



HEALTH, COMMUNITIES, DISABILITY SERVICES AND DOMESTIC AND FAMILY VIOLENCE PREVENTION COMMITTEE

Members present:

Mr AD Harper MP (Chair)
Mr MC Berkman MP
Mr MF McArdle MP
Mr BL O'Rourke MP
Ms JE Pease MP

Staff present:

Mr R Hansen (Committee Secretary)
Ms M Salisbury (Assistant Committee Secretary)
Mr Z Dadic (Assistant Committee Secretary)
Ms E Jameson (Inquiry Secretary)

PUBLIC HEARING—INQUIRY INTO AGED CARE, END-OF-LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

TRANSCRIPT OF PROCEEDINGS

FRIDAY, 13 SEPTEMBER 2019

Brisbane

MONDAY, 13 SEPTEMBER 2019

The committee met at 9.02 am.

CHAIR: Good morning everyone and welcome. Before we start I request that mobile phones be switched off or to silent mode. In the interests of your comfort and safety, please note that toilets are located down the hallway to the left. In the event of an emergency, please follow the instructions of parliamentary staff. You are welcome to use the cafeteria and coffee shop on this level, but please stay within this area on level 5. Also, for those with a hearing aid, you can set it to 'T' to access the hearing loop available in this room.

I now declare open this public hearing of the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee. I would like to start by acknowledging the traditional owners of the land on which we are meeting today. I am Aaron Harper, the chair of the committee and member for Thuringowa. The other members of the committee with me today are Mr Mark McArdle, the member for Caloundra and our deputy chair; Mr Michael Berkman, the member for Maiwar; Mr Barry O'Rourke, the member for Rockhampton; and Ms Joan Pease, the member for Lytton. Mr Marty Hunt, the member for Nicklin, is unable to be with us today.

The committee is a statutory committee of the Queensland parliament and as such represents the parliament. The inquiry into aged care, end-of-life and palliative care and voluntary assisted dying was referred to the committee on 14 November 2018. The reporting date for this inquiry has been extended and the committee is now required to report by 31 March 2019.

Today's proceedings are similar to the proceedings of parliament and are subject to the parliament's standing rules and orders. The proceedings are covered by parliamentary privilege, which means that witnesses are protected from legal action in respect of the evidence they may give the committee. If witnesses give evidence today that reflects adversely on an individual or organisation, it should not be taken as proof of the allegations being made and the committee may choose to receive but not publish that evidence.

The committee will not require evidence to be given under oath, but I remind you that intentionally misleading the committee is a serious offence. I also ask that everyone respect the rights of others to hold and express their particular views. I ask that witnesses take care when referring to acts of suicide or euthanasia.

This public hearing is being recorded and transcribed by Hansard, and witnesses will be provided with a copy of the transcript. All those appearing today have been provided with a copy of the instructions for witnesses, so we will take those as read. Media may come into the room, so you may be photographed today and images may appear on the parliament's website or social media pages. I now welcome our first witnesses for today.

LANDRETH, Mr Ian, Chief Executive Officer, Motor Neurone Disease Association of Queensland

THORPE, Ms Stacey, Director of Services, Motor Neurone Disease Association of Queensland

CHAIR: Thank you for being here. In our inquiry to date we have heard quite a number of cases, both written and verbal, from throughout Queensland of people suffering motor neurone disease. We have heard a number of concerns about the work that we are doing, particularly around the waiting and voluntary assisted dying. We are really keen to hear from your organisation, which clearly represents the views of the members you look after. Would you like to begin with an opening statement before we move to questions?

Mr Landreth: Thank you for the opportunity. Motor neurone disease is an insidious and dreadful disease. It has no known cause or cure. The average length of survival from diagnosis is two years. It is a progressive loss of muscle strength and the nerves controlling the muscles. Imagine sitting beside someone you love. Perhaps you are strapped into a wheelchair to keep you upright so you can breathe, and you have no ability to communicate anything to them—not how you are feeling, not something you need, not an idea you have had, for all of those things will be going on in your Brisbane

mind. You remain a thinking, feeling and creative soul with a sparkling intellect that is alive and yet you are unable to communicate. That is what many MND sufferers experience and they decline day after day.

