff, more people engaged by aged care providers?

MR HAYES: Because ultimately there's a funding issue. And this is a matter for, you know, obviously it won't be resolved here but we have seen over and over again that the lack of funding going into aged care is going to determine what facilities look like, what staffing numbers there currently are and how those staff are actually engaging with – with the residents or the clients.

MS HILL: You gave the example of a shared service being able to coordinate, for example, someone to provide mental health support or a psychologist.

MR HAYES: Yes.

MS HILL: How does it work in the current setting, to your understanding?

MR HAYES: I think it works at different levels. There's not one particular level. So for profit companies, may have a better access to those sorts of services. Certainly not for profit, a lot of the religious groups, particularly regional religious groups, they are struggling to actually comply with some basic compliance issues, let alone being able to engage allied health professionals on a regular basis.

MS HILL: What do you say that a minimum staffing standard should look like in the future?

MR HAYES: I think that's – again, I wouldn't be in a position now to actually advocate that, I would be speculating. I think this is something that the – as a consequence of the focus of this Royal Commission, could come to the point of indicating that the groups, whether the unions, the organisations, the government need to come together and agree what that minimum standard looks like and a minimum that can't fall below, and a minimum that is holistic in terms of its outcomes for the workers and also the aged care resident. So to say today, look, here's a minimum of X would not be factual. To say this group need to, you know, have a number of X, again is not factual. We're not dealing with what the numbers are, what the numbers are projected to be. So a simplistic approach to that, I think, would be disingenuous with this Commission.

But I think if we are going to have some kind of level of science around it, I think there needs to be a total commitment to work that number out with all parties playing their role because this is not something that we can revisit again in 10 years. We need to resolve it now.

MS HILL: In your experience, and what your members are telling you, what are the principles that ought to underpin a minimum staffing standard?

MR HAYES: One, that there is adequate level of RNs; there's adequate level of carers.

MS HILL: You're referring to registered nurses?

MR HAYES: Yes, yes. Yes, correct. So adequate level of registered nurses; there is adequate level of carers; there's an adequate level of allied health professionals; that there needs to be a minimum standard for any aged care facility and that is with respect to the fact that some aged care facilities may have 50 beds, some may have 100 beds, some may have 25 beds. Some may be public, some may be run by local councils, some may be run by religious groups and so forth. So it needs to be able to take in that whole level of different demographics and ultimately come to the point of what that number or what those numbers would effectively look like.

MS HILL: At paragraph 31 of your statement you consider the current system and you refer to a general regime of economising.

MR HAYES: Yes.

MS HILL: What do you mean by that, Mr Hayes?

MR HAYES: We're looking at economising through predominantly people who are engaged in aged care, part-time workers, not full-time workers. So suddenly then – they're not necessarily casual workers either by that stretch. So to have people engaged as part-timers as opposed to casuals, you will see a saving in relation to casual loading. So that's a small group there.

MS HILL: And what does that mean for the workers in those circumstances?

MR HAYES: It still means they're playing catch-up from day one. They don't have any guarantee of tenure. They don't have any guarantee that there's 38 hours a week. They don't have any guarantee of getting a loan. And can I say this: the majority of people who work in aged care are women. With the HESTA figures – HESTA superannuation figures, the average super balance for people working in aged care is $18,000. So that's an issue in itself. Getting back to your question, is that outsourcing – outsourcing your responsibility to a third party who may or may not have any interest at all and we can, in further submissions, be able to identify that very clearly. So whether it's actually employing people who are not well qualified, are not well-suited, could be predisposed to any kind of inappropriate behaviour, who are not well-remunerated for that fact either and, indeed, are exploited openly – exploited openly.

And if those labour hire companies, for a better name, are prepared to undertake that level of activity of exploitation with the worker, what care would they have for the facility or indeed the – their clients that are ultimately to be looked after in that facility. So we look at that. We look at areas where cleaning products may be watered down. We look at areas where incontinence pads and so forth are limited or, indeed, there's a suggestion that we should not be using as many. Like, I think the bottom line to this whole Commission is about dignity and I cannot imagine anything less dignified than that.

MS HILL: You give the example of there being a decline of other industries in this country and you've just stated then, consistent with other evidence that the Commission has heard this week, that the aged care worker is typically a female.

MR HAYES: Yes.

MS HILL: And we know that that person is typically older.

MR HAYES: Yes.

MS HILL: Does the Health Services Union have a view as to how the increasing demand for workers in this sector can be met in such a way that a broader spectrum of the community is engaged in that work?

MR HAYES: Yes. And I think this has been done in the past. I think if you go back to probably about the early eighties or mid-eighties, there's not too many people want to work in jails and there was not too many people who want to join the army. The government has taken on activities from a marketing point of view to actually develop those areas that people have an interest now. People have a predisposition or a – an understanding that aged care is not an area that you will get a great deal of satisfaction. We can absolutely say that nothing is further from the truth. We have seen in our organisation alone, people who used to work on the assembly lines of car factories who are now working in aged care who love it. One, indeed, has indicated that, you know, "I wish I had done this some years ago".

That level of human engagement, that level of involvement that has not been actually publicised and marketed that people can see that this is something more than a very bad preconceived idea that has never been actually ventilated in any other way. And I think if we can get people to understand that this is an incredibly rewarding area – I can give an example of my own time with dealing with this one guy – and this is probably going back about 25 years now. I still remember it vividly, how I spent time with him. He was telling me how he was a bomber pilot and flew Lancaster and the experiences that this gentleman had that I would never have in my life and the commitment he had and the dangers he went through. And then he told me about his family and how they all came together. It was just a spiritual incredible experience just to listen to.

I get emotional about that stuff, I've got to tell you, and that's not put out there into the community. And when you have an opportunity to be involved in things like that I think people are going to say, hey, this is something I want to be involved with. This is something that is not what I thought it was at all. And I think most people who work in aged care will tell you they go to work not for the money – and, clearly, they don't go to work for the money – they go to the work for the love of what they do. And I think this is something that this society has lost sight of at this point in time.

MS HILL: What strategies does the Health Services Union suggest could address the negative perception of working in aged care that currently persists?

MR HAYES: Look, I think it's about engagement. We talked about, you know, sort of respecting our senior people and I think it's just ticking a box, quite frankly, then we move on to whatever the next issue is. We really need to make our senior citizens – the people who got us to where we are – we need to make them special. There's another example that one of our senior counsellors – our senior vice president actually raised. She works in an aged care facility. She finds it so disconcerting that on Anzac Day that they will dress up, these guys, the veterans, get them ready for the Anzac Day march and it's such a special day for these people, you know, these women and men. And then after Anzac Day is over, then nobody comes and visits them. They're left by themselves. And it's only the people who are working in aged care who actually – who see them on that day-to-day basis, who give them that, you know, that level of respect, that level of dignity, that level of, you know, feeling that makes them who they are and who – the experiences that they had.

So I think that – what the – you know, I'm not going to tell the government what to do, but the fact of the matter is we need to start to put our forebears on a pedestal that they deserve. And we need to do that not only from a – from a funding strategy but we need to be able to do that from a community strategy which would involve a media strategy which would involve the engagement through local community groups that there's just not an aged care facility somewhere out there, that aged care facility is actually facilitated – I know there are some groups where children come into aged care facilities and those sorts of things. They're good first steps but we've got to be able to, as an industrial – an industrial community where we're seeing a lot of our manufacturing sector and other sectors slowing down, this is a growing sector.

And I think if we can do something as simple as promoting the positives within the sector, promoting that it's probably better to work in an area where you can care for people and get that emotional return as opposed to just, you know, putting cans on shelves at Woolies and getting the same amount of money I think, you know, there is an opportunity for the future to be different than it currently is today and definitely different where it was 20 years ago.

MS HILL: At paragraph 66 of your statement, you refer to cost shifting.

MR HAYES: Yes.

MS HILL: What do you mean by that, Mr Hayes?

MR HAYES: So this is another form of where aged care facilities try to cut back. Some live within their means. Some others may have other alternative strategies for it. But as my experience as an ambulance paramedic – and I've been speaking with our paramedic members recently – nothing much has changed. Particularly on a night shift when there's limited staff in an aged care area – or let's take it for in the middle of winter, 2 o'clock in the morning, someone needs a catheter change. So

what we would do is that they call the ambulance. They may call a doctor. They might call the registered nurse who should be on shift but to save costs they will put the registered nurse on call, and then call the ambulance. So the ambulance will then come at 2 in the morning, take the person out to probably about 10 degrees or less, take them to the hospital. They will wait around the hospital for about two, three, four, five hours and then probably about 6 o'clock, 7 o'clock in the morning they will be returned back to their bed.

MS HILL: What do you say the effect of cost shifting in the example you've given the Commissioners is on people receiving aged care?

MR HAYES: I think that is – I think it – is that what you're saying, how often would that happen? Is that what you're indicating?

MS HILL: What's the impact on people that are placed in that situation?

MR HAYES: It's dreadful. It's – number one, it's promoting a shorter life span. So bearing in mind we're talking about frail people now, taking them out in the elements and sort of upsetting – I don't like, you know, sort of waking up too many times during the night, let alone having a whole journey for something that can be done. So it has got a detrimental effect in the short term and the longer term for these residents. And ultimately it's something that an aged care facility, again, care being the ultimate word, this is something relatively straightforward that should be able to be done and if there was an RN on duty would be able to be done. So that's an issue there. There's other issues for the ambulance paramedics where people will fall over. The ambulance paramedic will be called many times to put people back into bed because there is a lack of staff to be able to get people off the floor.

So they're fundamental issue that, again, the cost goes onto the State government. There is, however – you know, I'm not just going to come here and bleat about things. The State governments have what they call now is extended care paramedics who look after low acuity-type work like those things. There can be arrangements made between the State services and the aged care facilities to be able to take those matters into effect. So an aged care resident doesn't have to be taken out in the middle of the night. There's actual someone – and I would advocate number one, that you would have an RN there who would be to undertake these sort of matters but for whatever reason if – and I can't think of – so I won't advocate that they shouldn't be there but there is extended care paramedics who actually can facilitate these matters without having to be taken into the public hospital system.

MS HILL: Do you have members working in home care as well?

MR HAYES: We have a limited number of members who work in home care, aged – United Voice have more – a vast majority have members who work in home care. It's a difficult area in its own right and I think something that's becoming increasingly difficult though.

MS HILL: What are your members telling you about their experiences working in home care?

MR HAYES: It's increasingly problematic. So many of our members would be on eight hour contracts a fortnight. They may – they may work several shifts. They may work limited shifts. When they're travelling to a particular location – I believe it's the first trip that they do is – is being paid for. Other trips that they may do during that period are not. We're also seeing that some people who may need to be at a particular place at – at 9 o'clock and then they may need to be there at 2 o'clock in the afternoon will wait around if there's nothing to do during the day. And so that's an area that we don't have a huge influence in or a huge membership base in, but that's my understanding at the moment.

MS HILL: The issues that you've described and given evidence in regarding staff and people working in aged care predominantly in residential care, is that in respect to aged care services in the city?

MR HAYES: No, it's the – both city and country. Country – regional areas is a lot more – a lot – it has got its own difficulties.

MS HILL: What do you describe as the specific difficulties?

MR HAYES: So in regional New South Wales – and I think regional Australia, the level of unemployment is a lot higher. The ability to attract the range of different resources is difficult so in terms of getting allied health professionals and other health professionals to be able to work in aged care is another challenge for those areas. Many of the aged care religious groups are subsidised by their metropolitan counterparts and quite frankly wouldn't be able to function without that subsidy going forward. So – and then you've got the tyranny of distance, generally. So you may have people who, from a resident point of view, who may be obviously in aged care but their relatives may be some hundreds of kilometres away. So having that family contact on a consistent basis is something that is difficult as well.

MS HILL: What are the specific staffing issues that your members are telling you they're facing in regional areas?

MR HAYES: Basically, one, is that there is not enough people on shift at any point in time.

MS HILL: And how does that impact someone doing their work?

MR HAYES: So if you could imagine let's say for a facility that may have 50 beds, you may have two, possibly three, people on an afternoon or an evening shift. You may have a medical emergency. Straightaway that will take two people away. And then you've got, potentially, if you have a third person, one person to deal with any other matters. Now, a person who needs a lifter to get in and out of bed, it can't be done by yourself. If someone has had a fall, how to be able to address that by

oneself. To be able to get meals out, to be able to actually get people to the bathroom on time; all those things are addressed in a very difficult way and, again, it will take a lot out of the resident. It will take a lot out of the – the worker who is currently there. So – and that's just I think a pretty average sort of day. There could be areas where you have a high intensity – sometimes, you know, there will be issues like gastro will go through an aged care facility, which can kill a lot of people.

These are serious things and so making sure that the appropriate cleanliness of an aged care facility is something that people don't generally think about. But if those – if those bugs are allowed to fester that can be catastrophic for an aged care facility. So it has – it has a real effect right the way through. Something that most people in this room would be able to cope with pretty well, as you get older your immunity is not what it was, so people are far more susceptible to illnesses and can be very, very serious.

MS HILL: Does the Health Services Union have involvement with workers who are working in regional and remote areas?

MR HAYES: Yes, we do.

MS HILL: How do you engage with those workers?

MR HAYES: We have regionally based organisers who visit them on at least a six monthly basis. And that, in New South Wales, for example, that means going right out to Broken Hill and all those smaller regional areas as well. So we make sure that we touch base with all of our members, at least twice a year.

MS HILL: What are your members in those areas saying that their issues are?

MR HAYES: They're saying the same things as every other person is saying, is that the work is so hard, that they care so much that their frustration is just overwhelming, that there is not enough staff. The training is insufficient. The recognition is non-existent. They are screaming out for help and not for themselves. For the residents. Virtually everyone will say it's about what I can't do for this resident. And I notice there's one comment made by one of our people that's, you know, what was your worst day and the member said not being able to help this resident enough before she goes to heaven. And I think that was really quite stunning for me, that comment.

MS HILL: Thank you Commissioners, they are the questions I would seek to take this witness to.