Our organisation and its national network raises funds for research in the search for a cure. We raise funds for the care and support of these Queenslanders until such a breakthrough is made. What we wish to highlight to this committee is the systemic discrimination against an MND sufferer. This is something that can be solved by the political leadership of this parliament if you have the will because you, unlike an MND sufferer, are able to express and act on that will.

The National Disability Insurance Scheme provides for a client focused management and care plan, and equipment and support to facilitate that if you have a disability registered with the NDIS before your 65th birthday. However, if you are diagnosed after your 65th birthday the only financial funding available is through a My Aged Care grant, which is not designed to support a disability. It does not cover equipment or coordinated care planning. It is means tested and requires a co-contribution and, at its highest, is maybe only 30 per cent of the level of NDIS funding available to you if you had not just had your 65th birthday. The time it takes to be granted this funding is often longer than the client has to live. The only support that these over-65-year-old Queenslanders, their families and carers get is from organisations like ours, from fundraising, donations and bequests. These charities save Queensland Health millions of dollars a year and Queensland Health's contribution has been zero.

Queenslanders with motor neurone disease need your political might to address the age and disability discrimination created by these government funding structures. They need you to fix it and they need Queensland government support in the meantime until that happens.

CHAIR: Thank you very much. Ms Thorpe, do you have a statement to make?

Ms Thorpe: No, I think that covers all I wanted to say.

CHAIR: It is a stark message you are bringing and it is exactly what the committee needs to hear in terms of the funding required to look after those people diagnosed with motor neurone disease. It is an interesting point that if you are 65 or over you go straight to the My Aged Care. In the 36 years since your organisation was established, how many members do you think you would have looked after in Queensland? You can take it on notice if you like.

Mr Landreth: Yes, we might have to do that. We know there are 257 currently that we are looking after. It is interesting that we start our monthly board meetings with a receipt of applications for members who may be clients but they might also be family members or carers, and then that is followed by a minute's silence for those who have passed since the last meeting. At the last monthly meeting there were 27 of those names on the vale list. It is something we encounter in our work every day from the people on our phones. If more of our clients had a voice late in their diagnosis to describe that pathway to you, then I am sure they would be here.

CHAIR: It is absolutely clear in your minds that funding is required to assist those people suffering from motor neurone disease, and the committee takes that on board. Are you able to reflect the views of any of those 257 members you are looking after at the moment with regard to the issue of our broader inquiry in terms of voluntary assisted dying? Have they passed any views on to you as the CEO or to Ms Thorpe in terms of accessing a scheme if it were to be legislated?

Mr Landreth: We have a really broad church in our membership, and that would include people who are desperate to find alternatives offered that are not currently available to them in the way of voluntary assisted dying. There are others who have a very staunch view that that is not even a choice that should be offered. For us as an organisation, to represent a position for our clients and those suffering MND is to disrespect that broad range. What we focus on is ensuring that they can access all the choices available to them within the legal framework and particularly focusing on the barriers to access. I know that where one of our board members was approached by somebody around the aspect of voluntary assisted dying, all we were able to do was refer them to what had happened in Victoria and what was available there. Our sister organisation in Victoria, the Motor Neurone Disease Association of Victoria, is obviously managing that with their clients because of the legal framework down there. It is not something on which we can take an advocacy position.

CHAIR: I respect that. It is certainly an issue that has brought some divergent views across Queensland. We have had people who are suffering write to us and come before us seeking choice. I was interested to explore that a little. Thank you, I have no further questions. I will open up to the committee for any further questions they may have.

Mr BERKMAN: Thank you both for being here. A dear friend of mine received the news just before Christmas that her mother has motor neurone disease; that diagnosis is fairly recent. For her that really reinforced the importance of choice, just as you have expressed in your submission, and

particularly around the question of VAD. We have seen in Victoria's model specific provision made for neurodegenerative disorders whereby a prognosis of 12 months is part of the eligibility criteria. Do you have a view on the adequacy or otherwise of that, given the average life span of two years from diagnosis?

Mr Landreth: I think Stacey might have some more comments about the progression of the illness, as she has experienced it with clients. I know from talking to my Victorian colleagues, the sorts of things they are saying around that are that, whilst the average survivability is two years, there are different types of motor neurone disease. Some varieties like the one that Stephen Hawking had can result in survival for a long time.

The comment that I think is most relevant is about how to manage it. The progression of the illness in terms of the disability and the lost abilities of the people is where the support is needed. The consideration of a neurological degenerative disease that creates the disability needs no arbitrary cut-off date, but from the time of diagnosis they need the choices around the care that is directed, that is self-directed—for them and their family members—that NDIS gives to the under-65s and is not available to the over-65s.

Ms Thorpe: To add to that, the predictability or the unpredictability of the disease means that, with 12 months, it is difficult to understand what somebody's condition will progress into in that time. It could appear to be a slowly progressing condition that changes rapidly. From today, you might think that 12 months seems a reasonable survival period and then next week that might change quite considerably, so it is really difficult to put a time frame on that.

Mr BERKMAN: In one of the alternative models, I think it is the Canadian model, eligibility rests on the question of the reasonable foreseeability of someone's death. That has been discussed by some experts in terms of the difficulties in prognostication more broadly, not just with conditions like MND. Do you have a view on whether that might be more suitable for sufferers of MND or whether that improves the choices and the decision-making framework from the perspective of an MND sufferer?

Mr Landreth: One of the suggestions that has been debated with the NDIS and the commission is that MND receive a definition that is not subject to the age barrier, so that whenever you are diagnosed with MND the NDIS would provide the same levels of client-centric, client planned care that the under-65s have. That is one suggestion.

Another suggestion is that the My Aged Care package has another level attached to it above level 4. The response to that, from some of the clients and family members I have spoken to about that, is that it is still so fundamentally different in that it is means-tested and there needs to be a co-contribution. You can read in the case studies we have put forward to you in our submission two very real cases where people are losing their livelihood. It is not only the person losing their life; the extended family and carers are placed into all sorts of financial hardship because the My Aged Care packages are not defined to handle a disability. They are not defined as helping to keep somebody with their care community and their family in their home, together. The one that seems to have the most traction and acceptance in our networks is that NDIS is working and it is being shaped and improved; it is just that it runs out on a person's 65th birthday as a cut-off.

Mr BERKMAN: Do you have any further comment on the question of the threshold for eligibility to a VAD scheme, the question of whether eligibility rests on a particular time frame or the concept of reasonable foreseeability of death? That was more what I was trying to express with that question. If the organisation does not have a position, I completely accept that and do not mean to push.

Mr Landreth: It is, just as Stacey said, really difficult. We had a fellow I spoke to who was keen to come along with me and talk today. About a week after that he became non-verbal. That was not a predictive position, so it is hard to take a position on a time frame that is associated with this disease.

Mr BERKMAN: Thank you very much.

Ms PEASE: I would like some clarity around the diagnosis. MND strikes people of all ages, I understand; it is not just an old person's disease that strikes people over 65?

Ms Thorpe: Yes, that is correct; it affects all ages, all adults.

Ms PEASE: Adults? So people 18, 16?

Ms Thorpe: It is unusual—very unusual in those.

Ms PEASE: What would be a general age?

Ms Thorpe: Fifties and sixties would be the most typical age that somebody would be diagnosed.

Ms PEASE: You talked about people who are living with MND and their experiences of the NDIS and not fitting into aged care. I would like to talk about what palliative care services are available. Are there specific needs for people living with MND? How does the community deliver those services?

Ms Thorpe: There are a wide range of palliative care services available. In terms of how the community delivers those services, it is quite separate from our organisation. We engage with our clients and give them advice on who to reach out to, but we do not actively involve ourselves in that process. We are certainly not experts in the palliative care space. We are more of a referral in that respect.

One of the things I would like to point out though is that, even though we advocate strongly for the NDIS being a really positive support for our clients, that handover from NDIS funding into palliative care means that somebody will see changes in their support staff. The NDIS will not fund palliative care services because they are funded separately. One of our clients could have built a strong team of support staff around them, personal care workers that they trust. Those same people cannot continue to provide supports if they are funded by palliative care services. It gets to that point where you are in that real end-of-life stage and then you will potentially have new people coming in and providing really intimate services.

Ms PEASE: Are people living with MND eligible to apply for home care packages when they turn 65, that is, get an ACAT assessment and someone comes out and have services provided that way?

Ms Thorpe: Yes, if they do not already have an NDIS package, they can, yes.

Ms PEASE: If you have been diagnosed with it before 65, it continues on?