COMMISSIONER TRACEY: Mr Hayes, you've described the breakdown in membership between the HSU and United Voice broadly along the lines of residential care and home care. But there's obviously an overlap. Is that demarcation arrangement peculiar to New South Wales or is it national?

MR HAYES: It's – it's peculiar to New South Wales as I understand it.

COMMISSIONER TRACEY: And is that because of historically - - -

MR HAYES: Yes.

COMMISSIONER TRACEY: - - - there have been State based arrangements.

MR HAYES: That's right.

COMMISSIONER TRACEY: Well, could you tell us what the position is nationally.

MR HAYES: Can I take that on notice, Commissioner.

COMMISSIONER TRACEY: Yes, certainly.

MR HAYES: I will get you an accurate answer on that.

COMMISSIONER TRACEY: It does, however, lead into a further question and that is the extent to which your two organisations cooperate - - -

MR HAYES: Yes.

COMMISSIONER TRACEY: - - - in dealing with issues such as training.

MR HAYES: Yes.

COMMISSIONER TRACEY: And things of that kind.

MR HAYES: I think up until probably in the last 12 months we've started jointly, United Voice and ourselves, the Our Turn to Care campaign. It has probably been going, actually, for 18 months or more now. That has been particularly focused on the aged care industry and the training, a whole range of matters that affect our members. We had, I think it would be fair to say, the three groups – the Nurses and Midwives, United Voice and ourselves all being acting, you know, unilaterally. But as time has gone on and over the last several years we're seeing that this is becoming something of not an individual organisation's interest. It's far bigger than that, and so over the last 18 months at least, we've been starting to advocate and agitate for enhanced training for enhanced conditions, enhanced government funding and so forth to be able to actually deal with this matter once and for all as opposed to the emerging piecemeal approach that has been happening.

COMMISSIONER TRACEY: And in your dealings with employers, am I right in thinking that the response you're getting from the employers about inability to do various things through lack of funding reflects a concern on their part, just as much as on your members' part, in other words, that they would wish to be doing more if they could?

MR HAYES: I would agree with that, Commissioner. Look, I think there are some – like every industry there's some areas of – well, some employers will exploit no matter what. But I think there's a lot of employers out there who are trying to do the best they can with what they have and what they have just simply isn't enough. So we have generally a good relationship with many employers and I think if we – if the employers could get to a point where they could adequately fund a whole range of their competing interests, that would take the pressure obviously off our members, support what their vision statements would be and also look after the residents at the end of the day. So this is, I think, one of those areas where many of us are on the same page albeit that we may be coming from different areas.

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

MS HILL: No, Commissioner.

COMMISSIONER TRACEY: Mr Hayes, thank you for coming and giving us your time this morning. It has been invaluable. Thank you.

MR HAYES: Thank you, Commissioner.

<THE WITNESS WITHDREW [11.03 am]

COMMISSIONER TRACEY: The Commission will adjourn until twenty past 11.

ADJOURNED [11.03 am]

RESUMED [11.37 am]

COMMISSIONER TRACEY: Yes, Ms Bergin.

MS BERGIN: I call Kaye Frances Warrener.

<KAYE FRANCES WARRENER, SWORN [11.38 am]

<EXAMINATION-IN-CHIEF BY MS BERGIN

MS BERGIN: Please bring up document number WIT.0031.0001.0001. Ms Warrener, there should be a hard copy of your statement there in the witness box in front of you.

MS WARRENER: There is.

MS BERGIN: Is that your statement?

MS WARRENER: It is, yes.

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

MS WARRENER: No.

MS BERGIN: I want to check one thing in respect of paragraph 33.

MS WARRENER: 33?

MS BERGIN: Is there any edits you wanted to make to the age of the family member that you describe?

MS WARRENER: Yes, my family member is currently 60 years old and went into – sorry.

MS BERGIN: Is she currently 67 years old?

MS WARRENER: Yes. That should be – that's wrong there – 67 years old and went into residential aged care when she was 61.

MS BERGIN: 61. Subject to those two edits, are the contents of your statement true and connect to the best of your knowledge and belief?

MS WARRENER: Yes.

MS BERGIN: I tender the statement of Kaye Frances Warrener, document WIT.0031.0001.0001 and the identified annexures, Commissioners.

COMMISSIONER TRACEY: Yes. The witness statement of Kaye Frances Warrener dated 18 February 2019 will be exhibit 1-61.

EXHIBIT #1-61 WITNESS STATEMENT OF KAYE FRANCES WARRENER TOGETHER WITH IDENTIFIED ANNEXURES DATED 18/02/2019 (WIT.0031.0001.0001)

MS BERGIN: Ms Warrener, what role do you have in respect of aged care?

MS WARRENER: I'm a carer for my husband, Leslie John Warrener.

MS BERGIN: And when was the first contact you had with My Aged Care about Les?

MS WARRENER: That was back in October 2016.

MS BERGIN: And why did you first contact My Aged Care?

MS WARRENER: Due to Les' – some restrictions, we were looking to have things put in the bathroom to help assist for showering and in the toilet area.

MS BERGIN: And how did you find out about My Aged Care?

MS WARRENER: With that, it was quite some years prior, I had a daughter who worked in the care – carers – at the carers situation – carers support, and she had given me a folder of information that we may need down the track as we aged. And I was – went to that and was looking through that. So that's how I come to ring the My Aged Care.

MS BERGIN: And what happened after you contacted My Aged Care?

MS WARRENER: Well, My Aged Care sent out a person to do an assessment on Les and from that we then were able to have the support for having the bathroom and the toilet areas fixed. And we had contact through those, through a different service provider and that to provide those services, and that's how that all came about.

MS BERGIN: So when was – when did this occur?

MS WARRENER: That was in November 2016.

MS BERGIN: And when did you first telephone My Aged Care to make the inquiry that you mentioned?

MS WARRENER: The first contact, yes, that was in October 2016.

MS BERGIN: What modifications were made to the bathroom after the assessment?

MS WARRENER: In the bathroom in the shower area they put two rails for access to hang on to in the bathroom area. And then in the toilet area, there was a rail put beside the toilet and a toilet raiser applied.

MS BERGIN: And was this part of the Commonwealth Home Support Program?

MS WARRENER: Yes.

MS BERGIN: What financial contribution did you have to make to the works that were done?

MS WARRENER: Well, we were charged from the service provider. They came out and measured it up, and then we paid an amount which was a lot cheaper than if I had have gone to – without having the support of that program. It only cost us $51 which was absolutely a financial help to us.

MS BERGIN: And so what else, apart from the bathroom modifications, has Les received through the Commonwealth Home Support Program?

MS WARRENER: Through the Commonwealth Home Support – which we still get that support at the moment – through the course of the journey, he has a service provider come out three times a week to apply cream to his legs and his surgical stockings – help him with those on and off because he has issues with his legs.

MS BERGIN: And what cost is that to you?

MS WARRENER: To us, that's $10 per visit and we get billed fortnightly.

MS BERGIN: And how often does the service provider attend at your house?

MS WARRENER: That's a Monday, Wednesday and Friday. But public holidays, there's no attendance unless you want to pay extra money, normal fees.

MS BERGIN: Okay. Now, so that's the Commonwealth Home Support Program.

MS WARRENER: Program.

MS BERGIN: Has Les been assessed for a home care package?

MS WARRENER: Yes, he certainly was. In November 2017 we had an ACAT team member come out to the house and Les was assessed for a home care package which is different to the Commonwealth package – program. So he was assessed and approved for a package 3, a medium package 3.

MS BERGIN: And when was this?

MS WARRENER: This was in November 2017.

MS BERGIN: Now, I will ask the operator to turn to KWH.9999.0001.0006. Is this the letter that Les was sent following the assessment by the ACAT team?

MS WARRENER: That was sent to Les, yes.

MS BERGIN: And how long – I withdraw that. What prompted your request for an assessment for Les at this time in November 2017?

MS WARRENER: Because of his health deterioration and things that I was doing for Les, at that stage I knew I had to go into hospital and so I rang to see what other assistance we might be able to get while I was in hospital.

MS BERGIN: Okay. And what happened at the – during the ACAT assessment at your house?

MS WARRENER: Right. Once the assessment was finished, the lady doing the assessment made a comment that, not to sit back and do nothing over the time while we were waiting, but to continually phone into the contact centre to try and find out where Les might be in the queue, and that was what was told to us on that day.

MS BERGIN: So after that assessment, what advice were you given about how long it might take for the level 3 package to arrive?

MS WARRENER: Right. We were told at the very beginning that it could be 12 to 18 months for the package.

MS BERGIN: Okay. I will take you to one of the – the second attachment to your statement which is KWH.9999.0001.0004. Now, is this – this letter in the first paragraph says:

> *You have moved up in the national queue and we expect that you may be assigned a home care package in about three months.*

And if I take the operator – if you could turn to the next page of that same letter, the date on that letter is 21 March 2018. So you received this letter?

MS WARRENER: We did and it made us very hopeful that the package was coming through, and that we were looking forward then to being able to access certain services for Les to put in place the more services. It made us very happy at the time and very thankful and so we just sat back and waiting to see – expecting that a package would be following very, very shortly.

MS BERGIN: And so in the three months after, how did you find out about the status of Les' application and his progress?

MS WARRENER: Right. So what I was doing, I was accessing the My Gov portal for aged care and in there will show you the sort of time that it might be but time went on and it was not till 10 months later that we received the next letter.

MS BERGIN: Okay. So I ask the operator to turn to KWH.9999.0001.0001. So is this the next letter that you were just referring to then?

MS WARRENER: That came on 5 February this year.

MS BERGIN: This year.

MS WARRENER: This year. Telling us that we had been assigned a level 2 package. It indicates in the letter, it's not the package – excuse me:

> *...not the package that you were assigned but this will help get you started for some of the services.*

MS BERGIN: And if the operator could, please, turn to the third page of that same letter. I will just identify the date on that letter is 5 February 2019. So how long then has Les been waiting for his level 3 package at the current time?

MS WARRENER: From 6 November 2008 – sorry, '17, up until February – and up until today we're still waiting for the home care package level 3.

MS BERGIN: And have you asked for information about Les' progress in the queue in relation to his level 3 package?

MS WARRENER: I certainly have. And this is where my frustration comes in because when you ring the contact centre they don't know. They can't give you an exact time or date of when you might be receiving the package. So to me, this is where you're given false hope that a package is coming through, but you cannot find out exactly what's happening. So otherwise you could cut the cloth to suit whatever the situation is, but it's – it's like – it's very frustrating and I've watched Les get very depressed over things, about not being able to get the package.

MS BERGIN: So how – what have you observed in terms of changes in Les since that first letter we brought up on the screen. You mentioned that you were hopeful when you were advised that it would be three months until the level 3 package would arrive. How has Les – how has Les' health changed since that time?

MS WARRENER: There has been a deterioration in his health. He has had a trip to hospital. He has cellulitis in his legs and Les also had – way back in 2008 he had a quadruple bypass. And from that time to now Les doesn't sleep in his bed; he sleeps in a chair. So the biggest thing for us has been wanting to get a chair that he can have the legs brought up, a footrest. He currently has a manual chair, but because he has arthritis in his hands he can't use the little button on the side to get that up for his legs. So what we did was we bought a little – what they call a little poofy thing for him to elevate his legs but that's a danger. He has already had a fall when he wakes up. He also has prostate cancer. So when he wakes up through the night to go to the toilet – and I think most people would agree – if you wake up in the middle of the night you're not fully conscious and he has tripped over that. It's just a dangerous thing.

So when we thought we were getting the package, we thought great, we can do away with that; that's a health hazard in the house and we can get him the chair. But having said that, on one of my calls into the centre I was told the money is not for that and I thought this is strange so - - -

MS BERGIN: So when you say the money is not for that - - -

MS WARRENER: For a chair.

MS BERGIN: - - - are you talking about the chair that is appropriate to sleep in?

MS WARRENER: Yes. The money is not for that. So I rang the service provider. We've already made up our mind way back then which service provider we were going with. So we've had constant contact with that service provider and I was told by the service provider, okay, that's wrong because this is an aid for – to stop further trips that would be – the money would be eligible for that.

MS BERGIN: So how did you acquire the chair that he's sleeping in at the moment?

MS WARRENER: Our daughter gave him that chair because she had changed her lounge suite so she gave her father that chair, but he just cannot manipulate the button on the side.

MS BERGIN: Okay. So it's a comfortable chair but it's not a chair that's designed to be slept in; is that right?

MS WARRENER: Yes. That's correct.

MS BERGIN: I think you mentioned that Les has arthritis in his hands - - -

MS WARRENER: In his hands.

MS BERGIN: - - - so does that affect his ability to utilise the buttons on the chair?

MS WARRENER: Definitely, yes.

MS BERGIN: So, overall, how long has Les been in the queue for a level 3 home care package?

MS WARRENER: From 6 November 2017 up until this point in time which is over 450 or 60-odd days. Yes.

MS BERGIN: 450 or 60 days. And how have you felt while Les has been in the queue this 450 days?

MS WARRENER: Well, it's hard to watch your loved one – I mean, we've been married for 56 years – to watch their health deteriorate. And I just feel with the extra support financially we would be able to help perhaps delay some of those onset things that are happening with age, like by hydrotherapy, physiotherapy. He's even finding it hard, now – we only have a small patch of area at home in the garden to

do; he will cut the grass but I have to do all the edges and things. You know, it's just too hard.

MS BERGIN: It's too hard. So when you say that physio might be helpful - - -

MS WARRENER: Yes.

MS BERGIN: - - - have you observed – have you a fear that Les has deteriorated faster than he might have done if he got the level 3 home package - - -

MS WARRENER: The support, yes.

MS BERGIN: - - - when you expected it?

MS WARRENER: The thing that I have witnessed and seen was prior – I'm trying to think of the actual timeframe now, but he did have a physio therapist and that coming out from one of the service providers. But that service provider was taken over by another company so they had to stop because the lasses that were doing it didn't know whether they had a job at that stage. So that has taken a couple of months for that all to play out. And the thing is that we've had letters from them to say we can resume that, because he was getting this support and the exercises were strengthening his legs. So I could see the difference in that. He was a very athletic person in his younger – younger years. So I could see that. But because of financial restraints – we are both on a full pension and we don't have any other income and we live in a rental property so just natural living is out there. So we've decided right, surely this package is not far away; we will just wait now till that comes in and then go ahead with the services.

MS BERGIN: Now, you mentioned that you've used the My Aged Care portal - - -

MS WARRENER: Yes.

MS BERGIN: - - - on the internet. What has been your experience using the portal?

MS WARRENER: For me, it's not a huge difficulty because of my work background. But what I've found – and it's a bit confusing to me – is you go into the portal and there are certain headings that you can access, one of them being the interactions. So under the interactions it will show you a date and a number against it each time that I've contacted the contact centre. But for me to get in there and open that, to have a look at what have they recorded for the last – and I've been trying this now for about six to eight weeks getting everything ready for this today, I couldn't get in. So I actually phoned and they put me through to the IT service department, but I've tried three times and I've had no response about this.

So I printed out the copy of the how to use the portal. It's about 27 pages long, so on one page it shows you on the specific page that I was trying to get into, it shows you a little thing at the bottom that says "Show all". That's not on my screen. The other

confusing thing was when I'm talking to my service provider and saying "I don't understand this". And she said, "Kaye I can get that information for you". So she went in, opened up all those things and read out to me what the contact conversation was, which I hand wrote down in preparation for this. So one of the questions I would ask about this portal is are there different degrees of access? So I as a client have one access. The service provider must have another access.

So I'm just a bit confused about how that physically works because as a privacy issue, certainly I should be able to see my own comments of what I've made, what are they putting in when we have this contact. I think that should be looked into on the portal side of it.

MS BERGIN: Okay.

MS WARRENER: But it is – it is a good tool. The portal is a good tool.

MS BERGIN: So how would Les get onto My Aged Care portal if you were no longer able to do it for him?

MS WARRENER: I would say with difficulty because, as I said, I've worked on computers so I have an understanding. But Les hasn't worked on computers. No. Unless I was sat beside him showing him, no, he wouldn't be able to access it.

MS BERGIN: So that would be an obstacle for Les - - -

MS WARRENER: Yes.

MS BERGIN: - - - using the – finding out about the status of his home care package.

MS WARRENER: Yes, yes. And there are lots of people out there in our age bracket that would have difficulty, I would say, accessing computers.

MS BERGIN: Okay. You mentioned that you've observed a deterioration in Les since he was assessed in November 2017 by the ACAT team. Has there been a reassessment since the first assessment was done?

MS WARRENER: Yes, which I did, from memory, October, about October 2018 when I phoned in saying I was concerned because we – remember we had had the letter in March so we're now in October 2018, where's this package? And so they said, "Well, the only thing we can do is have a further assessment". So this was all done on the one day, so I did get some phone calls back and they did an assessment over the phone. Now, to me, doing an assessment over the phone was not sufficient because the people who assessed him in 2017, there was no one to see the differences that I can see in that period of time. So a phone assessment, I don't think is fully acceptable.

MS BERGIN: Now, since you've received the letter about Les being able to access the level 2 home care package, what has happened in relation to the - - -

MS WARRENER: Right.

MS BERGIN: - - - level 2 home care package?

MS WARRENER: Yes. So we have until 2 April to have this on a contract with a provider. So because I said we had already chosen the one that we want, we've been in contact with them, but because they're very busy at the moment, they're actually physically coming to the house tomorrow to do a face-to-face meeting and create a contract for us for a level 2.

MS BERGIN: And have they described their contract as a home care agreement, or something like that?

MS WARRENER: No, because they haven't been out yet to the – they did send in the mail a brochure on their services and what they do but that's all we've had so far.

MS BERGIN: Okay. Now, turning to a different topic, how is culture relevant to the work that this Royal Commission is doing in its investigation?

MS WARRENER: For me, personally, my biggest thing is I think it's the respect out there in society about aged people and aged care. I don't think we're given the respect that we should be getting. I look at it as I just feel this, my own personal view, that aged care has become – we've become a commodity for people to make money on in certain areas. Now, I'm not saying everybody and there's some great places out there. But what I'm seeing, because I have – I'm retired, I have the time, I view the papers, I watch the TV, I listen to the radio and you're hearing these – especially with the abuse, elder abuse – but I just think – and I watch around and there's a lot of the service providers, the names that are coming up – because over the years I've watched – we've always had the – certain providers out there that we know the names, we know these areas. But we're getting so many new businesses popping up and I think no, everybody – everybody has – not everybody, that's stupid to say that – but the government has said we're going to have these packages, which is a great idea. So people have thought, great, new business, I'm going to have a bit of this. And they – you start seeing these providers which I don't think are 100 per cent fully trained, fully adequate, that are just interested in getting a new business started and getting some money from these – these government packages.

MS BERGIN: So you mentioned before that you have already identified the provider that you would like to - - -

MS WARRENER: Yes.

MS BERGIN: - - - work with and you would like to provide care for Les.

MS WARRENER: Yes.

MS BERGIN: How did you identify that provider as compared to the providers that you're talking about at the moment?

MS WARRENER: Okay. So the person I used to work with is working in the medical profession area on projects and she has been involved in the lead-up to all these packages and things. She had been to a lot of – a lot of meetings and things around what would happen with people, with packages and things. So she finds that – her words to me were, "Kaye, this provider is really down to earth and has the person at heart, not just a business, but the person". So I thought, well, that's good enough for me. And they also – I know that they run a very excellent respite centre and an end of care – end of life situation. So I thought, well, this is where we're at, this is where we're heading, so that's why I chose that provider.

MS BERGIN: So you've carefully researched the options - - -

MS WARRENER: Yes, yes

MS BERGIN: - - - and identified some providers that you feel are favourable and others that you're not as sure about.

MS WARRENER: In my mind, yes.

MS BERGIN: Okay. And so is there anything else you wanted to say to the Royal Commission about your experience with aged care and the aged care system?

MS WARRENER: Well, I have had – within the aged care I have a very close family member who went into aged care at a younger age, and is still in aged care now, but from – and she has been there six years. So in the very first instance when I was visiting this aged care centre, the first thing that came to me was the smell in this place. I thought, "No aged care". But over the last couple of years this aged care centre here in South Australia has changed hands. The gardens have been beautified; the whole place has been changed and painted and everything. And in these last couple of years visiting there now is – when I walk in, is totally different to when I first – so there is abilities for people to do better things and this is only a small home for the aged. So I've had, you know, that exposure to aged care, but the only thing is through the very first instance, I think, has put very fearful thoughts for Les and I to go into home aged care, so we're strongly trying to prevent going into home aged care.

MS BERGIN: That concludes my questions of this witness. Thank you.

COMMISSIONER TRACEY: Ms Warrener, the correspondence that you've exhibited to your statement indicates that at various points you've been given to expect that within a certain number of months certain benefits would become available.

MS WARRENER: Yes.

COMMISSIONER TRACEY: When those deadlines have expired, has My Aged Care taken the initiative and contacted you and told you that a deadline was not going to be met, or have you just had to wait for a while, nothing has happened so you then make contact.

MS WARRENER: Exactly right. And probably because we've kind of sat back and waited, my husband would say nothing – nothing has come yet, nothing has come yet. But watching TV and hearing the radio and different people ringing in about home care packages and how long they've had to wait, I was coming to the realisation, we've just got to wait. We've got no option to do anything.

COMMISSIONER TRACEY: I've read the correspondence and I can see nothing in it by way of explanation for the delays when they have occurred.

MS WARRENER: No.

COMMISSIONER TRACEY: When you have been speaking to the people at the end of the telephone line, have you ever been given an explanation as to why the – I won't say promised deadlines, but the – the expectation dates have not been met?

MS WARRENER: No. Because my background is in contact centres, I kind of have an understanding of how much knowledge the people that work in the contact centres have and are given, and I've asked the straight-out question, "Can you tell me when this level 3 package will come through?" and they just say "No, we don't know".

COMMISSIONER TRACEY: Well, that's – the "when" I understand but I'm more concerned about the "why".

MS WARRENER: No. There has been – no.

COMMISSIONER TRACEY: It has never been explained to you why the expectations haven't been met?

MS WARRENER: No. Because there's lots of – in my head, there's lots of questions about how are the packages handled from 1 to 4. Les is on a medium 3. Is there a difference in package 3? Are there levels? And if after you're assigned a package – and that was back in 2016 – it tells you – commonsense tells you there's going to be a lot of people along that time that are assigned a package and possibly, and would be level 4. So does that mean Les goes down the queue every time a 4 comes in? These are the sort of questions I would like to have some access to that sort of knowledge.

COMMISSIONER TRACEY: Nobody has provided it to you from the call centre or - - -

MS WARRENER: No.

COMMISSIONER TRACEY: - - - elsewhere?

MS WARRENER: No.

COMMISSIONER BRIGGS: That's a pretty concerning suggestion, and given the supply constraints that have been evident around the levels of packages, you may well be right. We will certainly follow that up and have a good look at it. Thank you for speaking to us today. It has been incredibly important. I'm wondering if you could give us any indication at all of when you were given a choice by the aged care – My Aged Care, do they say this is an approved provider or what happens as part of those communications?

MS WARRENER: No, with the – as regards to choosing your service provider, they tell you you can access that through the portal. There will be a list of service providers that you can go to, and when you look at brochures and things tell you on the brochures that there's an address that you can go into and bring up the service provider. But they don't point you in the direction of a – they don't tell you take this one. They leave – the choice is ours who we - - -

COMMISSIONER BRIGGS: So the free market is operating?

MS WARRENER: Yes.

COMMISSIONER BRIGGS: Do they give you information about the services that each of the particular providers provide, or is it an assumption that if you choose a provider they will then bring in extra services?

MS WARRENER: To provide, yes, because the service providers then have their own brochures and tell you what they're able to provide.

COMMISSIONER BRIGGS: We will, throughout the course of these hearings, explore the question of what the national queue means in practice - - -

MS WARRENER: Yes, yes.

COMMISSIONER BRIGGS: - - - and how that national queue applies across States and, indeed, regions within it. At the moment that's not exactly transparent to me at least, but I will have a look at that, and the situation as it relates to South Australia is clearly quite important. If you've been told you're getting a three month waiting period - - -

MS WARRENER: Yes.

COMMISSIONER BRIGGS: - - - and then, you know, all this time later you're still waiting, you've got to question how those different parts of the queue and the packages have been managed.

MS WARRENER: Yes.

COMMISSIONER BRIGGS: Yes. Thank you.

MS WARRENER: Okay. I hope I've been of some assistance.

MS BERGIN: Commissioners, if this witness may be excused. I have no further questions.

COMMISSIONER TRACEY: Ms Warrener, you have been of great assistance. Thank you very much.

MS WARRENER: Thank you for your time.

<THE WITNESS WITHDREW [12.10 pm]

MS BERGIN: We propose to call a further witness before the luncheon adjournment, if that's convenient to the Commissioners.

COMMISSIONER TRACEY: Yes, certainly. But you would like the hearing stood down briefly while the witness is prepared.

MS BERGIN: Yes. Thank you, Commissioners.

COMMISSIONER TRACEY: Yes. Very well. Well, the Commission will temporarily adjourn.

ADJOURNED [12.11 pm]

RESUMED [12.18 pm]

COMMISSIONER TRACEY: Yes, Mr Bolster.

MR BOLSTER: Thank you, Commissioner. I call Margot Jane Harker who is in the witness box, Commissioners.

<MARGOT JANE HARKER, AFFIRMED [12.18 pm]

<EXAMINATION-IN-CHIEF BY MR BOLSTER

MR BOLSTER: If document number WIT.0053.0001.0001 could be brought up, please. Ms Harker, is this your statement?

MS HARKER: It is.

MR BOLSTER: You can see it there on the screen.

MS HARKER: I can.

MR BOLSTER: You have a hard copy in front of you as well.

MS HARKER: I do.

MR BOLSTER: All right. Let us know if it's a bit small. We can make it larger for you at any time.

MS HARKER: Thank you.

MR BOLSTER: Are there any changes you wish to make to that statement?

MS HARKER: No.

MR BOLSTER: And is it true and correct to the best of your knowledge and belief?

MS HARKER: Yes, it is.

MR BOLSTER: Now, Ms Harker, I want to ask you some questions about the statement and about your story. You're currently 72.

MS HARKER: I am.

MR BOLSTER: And you were, for a long period of time, employed in the public service.

MS HARKER: And other things, yes.

MR BOLSTER: I think you told me outside that you have a PhD in history.

MS HARKER: Yes, I do.

MR BOLSTER: And you worked in that field in the Senate for a time.

MS HARKER: I did. Yes.

MR BOLSTER: All right. And you have been an independent person all your life.

MS HARKER: Yes, all my adult life, definitely.

MR BOLSTER: And you're currently on a level 4 - - -

MS HARKER: Yes.

MR BOLSTER: - - - Commonwealth home care package.

MS HARKER: Yes.

MR BOLSTER: And you also receive Commonwealth Home Support Program funding as well.

MS HARKER: Yes, I have done.

MR BOLSTER: We will talk about why you receive two packages in due course, but at the moment I would like to explore how you came to be in that position. You had a health problem, didn't you, when you were about 64?

MS HARKER: I had a stroke.

MR BOLSTER: Yes.

MS HARKER: Which came on very suddenly. And the Friday – I had been working during the week, I worked Monday to Thursday – I was with my daughter because it was her birthday, and at the end of the day I felt a bit dizzy. The next day I just collapsed completely at home, and I've had apparently an aneurysm and it was affected by high blood pressure and stress so that's what happened. I suddenly was in hospital.

MR BOLSTER: And how long were you in hospital for?

MS HARKER: All together about eight months.

MR BOLSTER: And I understand from your statement there was a – there was a long period of convalescence as well, and rehabilitation.

MS HARKER: Yes.

MR BOLSTER: What did that involve?