Ms Thorpe: Yes.

Ms PEASE: If you have been diagnosed after 65 and you have to apply for a home care package, are you aware of any delays? We have heard some harrowing stories of people who have been on a waiting list for four years. Have you experienced that?

Ms Thorpe: Yes, that is hard. That is absolutely our experience. In fact, I had an example just yesterday where a client was diagnosed post-65 and applied for an ACAT assessment. The client was put on a waiting list just to have the assessment, and we are talking three to six months before the assessment is likely to take place. We have been able to intervene and prioritise that more quickly. We have a number of examples of clients who will be assessed for a level 4 package and then they are on a waiting list. We are talking 18 months to two years before they will ever see any funding, and our clients will pass away before they have ever received any funding.

Ms PEASE: You have experiences of that happening where clients have passed away, waiting for their package to come through?

Ms Thorpe: Absolutely.

Mr Landreth: On Sunday we had a fundraising walk at Toowoomba. A recently widowed woman told me that she had received the ACAT assessment for her husband two weeks after he passed. They had stopped looking for it.

Ms PEASE: The chair relates a story that we heard in one of our hearings where a woman applied for it. It took eight years to be received. Her husband had died four years ago. Two weeks prior to the hearing she received the notification that he was eligible for it. Thank you very much and thank you for the great work you do in the community.

CHAIR: Well said. Hear, hear!

Mr McARDLE: Looking at your submission, you indicate there are 443 Queenslanders with MND and one half of those are accessing your organisation. Working on 220 with your organisation for today's calculation, how many of those would have been diagnosed after 65 years of age and would not qualify for an NDIS package?

Ms Thorpe: Just over half of those people were diagnosed over the age of 65.

Mr McARDLE: So 110?

Ms Thorpe: Yes.

Mr McARDLE: What is the cost in a dollar sense for a patient who is diagnosed with MND, from the date of diagnosis to the ultimate sad passing? Do you have any idea of what a person's medical costs are along that line?

Mr Landreth: That has been assessed in the Deloitte Access Economics document, titled *Economic analysis of motor neurone disease in Australia*. It breaks down the medical costs, the private costs and the value of life. You can split those out and do the analysis on that. I am not sure if they make an actual statement in the report that I can remember that actually quantifies the specific medical care costs, but it is a calculation in their report.

Mr McARDLE: We could look at that report and get a reflective idea of what those costs would be.

Mr Landreth: Yes.

Mr McARDLE: Would you mind seeking leave to table that report, if at all possible?

Mr Landreth: Certainly.

CHAIR: Excellent question. Is leave granted? Leave is granted.

Mr Landreth: I think I referenced the cost in the submission. The total cost of MND estimated by Deloitte Economics in 2015 was \$2.37 billion, equating to \$1.1 million per person. That is with the impacts on the economic value of life, as well.

Mr McARDLE: That is a wider figure than the strict medical costs associated with that. The \$1.1 million incorporates productivity questions, family impact, et cetera?

Mr Landreth: Yes.

Mr McARDLE: It would be good to get that document to go through, as well. I am quite shocked that 110 people are diagnosed over the age of 65 years for the simple reason that it seems to me that it is more in the late 60s and maybe even 70s that people are diagnosed, rather than in their 50s and 60s, proportionally.

Ms Thorpe: It is also worth noting that it takes around two years sometimes to actually get a diagnosis. From the onset of symptoms, given the challenges to actually diagnose motor neurone disease, it can be quite some time that passes before that happens.

Mr McARDLE: As I understand MND—and that is very embryonic knowledge—it is difficult to diagnose because it could be one of a number of matters. The fact that it takes up to two years for diagnosis could well mean that a patient or individual who is diagnosed will miss out on NDIS funding, because there cannot be certainty in the diagnosis.

Ms Thorpe: Absolutely.

Mr McARDLE: How many practitioners can diagnose MND?

Mr Landreth: I am not sure of the number, but I think that any specialist neurologist—it has to be a neurologist, does it not? I am not entirely certain of that, but it is not something that a GP can do. Because it is a neurological degeneration, it really does require a neurologist's input, if not their definitive—

Mr McARDLE: When you say 'neurologist', there are specialties in neurology. It would need to be a specialist in this area, would it not?