MS HARKER: Well, it was all done in hospital because I was, first of all, in the acute stroke ward. I went into one hospital but the main Canberra hospital was on the other side of the town. It had a stroke ward; the Calvary Hospital didn't so I was transferred across there. Then they have a rehabilitation unit and, you know, ward

12B, it was well known. They said there's a space in 12B so you can go in there, you can have rehabilitation. So that was – most people had three months. That was sort of regulated, you know, you can have money for three months of therapy and rehabilitation. Then there was a unit called the independent learning unit which is a halfway house to going home and I went into that for another two months, I think, maybe three.

MR BOLSTER: Now, you left the rehabilitation and went back to your old home.

MS HARKER: Yes.

MR BOLSTER: And there were problems there.

MS HARKER: Yes.

MR BOLSTER: I just want to take you back to the position in before the stroke. What was your intention; what was your plan for your future as you got older? What were you hoping to do?

MS HARKER: Before that point, so a few years, I thought, well, I will retire at 65 and I will do a lot of the things that I enjoy doing that you can do privately in retirement, including history and from a family history point of view and some more general research projects, I thought I would write more stuff. And just spend time doing a lot of things that I like, like reading – I was a singer – bushwalking, swimming, and that sort of thing, and that I might do a bit more travel but not too much, because I expected I would not have much superannuation, not much money to draw on. So that was earlier, but by about that time when I was 64 and I was working in this particular job and the one just before it, I realised that I was fine, I would love to go further on, I wanted to retire maybe at 70.

MR BOLSTER: All right.

MS HARKER: I knew I had – you know, my marbles were fine; I just wanted to keep going, and also because my super was really pretty minimal.

MR BOLSTER: Right.

MS HARKER: Like most women.

MR BOLSTER: Compare that to after you came home and there were problems with the home and you had to sell the home and - - -

MS HARKER: Yes.

MR BOLSTER: - - - buy the unit that you're now in.

MS HARKER: Eventually, yes.

MR BOLSTER: And you were quoted in an article in the Canberra Times as saying this – let me just read this to you, because I want to get your perspective on this. You said everything – your home meant everything to you; it was your independence. You said you've made it a beautiful nest:

I can play music. I've got my cat and my garden.

So that was something you said in 2015. You had been in that home; you had set yourself up in that home for some time. How important is it to you to remain in your own home?

MS HARKER: It's actually vital. And I have spent a few months in an aged care complex in a respite area after I finished in my – I had a second stint in hospital and they wanted my bed so I ended up in this place until my new house, my new unit was refurbished and made completely accessible. So I knew that any – I'm not somebody who's easily – who fits easily in any institution, but I think how I was at that time, how I still am is and independent thinker and I make my own decisions. I always have done. You know, I've always had a car, always had responsibility for getting it serviced, changed my own tyres, that sort of thing. That I thought, you know, being in an institution of any kind would take that independence and – independence and spirit away from me.

MR BOLSTER: All right.

MS HARKER: Whereas at home I had the opportunity to do what I wanted with it usually. You know, I could decorate it the way I wanted. I could, yes, I could sing, practice my choral music; I could do that stuff. I have never been without a pet and I had had two cats and a dog but eventually I ended up with one cat and I just felt I couldn't live without her.

MR BOLSTER: Right.

MS HARKER: If I live anywhere, it's important to have a warm furry presence nearby.

MR BOLSTER: All right.

MS HARKER: And, you know, usually, like, sleeping on me even though I end up with, you know, scratch marks everywhere but, yes, that is critical.

MR BOLSTER: Can we turn to the services that you currently need to get by because you get two levels of service. What's done for you in the day? Who comes and helps you on a typical day?

MS HARKER: There are two sets of service. In the morning, somebody comes about 7 or 7.30 and gives me a cup of tea because I have bad nights. I'm not a night person – I'm not a morning person anyway, and so they give me a cup of tea so I

revive slightly, and a bit of toast. And then I can get into the shower and then they dress me. That's one thing: I cannot dress myself, I can't undress myself. So they get me dressed. And I can't dry myself. There are parts of me that I simply can't reach and the paralysed side, you know, I can't use this hand at all and it's very heavy. You know, it's a dead arm. It weighs a lot because of – it feels like it weighs a lot. So a carer helps me with those things and prepares the day, because I spend a lot of time alone.

They make me a sandwich for lunch. They always make me a bit of – I always have fruit and they cut that up so I can have that later with my dinner because whoever comes in later to do the dinner hasn't got time to do that. So they prepare things so that they're available for me during the day and at night. And did a quick clean-up. Anything you know – I drop things a lot. There's always crumbs around and they tidy it up. And they feed the cat which, of course, she thinks is the most critical thing in the day.

MR BOLSTER: How long are they there for in the morning?

MS HARKER: 90 minutes.

MR BOLSTER: All right. And then in the evening?

MS HARKER: Most of the time it's one hour but when I started to – I started to get pre-prepared food, but not cooked, delivered, which was – everything else I had delivered before that, like Lite n' Easy was very low on the right kind of carbs or on meat or any sort of protein so I wasn't thriving on those things.

MR BOLSTER: So when the carer comes in the evening, what do they do for you?

MS HARKER: Well, first of all if it's a night when I've got some of the food to be cooked, they will start that off. Then, of course, they will feed the cat. And then they prepare other things like my meds have to be sorted at that time because I take quite a lot at night. And they bring out the fruit and put it there with some other things that I might need during the night.

MR BOLSTER: Yes.

MS HARKER: Then they set the bed up if it's not already and then they get me into my nightie and then I get to bed. If they've been cooking, then I get the food on a tray. I have a hospital-type bed and I have one of those tray tables on wheels. So that's all set up, and particularly has to be arranged so that – because I can only use it on my right side – it's reachable but also always on this side. And then, you know, if there's any time at all which is very rare, they will sweep around, do some washing up, that sort of stuff, every day.

MR BOLSTER: So you need two visits every day, seven days a week for essential things.

MS HARKER: Yes, yes.

MR BOLSTER: Does the fact that you have two packages mean that one package will not deliver all that you need?

MS HARKER: Neither of them delivers all I need.

MR BOLSTER: Yes.

MS HARKER: When I started off with an aged care package, home care package, it was not enough.

MR BOLSTER: And the CHSP, that - - -

MS HARKER: The CHSP - - -

MR BOLSTER: - - - fills in the gaps, does it?

MS HARKER: It was supposed to fill in the gap originally, and originally it did, because when I was on the package first of all and then consumer-directed care came in. At that point there was a sort of crisis amongst a lot of people who were receiving the packages because many of us at the highest level of need had been getting what they call cross-subsidisation which meant that at – usually with telling another client, you know, the care organisation – the provider had a block of money and they might have, say, 20 clients.

MR BOLSTER: Yes.

MS HARKER: Some on level 1 and 2, some on 3 and 4. And so people on 1 and 2 quite often only needed very minimal care and didn't really want to use everything, enough to use up their whole package. So a good manager of a provider organisation would go, "All right, do you mind if Margot has this" – and they didn't always tell them, I suppose. But mine was topped up that way so I had just enough money to cover at least my basics.

MR BOLSTER: At the moment, are you getting – do the two packages provide enough funding for you to get what you need?

MS HARKER: No.

MR BOLSTER: What's the gap? What do you have to pay for yourself to get what you need?

MS HARKER: I'm not paying anything myself at the moment. There is some emergency subsidy coming in from the government, I don't know how - - -

MR BOLSTER: Yes.

MS HARKER: - - - because the provider that I was having CHSP funding through collapsed, went bankrupt overnight. And after some fuss by the clients – I don't know how many of us there were, maybe 40 – the department had to step in and do something. They have said that they're going to organise another provider to have the CHSP funding that we had before, and then it will continue as before. It wasn't enough anyway. So what I had already done was, with the agreement of my other provider, divert some of my package funding to weekends and public holidays. I had lost that as part of the CHSP re-jig. So I got probably four-fifths of my needs covered by CHSP and they – that's mostly the morning care.

I did have weekends and public holiday mornings. That was now suddenly not available to any of us. I had to find some extra money, too, because CHSP, at that time, when that was taken away, no weekends, no public holiday, there was also a new co-payment introduced of $10 for every service. And I can't really afford that because I'm a full pensioner.

MR BOLSTER: All right.

MS HARKER: I've asked members of my family to help out with that.

MR BOLSTER: Let me talk to you about your providers. When you had the home care and the CHSP, they were different providers?

MS HARKER: Yes.

MR BOLSTER: So you had two people looking after the home visits that you received?

MS HARKER: Yes.

MR BOLSTER: All right. I want to ask you, did that create problems, that you would have two different organisations? Did they talk to one another, did they - - -

MS HARKER: No.

MR BOLSTER: - - - communicate?

MS HARKER: No, not really. The problem is that normally you would have a provider.

MR BOLSTER: Yes.

MS HARKER: And that is your provider and it will normally run your package and that's all. They will have other organisations they broker to. So there might be four or five, what I call agencies. They might actually be providers for other people but for the purposes of my care they're agencies and my provider brokers to them. All the payment goes through my provider to them. All the admin and my provider is a

case manager as well. So that's what normally happens. With the two, they didn't really talk to each other. The one that had been my package provider and thought of itself as the principal provider wanted to pretty much monitor and control and direct everything but – they didn't go to war or anything. They just didn't really talk to each other. I ended up being the intermediary; the piggy in the middle, I suppose.

MR BOLSTER: You talk about problems actually in delivery and people not turning up, having different carers from time to time.

MS HARKER: Yes.

MR BOLSTER: Could you tell the Commission just a little bit about that side of the story?

MS HARKER: Yes. With one of my providers at the moment, the one that's handling most of my evening care – so that's paid for by the package – I've had at least 12 months, probably the two months of this year and going back 10 – nine or 10 months of last year, in which there was, frankly, incompetence. That people who were on a roster didn't know they were on the roster; I hadn't got a copy of the roster. So those standard procedures where a coordinator will ring round the carers and say, "Would you be able to take Margot's shift on Thursday?" They then say yes or no. I get told that they're coming; I also get a copy of the roster. None of that was happening. But, yes, the main thing that was happening was that they might have said three weeks ago they were able to come on the Thursday of that week but they didn't go on the roster and they didn't – a lot of them just lived by getting up at the beginning of the week and going, "Well, who have I got this week". So they look at the roster, but they haven't had the call saying "Don't forget" or you know this is the length of time, details and so forth.

MR BOLSTER: You say that they do forget and that there were occasions when people don't turn up. What happens when someone doesn't turn up to help you in the morning?

MS HARKER: Different things. If it's morning, I can pretty much get myself out of bed. I can transfer to the wheelchair. I can get into the bathroom. I can go to the toilet, clean my teeth. I can go into the kitchen and I can make a cup of tea. A bit dangerous with boiling water but I'm very careful, and maybe get a biscuit or a snack, but that's it. I can't - - -

MR BOLSTER: You can't dress.

MS HARKER: I can get myself in the shower but I can't dress afterwards unless it's a hot day, I can go out in the courtyard and drape myself with something. I don't know. But, yes, it's just that, you know, basically there was a period where nobody came up, that this other provider had collapsed, and I just stayed in bed. It was - - -

MR BOLSTER: How long was that for?

MS HARKER: I did that for about two weeks until I convinced the other provider that they could actually send people to come and I would pay myself, and get my family to help - - -

MR BOLSTER: You mentioned that you had to pay for that.

MS HARKER: Yes.

MR BOLSTER: What did you have to pay for a visit to help you out in that way?

MS HARKER: I never actually found out. It depends on the time of day. It depends on if it's a weekend or a weekday, a morning, if they start earlier or later. And at night, there's a strange rule whereby if you have a service that goes after 8 o'clock, maybe it's from 7 to 8.30, then you get charged at the post 8 o'clock rate for the whole thing, so you get charged, you know, double backwards. But yes, the mornings, I pretty much stayed in bed, managed to get myself sometimes into a loose outfit of some sort and get myself out into the garden but that was it, really. Unless – occasionally a friend came to help out and one or two former carers who had been with this organisation also came in a friendly way to help out which was wonderful.

MR BOLSTER: That leads me to one of the things that really struck me about your statement. You talk about the loneliness of someone in your position on home care. You're not in a residential facility with a whole lot of other people. You're at home exercising your right to be independent. Can you tell the Commission, how does loneliness affect someone in your position? How does it feel?

MS HARKER: I think it's emotionally very crippling in the sense that it overtakes you quite a lot at certain times. I've also discovered – because I was 64 when I had the stroke and I'm now 72, but there has been a kind of accelerated ageing that has gone on in this time. And I've spoken a lot to older people in my research in history and I've spoken to people between 80 and 95 about their experiences as young people. And they can always bring up memories, clear as crystal, older people do. I've discovered that as I became older in that sense, I get assailed by memories. Anything, any smell, any sight, and even going around Canberra in wheelchair cabs. I lived there for a long time and I went to university there first, then I lived away but came back. I remember it as it was and it's completely being ruined, destroyed; they're knocking down houses and old buildings and so forth. So I will be going along a main road where they're putting a light rail and I see that the things that I used to – places I used to go to and see people, are no longer there. It's not just that I feel that loss but I'm assailed by those memories. So when you're alone – I'm presuming a lot of people are like me – the memories come back and often they're – you're sad because you're not going to get some of that stuff back ever again.

MR BOLSTER: Do your – do the packages allow for that in any way? Do they – does the companionship – is there companionship or is there anything in the services that you receive that assists you with that particular problem?

MS HARKER: No, no. The idea – there are provisions in the – possibly the regulations, if not the Act – the aged care packages are to pay for certain things: going to conferences, travelling to places to get information. And there have been a lot of conferences on since I had the stroke, many of them history and – or, you know, social or cultural studies. I've still got a lot of that in my head and I've actually got a book that I want to publish but I haven't been able to get into it. That sort of thing they do allow for, and – but I don't really – I don't know how that would help me.

MR BOLSTER: Yes.

MS HARKER: It's very hard to travel in my situation. I know.

MR BOLSTER: You talk in your statement about being stereotyped. Can you give us your perspective about that? What does that – what does that – what effect does that have on you?

MS HARKER: Well, it is – it has changed according to, if you like, where my spirit was when I had the stroke. I had been through long years of single parenting. I had had breast cancer and a few of these shocks in life that – and my marriage had broken up several years before. These sort of shocks that get you wondering who you are and where you are in life and so forth. But I had always just sort of pushed through and managed to find something that I could grab onto, and I was – I think very strong and a survivor. So that's how I saw myself. I had been in a lot of environments where I felt that there was a fit. I think there's a lot of environments where I thought I didn't fit. But when I had the stroke I was in a position where I thought I'm, you know, almost at the peak of my powers and I was doing something that I really loved which was writing and editing in a particular department in the government.

And I had come to that at, you know, at least, what, 60 and people – people respected me. And I and a couple of friends who were all about the same page, women who had done degrees in arts or social studies years before, we had had this constant fight in that in the baby boomer generation, you just knew you were going to work, there was never any question of not working. Women or girls thought, yes, I will get married but I will work before that. Many more of my generation went to university so there was this sense that if you got a scholarship or if you got free university, any of those things, that you needed to pay back somehow.

MR BOLSTER: How are you treated now? How do your carers respond to that sense of you that you have?

MS HARKER: It really varies. I say in my statement that quite a lot of them are very young, very young girls – 17, 18. And I think they find – many of them have no training. Of course, you get to that age you haven't even been to the Institute of Technology and got your certificate III or IV. So they think they've got a good idea, you know, my granny was like this and I looked after her and so forth. They think

I'm going to be maybe a sweet old lady and I turn out not to be quite so sweet just because I sort of – I think I want to talk to them more about things and I'm quite assertive. They want to find out about me. They say we want to hear your stories. They do, they genuinely want to hear the stories and some of them are wonderfully interested and I will talk the hind leg off a dog, that's not a problem for me, but there's not enough time.

MR BOLSTER: What is the deficiency that worries you the most about the carers that come and see you? Where can it be better?

MS HARKER: I think a lot of people, if they particularly haven't run their own domestic household or their own place of living, don't really have – I think what I would call domestic commonsense, where I feel I keep saying to them, just flick your eyes around, flick your eyes around and don't take a boy look – sorry about that – but don't look in the fridge and say, you know, the peanut butter – not peanut butter, the milk, there's no milk there. And you say, "Have you looked behind the things in the front at that level?" No. Then I'm in my bedroom and I hear them going "There it is". So I've introduced quite a few young Filipino girls to the idea of "boy look", which they went "That's very funny" They like that.

MR BOLSTER: How's the language? Do you find that a problem?

MS HARKER: With people from the Philippines and India, which is where a lot of care workers and nurses and nurse assistants in Canberra – they're recruited from those two areas, not so much language problems, most of them speak very good English. Idiomatic Australian conversation, they find a bit hard. They don't understand if you make an allusion to something being cactus or, you know, something like that; my leg's cactus. "Oh dear", you know, so that creates problems. It takes time always. It's more lack of cultural perceptiveness and understanding some of those subtle things that we all find, you know, if you go overseas myself and you're sort of totally baffled by some things. So yes, people who – who, particularly from certain cultures where they're used to only being told what to do. The education system says you sit there, we will pour information into you. There's no sense that people can be self-starters, that they can find their way around and use their intelligence in that practical way.

That is really irritating because if we have in the morning a 90 minute shift, they have to do – and there's a long list of things to do. Some days I say don't do these, it's not so important today. But they worry that they need to get through it and they need to leave on time. There's a lot of pressure on them to leave on time. So if I have to explain everything – and I'm afraid I have a standard response which is read the fridge because the list of tasks and the details about it are always on the fridge. They get them on their mobile phones. They're supposed to look at it the night before but they don't all have time. So the sort of young girl usually leaning against my bedroom door saying, "There's your tea; what do I do next?"

MR BOLSTER: Right.

MS HARKER: I go, "Read the fridge". So, yes, that's the hard bit where I have to direct again and again and again, it's exhausting and it's a waste of time. It's inefficient.

MR BOLSTER: That's gets me to my next question, the phrase "consumer-directed care" has literal meaning with your carers.

MS HARKER: Too literal. And I feel your provider is supposed to provide somebody who, in the ideal world, will ready to – up and ready to run fairly quickly. There's one thing I didn't say in my statement which is in training carers, one of the best methods is what we sometimes call buddying or shadowing in which if I've got a new carer who is going to start next week I will say to the provider or the agency – they broker too – can they come for a buddy shift so that they've observed what the carer does, and carers love that. They tend to say – you hear them saying, "Now, what Margot likes is this, and let's just put this here" and, you know, she likes such and such and she's always better if – and so they love to do a bit of teaching on the job and they can see the results instantly. And, you know, if then the new person comes next week and I manage to say to the other person, "You did a good job. She's doing very well". That's a very, very, I think, empowering thing for carers to do and it's a very good way of learning; it's experiential.

MR BOLSTER: Can we talk then about consumer-directed care?

MS HARKER: If you have to. I'm sorry, the word "consumer" I really hate.

MR BOLSTER: Why do you hate it?

MS HARKER: It puts people who are clients into a different relationship with the government which – with society, basically. It's like, you know, when I flew here and they said all customers get on the plane. Why have I been a passenger all my whole life, you know, the idea of being a customer of an airline is – I'm just a bit old-fashioned; I don't like that but, again, it's all a financial relationship and when you're a consumer, it's good in the sense that there are consumer organisations and there are agencies that look after consumers' interests, but it's commercial relationships that they are concerned about. And if I'm consuming something like a new mobile phone and it's rubbish, I will go back to, you know, whatever the firm is I got it from and say, "Look, this is rubbish and I know my rights and I've been watching, you know, this check out on TV" so blah, blah, blah.

MR BOLSTER: It sounds like you do that with your providers, too.

MS HARKER: I try. I try because I think that's important. But I don't feel that I'm a consumer in that commercial sense. I think the sense of service has got lost in that and I – you know, we all say there's terrible service in shops or whatever but it's different from being – having somebody giving you a service in your home or a nursing home or anything like that.

MR BOLSTER: Right. Just – I just wanted to go back to one thing from right at the beginning. When you needed the changes to your home, to your new home in order to presumably to get the wheelchair in and out, to arrange things so that you could do things for yourself.

MS HARKER: Yes.

MR BOLSTER: The cost of that, any part of that come from the government or was that out of your own - - -

MS HARKER: Not that one, no. The previous – my house that I was living in when I had the stroke, there was an arrangement whereby the ACT Government contributed to modifications inside and out, I think, but there was a very big co-payment. So I think the mods came to about 22,000 and I ended up paying 8,000 upfront.

MR BOLSTER: I think you mentioned that under the NDIS, if you were in the same position today and you hadn't turned 65, the changes to your house would be funded under that scheme, but if they happened to you after you turned 65 and you're in aged care - - -

MS HARKER: Yes. When I had the stroke - - -

MR BOLSTER: - - - bad luck.

MS HARKER: - - - at 64 the NDIS legislation had only just recently been passed including the amendments that said anything that a person does pursuant to the NDIS Act that is in breach of the Age Discrimination Act is not in breach. And nobody knew that. It hadn't been written about and I read the legislation and I, you know, was very angry about that because it meant, basically, anyone who was 65 and over was not eligible. Eventually, that caused an outcry when it became generally known and they changed the rules that if you are on NDIS and turned 65 you may choose to keep it but I couldn't go on it in the first place because I only had four months of being 64 and the ACT hadn't fully signed up and wasn't starting its program yet.

MR BOLSTER: All right.

MS HARKER: So that's the situation.

MR BOLSTER: You, at the end of your statement you say that you have a message for the Commission and you set out a number of matters there. Is there anything you want to add to that or anything you want to emphasise? What's the most important thing that you would seek to convey to the Commission?

MS HARKER: I would say there are three, really. You can't get around the fact that aged care of all kinds is not funded adequately, and I don't think anybody in my situation would disagree with that. There's a sense in which we feel the Australian

population doesn't think that we deserve quite as much and it's a bit sort of icing on the cake. There is no sense of us having served our community or our nation during your working life of 40 years or whatever. I seriously think if that attitude can be changed, there has to be sort of, you know, the Productivity Commission and other organisations have to keep reporting on – based on research and, you know, coming up with the kind of recommendation that governments do seem to depend very much on those things.

Pointing out the ways in which society generally is better if older people are still utilised as full members of society. I serve on two boards, community organisations, so there's this big sense that I could be still seen as contributing, even though I've been in aged care and I have a very severe deficit physically. There's more than that. Older people of every status or kind are amazingly valuable to the school system; they do a lot of work voluntarily in school systems. I think they basically keep a lot of younger people in work because they look after the children; they look after the grandchildren, an enormous of that. So those sort of perceptions, I think, would maybe help to change society's attitudes to funding. Whether that's a bit idealistic of me, I don't know, but I'm of that – somebody ought to do something about it.

MR BOLSTER: All right. Was there any - - -

MS HARKER: The second - - -

MR BOLSTER: So the second point, yes.

MS HARKER: The second thing is that where people are actually in aged care, carer quality can be improved hugely through education and training and development, including, you know, in-service development and I think the principles of most provider organisations have not been trained in how to manage an aged care provider organisation. They may be experienced managers; they may be good administrators. They may be okay at running budgets, handling government money and all that, but they – there's a whole thing about attitudes and about competence which is not being – it's not at its peak. So that – with that question, again, of funding, but you have to have the attitude and the will and the idea of being innovative and forward-looking. And I think baby boomers, as they come along – I'm of the age where I'm at the very beginning of that cohort – they're going to expect more and if they've got any spare money they're probably going to be prepared to do co-payments and help out in other ways financially. There's a sense of responsibility for self that a lot of people in my age group have. So there's those things.

And I think the third thing is, really, runs on from that, and that's the idea that if people generally, including younger people who are now – and people are now looking at, god, they're going to maybe work until I'm 70 or – and that sort of policy has gone pretty much but people are still thinking that that's possible for them. They could actually have to work much longer than they expected so they're going to have to amass a superannuation and private funding and all that sort of thing. So if they're

already focusing their mind on their ageing and what facilities there are and they're seeing their own parents often in institutions, not being stimulated and sort of fading away, that's a good opportunity to talk about things like innovation and different models of – of care and the sort of offerings that you can give to people as they age. I think that's very important.

MR BOLSTER: Right. Is there anything else?

MS HARKER: No, I think that's it.

MR BOLSTER: All right. I have nothing further. Thank you, Commissioners.

COMMISSIONER TRACEY: I don't think you've tendered Ms Harker's statement.

MR BOLSTER: I haven't. I formally tender WIT.0053.0001.0001. Thank you, Commissioner.

COMMISSIONER TRACEY: Ms Harker's statement dated 23 February 2019 will be exhibit 1-62.

EXHIBIT #1-62 MS HARKER'S STATEMENT DATED 23/02/2019 (WIT.0053.0001.0001)

COMMISSIONER TRACEY: Ms Harker, does the care packages that you receive extend to assisting you to attend medical appointments, go shopping, things of that kind?

MS HARKER: No, not really. All my transport, which is a subsidy of 20 – 75 per cent on disabled taxi fares, that's all supported by the ACT Government.

COMMISSIONER TRACEY: And what about your community involvement? You mentioned you, I think, are a member of some boards. Do you need to go to meetings and - - -

MS HARKER: I do, yes. My taxi fares are usually paid for by the organisation and they, at my suggestion, started to get Cabcharge dockets that they – tickets that I can use and so I don't have to pay anything towards those. Apart from that there's no benefit that I get, financial, and no support and I was going to say about GPS, for instance. My GP doesn't bulk bill. I end up having to pay the gap myself every time. I get a bit of free treatment. I have Botox injections in my leg to ease the stiffness; every three months I have those. That's free because I was an acute care patient and now I'm an outpatient so that's still covered by – the ACT Government covers that.

COMMISSIONER TRACEY: And how do you find the services provided by the taxi service? We hear horror stories - - -

MS HARKER: Yes, there are many horror stories.

COMMISSIONER TRACEY: - - - about the time that elderly and disabled people are left stranded because taxis don't turn up and things of that kind. Have you had that sort of experience?

MS HARKER: I did very early on. And at one point a driver said I could – he would take me out and leave me on the side of the road because I insisted that he put a seatbelt on me. He said "No, it's not necessary". And I said, "Well, you had better stop the van because I'm not going any further unless you put the seatbelt on". In a wheelchair – and this was a manual one, it was a bit smaller, but you're quite high up and you can be flung around, it's dangerous, even with your brake on if they brake suddenly. So I had this difference of opinion with this guy and he said, "All right, I will take you out. I will put you there, I will call another cab. There will be someone who will put a seatbelt on but I don't care". At that point, I said to some friends as I was meeting them, and I said I think I've just seen the future. And I thought if it's going to be like this until I die, I don't want any part of it, really.

Luckily the ACT Government, under a particular chief minister, was right onto this and they called them to account. And they had reports – they've introduced a lot of new rules and regulations. And there's also a number you can phone. If somebody commits some sort of travesty like, I've seen refusing to take somebody in a wheelchair which is a fold-up wheelchair or with a, you know, wheelie-walker, that sort of thing, I've actually seen taxi drivers refuse to take them. And so you just call a number and you give them the taxi's ID number, and then this person is taken off the road for two weeks, lose a lot of money and has to go for a bit of re-education. So that's the sort of thing that they've sorted out.

They've pretty much rearranged things; rules about cleanliness because a lot of those wheelchair taxis get very grubby because they do take a lot of groups of children to and from some of the special schools and these kids – if you lift up a seat there's always a blob of chewing gum underneath. The rules are the drivers are supposed to keep them absolutely pristine but it's very hard for them to do that. So I have fewer complaints than I would have but there are still a lot of issues and it's very hard to get those sorted.

COMMISSIONER TRACEY: We've been told about an alternative model of aged home care referred to as the Belgian model under which a younger person is provided with a bed and accommodation in an older person's home in return for caring services. Is that something that would appeal to you?

MS HARKER: I saw some of that mentioned on a news program or a documentary. I think it's a wonderful idea. I'm not sure that I am the sort of person who would necessarily benefit from it or they would necessarily benefit from – except by, you

know, I'm quite close to both the universities in Canberra and if the students want to be really close and have decent accommodation, that would be very good idea for them from that point of view. Actually, when I am alone during the day, despite being quite lonely, I – I need that time. I need to be on my own because of the things I do. I do research. I listen to music. I've got used to it over many years, since my marriage broke up. So you learn to live with that and some of the time you – you need it.

But what I really need more than anything is adult company, particularly I read something that one of the American poets had written which is as I age, being with friends who – no, being with people I love is enough, and we all become more family-centric and more, in my case as well, my very small family, old friends who are, in a sense, siblings and, you know, dear people from many, many years and we know each other very well, that's really the thing I would cherish most, like to have more of. But I also love going out. You know, I was always somebody who had my own house, had my own car. I like driving sometimes and I like going, you know, Canberra to Sydney and visiting people and I like going to the Blue Mountains where I did a bit of a writer's residence for a while. So I could get in my car and just go. I cherished that and I wish I could have it now. It's very hard not to do that, not to be able to go to the coast for instance.

But if I can't do all those things, just getting in a cab and going to the National Gallery, or the museum, or even somewhere where there's a nice coffee place, you have – meet a few friends, that sort of thing. That's what I would really like. I don't know that any person living in my unit, which is actually – it's two bedrooms, it's very small. There would be a sense of bumping into people, I think. Maybe I don't tolerate this anymore like I used to.

COMMISSIONER TRACEY: Thank you.

COMMISSIONER BRIGGS: Ms Harker, hopefully after this hearing you may well get a few phone calls from your friends taking you out.

MS HARKER: I hope so.

COMMISSIONER BRIGGS: Can I just follow-up a couple of things in your evidence, and it follows on from a previous witness today. And that is the question of the availability of care services on weekends and on public holidays and after hours and so on. Can you take the Commission through the availability of services or the costs of services at those times?

MS HARKER: The cost varies hugely, just to pick that point up first. My main provider at the moment, because they're brokering out to a couple of agencies who give service and they've got very good care workers who come to my place, but the coordinators, the people working in the office of the provider, just seem to be totally swamped. They don't seem to get anything organised very well, particularly sending out their invoices, because if it's paid from package funds or CHSP funds, my

provider pays it to them. And they pay – they pay it to the person. So we're getting invoices coming in six months after the service has been given and some of these invoices are for the period 10 to 20 of May. Instead of saying person A came these hours and did this job, and therefore we should have an hour and a half of, at $56 an hour, that sort of thing. So I lose track of that. I get these huge statements at the end of every month and I realise after a while that there are so many invoices haven't come, so money that I expected to be paid hasn't been paid out yet. And I've been having for years false – false large amounts which are really, basically, amounts that are already pre-committed because the service has been given.

And so I've pretty much given up trying to track the variations. Each of the agencies charges different amounts. One of the agencies I had only employed nurses, all RNs. And RNs have a minimum hourly rate that they've negotiated over the years because they were strong – became strongly unionised and active in political terms, so they get a lot much – a lot more money than people who either have a certificate III or IV, and generally care staff get not very much money at all. Sometimes I have one of my carers work from a Saturday night and I say, you know, there's this rate you get after 8 o'clock and she would get a bit more, Saturday is always more. And she says, "I haven't seen it" and she says, "I haven't been paid for three weeks anyway". So all that stuff is going on.

The big problem is the youthfulness of the main part of the carer workforce. Fridays and Saturdays have always a bit hard for me in terms of getting somebody. There are times when your provider will say we've rung everybody, they just can't come and, of course, they can't come because they're going out, they're getting a life, you know, and people take themselves off the roster for holiday periods and for weekends because they want to go clubbing or to a festival or something like that. That is always an issue. Sometimes, when people are available, they may be people who've come from a different culture and are not very au fait with the way things are, but they also haven't built up a base of friends and activities yet so they're prepared to come and those shifts, of course, are more valuable to you as a worker.

So often my big issue is that if they can't find anybody, sometimes they send me a surprise, somebody who I – I probably have met once or twice before and have – always give feedback and say I don't think there's a fit here, we don't seem to chime together somehow. But there's this thing, take anybody, we can't find anybody, it's either that or nothing. And at night, getting myself to bed and getting some dinner is very hard. So night – a night person is very important. I keep pointing out to people who say, haven't you got friends who can come and do it. I say my friends will be 72 and upwards. I do have a lot of young friends but, of course, they're all busy. They're overseas, they're doing their very busy jobs and so forth. So getting somebody to help out in my friendship group, you know, they're all half-crippled with arthritis and bending over, say, "My back", you know, so I can't ask them to do – it's very heavy work, some of it, and I'm not easy to manipulate and get into clothes and so forth, so - - -

COMMISSIONER BRIGGS: You mentioned about, earlier on in your evidence and indeed in your witness statement, you mentioned that you were receiving the two packages. I'm assuming but can you correct me, that it must be incredibly common for people who are getting the home care packages or the care packages to also be getting CHSP, is that how it works?

MS HARKER: I don't know to be honest. Again, because of what I said earlier in the statement, because we don't talk to – we don't know who the other recipients of home care packages are. Occasionally I run into somebody who was in the rehab ward with me in Canberra Hospital. Occasionally I might be going to a physio and go "I remember you, what are you doing?", so some of them are receiving packages. We tend not to say, "Let's keep in touch". Often they don't want to be reminded of that time when we were regarded as crocks and cripples and we were treated in this negative way. So there's not that urge for them to keep in touch but the only – what happened when the transfer to CBC of the packages, the cross-subsidisation that had been going on disappeared because everybody's package adhered to them, that was supposed to give everybody a bit more control over the services they got, and they got to choose things, if they didn't – if they were able to let one kind of service go that meant they could use another thing that was a bit more a special luxury, something they really wanted to do but hadn't been able to.

So I do know that I was affected that way. I was told your package now is not going to be enough because there's not going to be topping up from somebody else's and, sorry, you're going to have to pay $2100 roughly per month to make up that shortfall. And we got this options from our providers but essentially I think the department had said to them, this is what you're going to have to do. We were told pay the difference yourself, get your family or friends to stump up the money, or go into a nursing home, or reduce your services. Of course, that was the first thing that was offered. We won't come to you on weekends, we won't send anybody in the mornings, we will cut your hours to half an hour, or something like that. So those sorts of alternatives were given to you and if you couldn't meet any of those, it was a nursing home for you pretty much and they said you can save a bit of money by managing your own package, because they were charging administration and case management fees every month.

With the one I was with at the time, their admin and case management fees came to nearly $2000. So I actually said to them, if you can work smarter and more efficiently with the same staff, because everybody else seems to be able to do that, you can save that money so you are charging me a lot less. I said I can't do my own management. I would be doing that eight hours a day and I'm – I'm not able to do that. I'm doing quite a lot of my own management and admin now, because there have been so many shortfalls. But that was what they said. Do all those things, or just go into a nursing home, it's much easier. We all came back with, well, a few of the people I knew, where are the nursing home beds for a start but also, why should we? We don't want to. We're independent. We're perfectly able to manage in our own homes and we know that government policy has been for many years that the

ideal is to have people living in their own homes. It is cheaper, it's more efficient, it's actually more economical for the economy as a whole.

So I was riled about that so I just went to them – I didn't go to the media – I started an online petition with Change.org. And Change.org picks up certain petitions that they think are going to run really well and so mine – they actually then emailed some of their millions of followers around the world and, suddenly, you know, in a day you get another 20,000 signatures. By the time I was running it about 50,000 and I was doing better than Johnny Depp. That was the thing; there was a petition to save Johnny Depp's dogs and he wasn't getting as much so I was rather proud about that. But the media got interested - - -

COMMISSIONER BRIGGS: I think you should.

MS HARKER: Sorry?

COMMISSIONER BRIGGS: I think you should be proud of that.

MS HARKER: Yes. So I was – yes, I became a bit of a five minute media celebrity. But the ABC came and did a very long interview on camera and Norman Hermant who was the reporter asked me a question that we had already discussed. He said, "What if you do have to go into a nursing home, if none of these alternatives are met, if nobody can come to the fore, if the government doesn't change its policy what are you going to do?" I said, "Well, I thought of killing myself" and I wouldn't be the only person who has thought that. And because the petition site had the option for people to not only sign the petition but to send an email to them, which they passed on to me, there was quite a lot of – I got – that was the only time I've actually been in touch with lots of people, maybe – well, 20 or 30 who were in home care or who – several of them were women whose husbands were receiving home care because they had got mild dementia or they became physically incapable and they wrote to me and said, this is my experience, and I can't go on like this, you know, we can't afford it.

So they asked me for advice, which was just I said write to the government. Suddenly there was this crisis number you could call and you could write to the Minister. I suggested all that and I said get yourself an advocate because they're all around Australia.

COMMISSIONER BRIGGS: The management fee you referred to, the first offer I think it was $2000 a month, that's - - -

MS HARKER: Roughly.

COMMISSIONER BRIGGS: Yes. So, you know, so that's probably $24,000 a year or somewhere between 20 or $24,000 a year. What's the value of your care packages, do you know that off the top of your head?

MS HARKER: About 40,000, I think; maybe 50 now. It has gone up.

COMMISSIONER BRIGGS: So that's a very high proportion of your care package suddenly disappearing.

MS HARKER: Yes, yes.

COMMISSIONER BRIGGS: That is something that we will explore throughout this Royal Commission.

MS HARKER: I left that organisation, by the way, and got a new provider. And I still occasionally had emails and newsletters from the previous one and I was gratified to see that they actually dropped their administration fee considerably in the next six months.

COMMISSIONER BRIGGS: Good.

MS HARKER: So I regarded that as a bit of a victory but, yes, there was a lot of, I think, gouging going on and just inefficiency.

COMMISSIONER BRIGGS: Thank you.

COMMISSIONER TRACEY: Anything arising, Mr Bolster?

MR BOLSTER: Nothing arising. Thank you, Commissioners.

COMMISSIONER TRACEY: Ms Harker, thank you for coming all this way to share your experiences with the aged care system with us. You've assisted us enormously in improving our understanding of the practicalities faced day by day by - - -

MS HARKER: Thank you.

COMMISSIONER TRACEY: - - - people such as yourself, and we're very grateful to you for having done that.

MS HARKER: Pleasure.

<THE WITNESS WITHDREW [1.20 pm]

COMMISSIONER TRACEY: The Commission will adjourn until 2.15.

ADJOURNED [1.20 pm]

RESUMED **[2.15 pm]**

COMMISSIONER TRACEY: Yes, Mr Bolster.

MR BOLSTER: Yes, thank you, Commissioners. I call Mr Barrie Anderson.

<BARRIE ANDERSON, SWORN **[2.16 pm]**

<EXAMINATION-IN-CHIEF BY MR BOLSTER

MR BOLSTER: Commissioners, if document number WIT.0030.0001.0001 could be brought up onto the screen, please.

Now, Mr Anderson, if you can just look at that screen in front you, and it should show you a copy of the statement that you signed in this matter.

MR ANDERSON: Could you speak up a little?

MR BOLSTER: I will do my best. If you – is that – can you hear me now.

MR ANDERSON: That's better.

MR BOLSTER: Good. Okay. In front of you – you're holding a copy of your statement and the statement should appear on the TV screen in front of you as well. That's the statement that you signed the other day in relation to this Commission.

MR ANDERSON: Correct.

MR BOLSTER: Right. Do you wish to make any changes to that statement?

MR ANDERSON: Not to this, no.

MR BOLSTER: Are its contents true to the best of your knowledge and belief?

MR ANDERSON: That's so.

MR BOLSTER: Commissioners, I tender Mr Anderson's statement, that is document WIT.0030.0001.0001.

COMMISSIONER TRACEY: The statement of Barrie Anderson dated 15 February 2019 will be exhibit 1-63.

EXHIBIT #1-63 STATEMENT OF BARRIE ANDERSON DATED 15/02/2019 (WIT.0030.0001.0001)

MR BOLSTER: Now, Mr Anderson, if you can't hear me at any stage you just let me know.

MR ANDERSON: I'm having some difficulty in hearing you.

MR BOLSTER: All right. I will bring the microphone a bit closer. Your statement, Mr Anderson, it relates to your experience, your very long experience of caring for your wife, Grace.

MR ANDERSON: That's right.

MR BOLSTER: Correct.

MR ANDERSON: Yes.

MR BOLSTER: And you could hear me then okay?

MR ANDERSON: Yes.

MR BOLSTER: Good. All right. Now that has followed a diagnosis of dementia for Grace in 2002; correct?

MR ANDERSON: Correct.

MR BOLSTER: And you're 86, as we speak.

MR ANDERSON: I am 86.

MR BOLSTER: And Grace is 85.

MR ANDERSON: Correct.

MR BOLSTER: And you've been married for 64 years.

MR ANDERSON: 64 years is correct.

MR BOLSTER: And you live in a retirement village.

MR ANDERSON: I live in a retirement village.

MR BOLSTER: Yes. And Grace lives in a nearby residential aged care facility; correct?

MR ANDERSON: That's correct.

MR BOLSTER: All right. And she has advanced dementia?

MR ANDERSON: She has advanced dementia.

MR BOLSTER: Can you tell the Commission what state is she in at the moment? How would you describe her health at the moment?

MR ANDERSON: Well, actually I am looking at this – the current situation and the future that we've reached the palliative care stage of Grace's life, basically.

MR BOLSTER: Yes.

MR ANDERSON: As such, and that's the direction that we – that I, in particular, am making sure is going to be the – an environment where, in fact, she gets the maximum of care and attention to make the dignity of her last days significant, basically.

MR BOLSTER: Let's just stop there on that extremely important issue. What does she need done for her at this stage?

MR ANDERSON: Sorry, I can't hear you.

MR BOLSTER: I'm sorry. What is it that she needs done for her at this stage? How advanced is her dementia?

MR ANDERSON: Well, I'm not a medical expert but in theory, we are in a situation where Grace no longer recognises me or actually can speak, and in theory there's not many more steps I believe that can be taken - - -

MR BOLSTER: Yes.

MR ANDERSON: - - - that will impact on her health other than what it is at the moment. And in theory, in talking with the professional staff, they have perhaps indicated that Grace's life span is in its final stages.

MR BOLSTER: Yes. The day-to-day care, though, that Grace needs, I take it that she can do nothing for herself? She can do nothing for herself? Everything has to be done for her.

MR ANDERSON: No, no. She is fed each day by either myself or a staff member, and her meals are actually to the puree stage which means she – they've acknowledged that she might have a swallowing problem.

MR BOLSTER: Right. Okay. And how many hours a day do you spend with her attending to her?

MR ANDERSON: I spend pretty well every day, and I try and – so that while I'm there it's for at least two hours as such, which gives me a chance to socialise with Grace and also to feed her, because I think that's important that I get some involvement in her process of eating as such, because there is a tendency to – for staff sometimes to perhaps be too busy to feed her properly, basically.

MR BOLSTER: All right. All right. We will come back to that a little bit later, but I just want to go back a step to when Grace was first – when you first noticed a problem and in your statement you say that was around 2000, which led to a diagnosis in 2002. What was it that you saw in Grace that led you to seek medical advice?

MR ANDERSON: What I saw in Grace actually I dismissed it firstly as being sort of forgetfulness. But the first occasion I can really recall with any accuracy was we were with a group of people at Mount Gambier and for some reason or other Grace got lost or got dropped off the group, I think they call it ..... therapy or something like that. And in theory we had a situation where she was in Mount Gambier, a foreign location to her, and fortunately the group that we were with had people from Mount Gambier and were able to sort of – we mounted a quick search and located her and everything was fine, but I just dismissed it as being forgetfulness. And there were other instances. Our church actually for many years put on melodramas that would run for something like about a fortnight and Grace always had an integral part in it in some shape or form but in the end when she was learning her lines or giving them on the night you weren't quite sure which line you were going to get, actually, because as she got – she couldn't recognise that there was some sequence to the – the number of lines that she had to give. And that – they are the two most vivid memories I've got of her – other than when at home, she was perhaps frequently asking me what would be the time and what day it was, and I thought well, that certainly is - - -

MR BOLSTER: Yes.

MR ANDERSON: - - - an element of forgetfulness but it was the number of times that she would ask me as such, that sort of, I think, in the end signalled that it wasn't forgetfulness, basically.

MR BOLSTER: You saw a doctor and you got a diagnosis. Could you describe how the diagnosis process played out? Did it take a long time? What was involved in all of that?

MR ANDERSON: No, I would think in terms of time it was relatively quick. I happened to be in – we happened to be, rather, in Marion and I happened to notice that the Alzheimer's Association had a booth and I thought, well, given my doubts about the – perhaps I was wrong with Grace being forgetful, I would pick up some pamphlets and having sort of picked up the pamphlets, take them home, and within days the Alzheimer's Association was actually sitting on our – in our lounge room talking about the journey that Grace might be on, basically.

MR BOLSTER: If we could just turn up, please, paragraph 14.

MR ANDERSON: Yes.

MR BOLSTER: Have you got that there, Mr Anderson?

MR ANDERSON: Yes.

MR BOLSTER: Do you see there you're talking about navigating the system.

MR ANDERSON: Yes.

MR BOLSTER: Setting up a network of people who could help you and you say it wasn't an easy task. What was difficult about finding your way with Grace with a fresh diagnosis of dementia.

MR ANDERSON: I think in terms of not being easy was the fact that this illness that Grace has got needs to be looked at in the terms of that you need to talk to more than one person or more than one organisation in the equation, basically as such, and that's not all that easy if you're starting from scratch, basically.

MR BOLSTER: Are you talking there about the people – different organisations providing different types of help for you and her?

MR ANDERSON: I was talking from the range of the Commonwealth Government through to perhaps the Alzheimer's Association - - -

MR BOLSTER: Yes.

MR ANDERSON: - - - and organisations like that, basically.

MR BOLSTER: Where did you find the most help? What was the most helpful thing for you and Grace at that time?

MR ANDERSON: What was the most stressful?

MR BOLSTER: Helpful.

MR ANDERSON: Helpful.

MR BOLSTER: Helpful.

MR ANDERSON: The – in essence, the – I would say the personal approach rather than using telephones and whatever to make the connection you needed to make basically.

MR BOLSTER: And where did you see that? How did you – who gave you that personal attention?

MR ANDERSON: Places like the Alzheimer's Association which is now Dementia Australia.

MR BOLSTER: Right. Okay. Now, I want to turn to the issue of the home care that you received following the diagnosis. You and Grace were living at home at the time. What did the two of you need to care for her in the early days?

MR ANDERSON: What did we need?

MR BOLSTER: Yes.

MR ANDERSON: We needed to have things like showering and personal requirements like that, in particular, and the – the fact that there was an ability to have respite if needed, in my case, basically, or in terms of with Grace, if for some reason or other I had a significant appointment to make, then they would provide somebody to sit with Grace for the duration that I was absent from home, basically.

MR BOLSTER: Right. How important was the respite care for you?

MR ANDERSON: I think respite actually is vital, not only to the cared for but the carers. Too often the carer gets excluded out of the respite system, but I think there is a need to recognise that I would need as much care if I was going to look after Grace for any length of time as this turns out, that that care would be available to me, or to put Grace into respite and be it for half a day, a day, or a weekend or whatever, basically.

MR BOLSTER: How long a period did the respite usually go for?

MR ANDERSON: In terms of if you were to divide the number of times we had respite, I would say effectively a half a day a week.

MR BOLSTER: Yes. All right. All right. And so that enabled you to go and do things in your own life.

MR ANDERSON: Yes.

MR BOLSTER: Take a break and recharge, is that what you would say? All right. Okay. What were the things about the package that you were on that were not as good as you would have liked? How could your package have been better for you and Grace?

MR ANDERSON: Well, I think at that stage of the game the packages were of two levels or three levels, as I recall, and in theory were administered by organisations that – that looked after those aspects of grants and the likes. Our first contact was

with the Masonic Village. The – we were given a package at the lowest level when – and then Grace actually then progressed to the highest level in terms of - - -

MR BOLSTER: Yes. So how many years were you on the home packages for? When did she go into residential care?

MR ANDERSON: In retrospect I would think at least a couple of years.

MR BOLSTER: Yes. Okay. And what was the – as she – as the package became more – provided more for you, there obviously came a point where it wasn't enough and she had to go into the residential care. What was the – what was the breaking point for you that meant that you couldn't cope with looking after Grace at home?

MR ANDERSON: In theory, the – the level of care really extended to the point where her general health was that she became incontinent and that changed the scenario quite significantly because actually that's the point of time where I actually was forced to concede that I couldn't really look after Grace even with the packages we were getting, and that she needed to be in care as such, basically.

MR BOLSTER: Who makes that decision? Who made that decision for you and Grace?

MR ANDERSON: Well, essentially I did, because Grace may have had an input but in terms I was – I suppose I was making the decision as an advocate on behalf of Grace as such.

MR BOLSTER: You've been her carer then at home for a number of years.

MR ANDERSON: I have.

MR BOLSTER: Can you tell the Commission what it's like to be a constant home carer for someone like Grace, someone with dementia, over an extended period of time?

MR ANDERSON: Well, I think, as fundamentally as a carer you actually have to acknowledge that there are going to be some changes in your life. So you actually have to get used to the idea that it's an environment where change is likely to happen, slowly or quickly; it depends on the circumstances. You need to be able to sort of not get angry. You needed to do lots of things that – you need to learn to become a better communicator. You needed to become more sensitive to things like shaking hands, cuddles, all those sorts of things, massage, which up until that point was sort of not on the horizon, basically.

MR BOLSTER: Yes.

MR ANDERSON: So – and you've got to have a sense of humour. You need to be able to say at the end of the day when I go to bed I can sleep well. You need to be

aware of the fact that the medication regime might change and as such suddenly what was normal yesterday isn't quite the normal today in terms of their general disposition. I can remember Grace really changing from being an owl to a fowl because of medication which meant that – that impinged on our social life and all sorts – eating – eating requirements and such like. And so the – I think, fundamentally, as a carer, you've got to acknowledge that there will be significant change in your life and you actually can't ignore those aspects of – I mean there are many more but I can't think of any more off the top of my head at the moment.

MR BOLSTER: I expect that it took some time for you to adjust to these things, did it?

MR ANDERSON: It takes some adjusting but in theory, when you've been together for quite a long time, I think the adjusting actually is accelerated because you're really wanting to be caring for your wife as such in the circumstances.

MR BOLSTER: Yes. Was there help there for you from agencies or other people as you chartered this course and - - -

MR ANDERSON: No, actually, we were able to in the first part of our journey to cope between the two of us, actually, and apart from the things like showering and things like that, they were still ongoing, but – but in theory we reckon we were doing pretty good, actually.

MR BOLSTER: Good. Now, I want to talk about the actual residential care itself. In your statement you refer at paragraph 21 that Grace went into quite a small facility at the start.

MR ANDERSON: Yes.

MR BOLSTER: You have quite a positive view about it. Could you tell the Commission, what was the – what were the good things about that facility? Why did you like it so much?

MR ANDERSON: In terms of Grace moving into care as such, after had she been assessed, I pursued a course or direction on finding the best place that I could find in the immediate surrounding area for Grace to be admitted to, basically. And – and in theory, the circumstances of those was I – in my looking into accommodation as such, I was looking to try and replicate the environment that we were in the minute, living at the time, and that was a homeliness about it. And in theory I had started on this exercise and I had got to an organisation which I was about to leave after making some inquiries, and the receptionist said to me, why don't you try such and such an organisation down the road. And I thought, yes, that's fine but I didn't even know where it was. But having said that, she sent me on my way and obviously made a phone call or whatever, because when I got there, the – the resident or site manager was there to greet us – or greet me, rather, and said what – have you got three-quarters of an hour to spare and I said yes, and she said, well, this is it.

And in theory I entered an environment that I felt comfortable with and there was no slamming of doors or ventilators on to take away odious smells and the likes, and I thought well, the openness of the place attracted me in the first place, I suppose. I thought I can safely put Grace in there and I feel that that – that I felt comfortable with that decision, basically. But it didn't replicate in total, but it looked like a series of houses, it looked very similar to the house that we had lived in, basically.

MR BOLSTER: And what – you say in your statement that it was the age of the facility and the fact that it had to be replaced that was the only reason you had to go somewhere else; is that right?

MR ANDERSON: Yes, and that's based on the fact that the – the establishment perhaps mightn't have been up to scratch with health and safety regulations. It still had a mixture of two to a room and some with ensuite and in theory the management further down the track decided that it would be time to renovate the place where Grace was in, and at the same time build on an additional accommodation on another site, which catered for about 125 new beds, basically. And in that context, the – that was the context of the – the assessment I suppose really, that we – I was motivated by what I thought would be suitable accommodation for Grace.

MR BOLSTER: Yes.

MR ANDERSON: And in theory I was sort of prepared to say, well, you've only got X number of en suites but – which the new place has got plenty of actually and - - -

MR BOLSTER: Let me ask you this, about the choice, your initial choice and then thinking about it when there was a replacement; was it up to you to find out the details about the facilities? Was it left to you to identify what the potential nursing homes were? Or did you get help from anyone else?

MR ANDERSON: Yes. You were encouraged in general, once you got then assessed as being eligible to enter an aged care residential, the ..... was, well, now you can go out and explore possible vacancies or whatever as such.

MR BOLSTER: Was there any information that was made available to you about this is a good nursing home, this is a bad nursing home.

MR ANDERSON: No. No, actually the only information I got was usually a pamphlet or two about the operation of the place, basically.

MR BOLSTER: Yes. All right. Now, I want to talk to you about the actual care that Grace is receiving now. And you talk about some of the programs that you think are valuable for her. One of them is the music program.

MR ANDERSON: Yes.

MR BOLSTER: Why is that particular music program of value, do you think?

MR ANDERSON: I think it's very important in terms of not only Grace's wellbeing but mine, and in theory music, I believe, is – it touches the soul. We can – with the music that Grace is provided with at the moment, we can reminisce and reminisce or think about past times, and – and I think that music has – is underestimated in its total value of how it can enhance people's lives, basically.

MR BOLSTER: Yes. You say in your statement, or you refer to what you call eureka moments.

MR ANDERSON: Yes. Yes.

MR BOLSTER: What are they? Can you tell the Commission what that means to you?

MR ANDERSON: They're when – actually, they don't happen very frequently and they're likely to occur and carry on less infrequently in the future, but there are moments when actually I will play a – we will be listening to the iPod that Grace has got and in theory it will – it will hit on a tune that will respond to her emotions and I'm positive that actually when that happens, where her eyes may have been perhaps dull and a bit clouded, suddenly, or I believe light up and in theory we have shared together a moment in time where Grace has been in empathy with the music and – and I find great delight in that aspect of music, basically. Actually music, I think, really fuels your emotions. There's no doubt about that. And I think that there should be greater emphasis on music in terms of its therapeutic values as such, basically.

MR BOLSTER: Now, you say – you talk about the way in which you communicate with Grace in paragraphs 41 and 42 and you refer to touch and eye contact. What would you like to tell the Commission about the ability you have to communicate with a person with dementia even though there's obviously a problem there, communicating in other ways.

MR ANDERSON: In theory I – we had reached a stage in our life where – when the music program was first mooted that Grace had already lost the ability to recognise me and to know who I was to the point, I think, she thought, well, here's a grey-haired old bounder trying to chat me up, basically, as such. But in terms of music, the – we will be hypothetically playing the – the iPods and I'm listening – I might add, I've been trying a little experiment of late. I know that she doesn't recognise my speaking voice anymore but I put my hand up to sing and I'm wondering if actually my singing voice will have a greater impact than my spoken voice literally. But having said that as an aside, the ability to sort of be in an environment where music is so important, it's – it's one that is that, again, you can't possibly think, well, it's not a that brought a response from Grace either by tapping her toes or her fingers or whatever, to in that environment where if I was to play the same tune tomorrow, she wouldn't recognise it.

But – and in theory, I would have to make an observation that even though we've selected music that we think is fine for Grace, there are some pieces of music which she associates much easier, really, and that's children singing. And if we're playing The King and I, I can usually get a response out of her because children sometime along the line are singing a tune that Grace recognises as such.

MR BOLSTER: If you go, please, to paragraph 45, just on this last point I wish to raise on this communication issue, you mention there carrying a bag of diamonds in your pocket. What - - -

MR ANDERSON: I'm delighted to talk about that.

MR BOLSTER: Can you tell the Commission what's happening there.

MR ANDERSON: Well, it comes in the first place the recognition that Grace could no longer correspond with me speaking, and me responding. We had gone from a two-way dialogue to a one-way dialogue and I thought, well – to myself – I need to actually find some mechanism by which I could supplement the – the one directional approach that we were forced into, and I had this thought, well, why don't I actually have a bag of diamonds in my pocket which sort of has a sort of a ..... about it in the context that the biggest – when I say to Grace that I love her, I would get a response from a previous time that she loved me too. So I – I thought well, what I will do is I will certainly say to her, for as long as she's about the place, that I love her, and I needed to sort of get a feedback in terms of – in this case I've used diamonds and if I pick out the biggest diamond out of my bag of diamonds, it's got "Barrie, I love you too", and I've heard that plenty of times up to the point I can no longer hear her say it to me physically but in theory I know that in a past time when I've said to her, "Grace, I love you", she has said, "Well, Barrie, I love you too".

My diamonds really then extend to things like not questioning her, but asking her, comments about what's her favourite song or what's her favourite film or whatever, and I've got a diamond for most occasions I think, really. And I do rely emotionally and physically on the fact that I can still take a big diamond out of my bag which says, "Barrie, I love you too".

MR BOLSTER: All right. I want to talk now about some care issues. One of them is dental care and you have a view about that. What does the Commission need to know about dental care for people like Grace who really can't take care of their teeth themselves?

MR ANDERSON: Sorry, which paragraph was that?

MR BOLSTER: Dental care. Paragraph 33.

MR ANDERSON: 32.

MR BOLSTER: Sorry, 32, is it?

MR ANDERSON: Yes. Okay. In the circumstance I'm certainly quite satisfied that the care that Grace is given, being given where she is at the moment and in her previous environment – there has been a – in recent times where she is at the moment, the organisation chose to abolish the catering agreement and the cleaning agreement and the – the area that affected us most, I suppose, was the transition from an outside source being the provider of food to the management providing food as such which led to a few hassles like people weren't getting the right meal at the right time and such-like. But in theory, Grace was on the – had a number of occasions like that because she is on a puree diet and suddenly they are the exception rather than the rule where Grace is at the moment.

Most people can either feed themselves or be fed, and in theory it was a little frustrating at the beginning until they sorted out the catering arrangements to say, well, look, Grace was getting fed perhaps at the right time basically because they had either forgotten to make up a meal for her as such, but that's all solved now.

MR BOLSTER: What about dental care? What's the importance of dental care for someone like Grace.

MR ANDERSON: Sorry?

MR BOLSTER: Dental care. Her teeth.

MR ANDERSON: Yes. I don't think we've got enough dentists in the system, to be quite candid. And I think – I'm arguing that dental care is important. It actually, it needs a great deal of diligence and attention to because all the food goes through our mouths. Lots of infections get created because of the oral situation of our teeth and gums, and I think that there should be in residential care a regime by which there is regular dentist to come and sort of analyse the – people's, or the risks, their teeth as such, and gums. And, also, I think there is a need to make sure that if we're going to get quality staff, that they actually are trained in some aspects of dental care, because in theory I believe dental care will extend the life of many people, whereas if they're unattended to, they will actually succumb to either some sort of disease or illness because it has been – and the state of their teeth and gums.

MR BOLSTER: Quite. Let's just talk about – you say that dentist comes once every six months. Is that your private dentist or is that a dentist that comes and sees everyone?

MR ANDERSON: No, it's a dentist – it's a private dentist that comes and – as such.

MR BOLSTER: You pay for that dentist to come in?

MR ANDERSON: I pay for the dental to come in, basically. But I think that in theory it should be an extension of dental care because when we've been in the past prepared to look at children's teeth and the way that they are, that there's a regularity that needs to be observed in terms of actually care to people in residential care.

MR BOLSTER: Another thing – I just want to turn to another topic. You say in paragraph 35 – this gets back to communication – and you say that staff tend to be more motivated towards those residents who can talk.

MR ANDERSON: Yes, yes.

MR BOLSTER: Can you tell us a bit about that? How do you observe that when you're around Grace and the staff are there?

MR ANDERSON: Well, those observations are built on the fact that I visit Grace each day and I give her her meal each – at least a meal each day, and the time that she's out between meals, and in theory we have a situation where – and I think it's just human nature, there's a tendency that we will talk to people who can respond back because we get back to this two-way dialogue that needs to be maintained as long as you possibly can do – maintain it basically, as such.

MR BOLSTER: All right. What would you like to tell the Commission about the staff, generally? Where do they do a good job and where do they fall down sometimes?

MR ANDERSON: I think they can do better.

MR BOLSTER: How can they do better?

MR ANDERSON: Well, I think – again, I believe that in my working career, I worked for a firm that had an association with all capital cities in Australia and the likes, and the emphasis was, in fact, that they recognise as part of their slogan that people were the most important assets we've got. And if we – if I apply that to the situation in residential care, in theory I would argue the better the staff are trained, the better the quality of care would be as such.

MR BOLSTER: Do you see the staff being comfortable with dealing with an advanced dementia patient where Grace is at the moment?

MR ANDERSON: Actually if I – to – to err on honesty as such, they're – there's a difference between aged care and residential and out – and - - -

MR BOLSTER: Dementia.

MR ANDERSON: And dementia care. The system at the moment seems to be to me to be directed at the lower end of the scale in terms of care, and in theory the qualifications and the likes to sort of – for people to operate in that environment is – is such, but again, I think the treatment of dementia requires very special skills, which don't necessarily apply just for straight aged care people, basically. They've got to be better qualified in terms of response and as to emergencies and the likes, basically.

MR BOLSTER: What are the little things that staff can do to make a difference for the dementia residents?

MR ANDERSON: In an idealistic world I would love one-to-one relationship, basically, but in theory, there is I don't believe enough – enough, you know, attention paid to staffing levels. I think it's easier to find out the staffing levels for children and kindergarten than at the other end of the spectrum. When you're very old, nobody wants to know about a staffing ratio as such. But I think it's absolutely critical that that – that's an area that needs to be improved greatly.

MR BOLSTER: Where Grace is at the moment, is there always a nurse on duty?

MR ANDERSON: Yes, yes. And the other thing I can say in the defence of where Grace is, that they are actually committed to as many full-time staff as they can get as in – as against relief staff from agencies and the like. I'm not knocking agency staff or whatever but they bring a different feel to the arrangement, whereas if you're a full-time staff, there's much more likelihood that you get to know people, know their idiosyncrasies and their funny attitudes or whatever, as against an agency staff who comes in only to fill a vacancy if somebody has reported in sick or whatever, basically.

MR BOLSTER: All right. In the organisation where Grace is is there a turnover of nursing staff that you observe?

MR ANDERSON: I think the biggest turnover occurred shortly after the – I suppose you would call it an amalgamation where - - -

MR BOLSTER: Right. When there was a change of venue, when the building works occurred.

MR ANDERSON: Yes. And in theory, it even bordered on, well, the transition, lots of people didn't know where to find such and such a thing they might need which was time consuming. I mean the – and you don't really want temporary staff saying well, who's Mrs Smith. You know, you have to say, well, three doors down the track, you knock on Mrs Smith or Mrs Jones or whatever. They lack that sort of intimacy between the people they're looking after, basically.

MR BOLSTER: But you're getting that now?

MR ANDERSON: Yes, I think that's – there's been a diminution in the number of staff that transferred across, either by voluntary means or retiring age or whatever, and in theory I suppose the – in the total staff element that there are now very few that from – translated from their old previous - - -

MR BOLSTER: Yes.

MR ANDERSON: - - - to a new regime. And I think that actually kicks in with the culture actually as such, strangely enough, I believe. Because all of the organisations, no matter how small or how big, have a culture about them and how they operate and it sometimes can be confusing when you get two or three cultures at the same site trying to work out what is the general wellbeing for people as such.

MR BOLSTER: On that topic, I just wonder if you could have a look at paragraph 49 where you talk about what you refer to as the small dignities that you think need to be observed and honoured by staff.

MR ANDERSON: Yes.

MR BOLSTER: What do you mean by that?

MR ANDERSON: Recognise that people have a – a private space. It's their room or whatever, their building. And in theory too many don't pay perhaps enough attention to the fact that it would be lovely for the person whose privacy is being invaded to say, "Look, you can't come in". They're even denied that. They're not – you need to perhaps, as a role model, knock on the door and announce yourself and say "I'm here to have a chat" or whatever as such, and it's like, if you drop off any of those little elements it's like an intrusion into their privacy. I mean, their room is their world.

MR BOLSTER: Yes.

MR ANDERSON: And in theory I think that perhaps it's more pronounced in hospitals where anybody just rushes in without doing a thing on – knocking on the door or asking if they can come in. I mean, you're denying the individual and making a decision, really, and it's their realm and they should make the decision whether you should come in or come out, basically.

MR BOLSTER: Finally, Mr Anderson, I've just about finished but I would like to ask you just one more question before we wrap up. You say that you think there needs to be awareness raised about the impact of dementia and the ways we can recognise and care for people living with it in our community. What's the most important thing that people need to know about people like Grace who have an illness and it's called dementia?

MR ANDERSON: Sorry to be asking you to repeat it but what was - - -

MR BOLSTER: I do apologise. You say that there needs to be awareness raised about the impact of dementia and the ways we can recognise and care for people living with it in our community. What's the most important thing that people in the community need to know about living with dementia?

MR ANDERSON: I think top of my list would be stigma and in theory that would be without doubt the area that – that concerns me most. I would like to put in place

idealistically a scenario where in theory if a new development came into being, that there was provision within that – that very framework to have what I would call a cluster – a situation where the local community could actually – from youngsters to oldies could communicate with one another and – and in theory so long as it had primarily at the top of the requirements, which would be that they have adequate provision for the services that they need, be they a doctor or a dentist or a hospital or whatever, but in theory, and also constructed that if there was to be idealistically some arrangement like that in the – in the future planning – I mean, we plan for schools, we plan for home – kindergartens and the likes and we are neglecting, I believe, lots of people that could benefit by just their interaction in a community.

But it would be so constructed that no matter what happened, all the – in the case of if it was a cluster, all would come back to a central location. So if you started on a pathway, if you went along the pathway long enough, you would be back to where you started from, basically.

MR BOLSTER: Right.

MR ANDERSON: And I think that future developers need to consider the benefits, I believe, I think there would be a savings to the government. I – I can't say that I'm completely in favour of high rise. I don't think that's the answer to accommodation, because we're talking about people that have lived often in their homes for so long and in theory they just don't want a bland room. They want something that's actually reminiscing or reminds them of their – their home as such, in a past time.

MR BOLSTER: Finally, Mr Anderson, right at the end of your statement in paragraph 56, you talk about what you say when people ask you about how to care for Grace. What do you tell them; if you could read that out, I think it would be valuable.

MR ANDERSON: It's a fairly simple message, actually, to walk in Grace's shoes, to recognise that she's had a rich past, that there's a present and that she has an evolving future.

MR BOLSTER: I've nothing further. Thank you, Commissioners.

COMMISSIONER TRACEY: Mr Anderson, thank you very much for sharing with us your deeply personal experiences of caring for your wife. We deeply appreciate it because one of the things that we have to do is make recommendations that are designed to improve for the future the care of dementia patients. And you have assisted us very considerably in understanding the needs of such patients and their carers, for whom we're also very concerned. So thank you very much for your evidence.

MR ANDERSON: Thank you, your Honour.

COMMISSIONER TRACEY: Please feel free to leave the witness box. There's some administrative matters we need to attend to.

<THE WITNESS WITHDREW [3.05 pm]

COMMISSIONER TRACEY: Yes, Dr McEvoy?

DR McEVOY: Commissioners, you might recall that when Mr Versteege of the Combined Pensioners and Superannuants Association gave evidence last week he made observations about the report entitled A Matter of Care – Australia's Aged Care Workforce Strategy, a report of the Aged Care Workforce Taskforce. As a consequence of those comments, Professor Pollaers was asked by letter from the solicitors to the Royal Commission dated 14 February 2019 to respond to those comments. Operator, if you could bring up, please, ACW.9999.0002.0001. And in response to that letter, Commissioners, Professor Pollaers has provided a document dated 20 February 2019 which, Operator, if you could bring up is ACW.9999.0001.0001. I would simply seek to tender both those documents, Commissioners, and they can be tendered as the one exhibit.

COMMISSIONER TRACEY: Yes. Thank you. The letter of the solicitor for the Commission to Professor Pollaers dated 14 February 2019 and Professor Pollaers' response dated 20 February 2019 will collectively constitute exhibit 1-64.

EXHIBIT #1-64 LETTER OF THE SOLICITOR FOR THE COMMISSION TO PROFESSOR POLLAERS DATED 14/02/2019 AND PROFESSOR POLLAERS' RESPONSE DATED 20/02/2019 (ACW.9999.0002.0001 & ACW.9999.0001.0001)

DR McEVOY: If the Commission pleases.

COMMISSIONER TRACEY: Thank you.

DR McEVOY: Thank you, Commissioners.

COMMISSIONER TRACEY: The Commission will adjourn until tomorrow, not before 12 midday.

MATTER ADJOURNED at 3.08 pm UNTIL FRIDAY, 22 FEBRUARY 2019

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