Ms Thorpe: There are a number of MND clinics with specialist neurologists at various hospitals around the state, but private neurologists will also diagnose MND.

Mr McARDLE: You have been asked questions about VAD. You are neutral in relation to whether a member of your organisation accesses that. You would provide the information for them to make the choice; you would not be an organisation that says, 'No, we will not provide information in relation to VAD', if requested?

Mr Landreth: If requested and it was a legal option in Queensland, then we would provide that.

Mr McARDLE: Of course. Thank you, Chair.

CHAIR: That was an excellent way to start our final day this week, having your organisation here representing over 450 people diagnosed with MND in Queensland. We thank you for the work you do. We thank you for your attendance today. I call up our next witnesses.

EVANS, Ms Leanne, Senior Policy and Relations Advisor, Exercise & Sports Science Australia

HOBSON-POWELL, Ms Anita, Chief Executive Officer, Exercise & Sports Science Australia

CHAIR: I welcome Ms Evans and Ms Hobson-Powell. Would you like to start with an opening statement before we move to questions?

Ms Hobson-Powell: Firstly, I begin by acknowledging the traditional owners of the land and pay my respects to elders past, present and emerging. I seek leave to table our submission to the royal commission into aged care, if that is possible?

CHAIR: Is leave granted? Leave is granted.

Ms Hobson-Powell: The current aged-care system does not focus on wellness and reablement to support older Queenslanders to achieve greater independence and quality of life and to live their lives to the fullest. Access to exercise services is an essential component to ensure a wellness and reablement approach to the aged-care sector. Ensuring access to exercise services at all levels across the aged-care sector will allow Queenslanders to maintain independence, functional outcomes and quality of life.

The current funding model within aged care does not support the delivery of exercise services, therefore, many people are missing out on access to services that will make their lives more enjoyable, healthy and independent. For example, falls prevention and keeping people mobile are key outcomes of the aged-care sector, yet every day decisions are made to keep people from moving about, thus resulting in muscle wastage and consequently falls, decreased mobility and loss of independence.

The current AIHW report documents that only 25 per cent of people aged 65 years and older meet the physical activity guidelines and this number decreases with age. State and federal government funding is needed to be allocated to improve these numbers and it will also help the government long term with healthcare costs associated with inactivity. ESSA hopes to support the Queensland government in improving the health and wellness of Queenslanders, especially those accessing aged-care services.

CHAIR: I was interested to read of the savings. Can you reference the research you have done on prediabetes, diabetes type 2, mental health and cardiovascular disease, and there is a significant savings there, in terms of getting people out, active and mobile?

Ms Hobson-Powell: Absolutely. We are happy to table, on notice, the full access report, which has all of that economic data. A lot of research has found that there are cost savings, particularly in prediabetes, diabetes, mental health, cardiovascular, back pain and osteoarthritis. Obviously people in the aged-care sector will suffer from one or many of those conditions.

CHAIR: You have sought leave to table that?

Ms Hobson-Powell: We will have to provide it on notice.

CHAIR: That would be excellent. The Health and Wellbeing Queensland Bill was passed recently. Will you be talking with that particular body, once it is established?

Ms Evans: Yes. We have actually attended the briefing. The minister was unavailable, but his chief of staff delivered a briefing, across the road at a QUT facility. We are certainly aware of what is coming. We are seeking opportunities in terms of how we might support Health and Wellbeing Queensland to do its work.

CHAIR: Aged care is a focus of this inquiry and certainly we have heard of challenges around funding, and getting people active and mobile is one of the key drivers in the health promotion space. I will move to questions from the committee, but firstly I want to congratulate you on the research that has been done. From reading your brief, quite a number of you have conducted significant research over some period to land on those numbers. For the baby boomers in the room, I hope that that will get more people active in their ageing communities. We have an ageing population and we want to keep people healthy well into their senior years. Are there any questions from the committee?

Mr BERKMAN: In your submission, you have noted that the charging of GST is a substantial barrier to Queenslanders accessing exercise physiology. Has the federal government provided any advice as to why that does not classify as an eligible health service for the purpose of GST exemption?

Ms Hobson-Powell: We can do a short version or a long verse.

Ms Evans: It is an issue that we have been working on over a number of years. We continue to meet with Treasury officials, various ministers and advisers in terms of the issues. The nub of it was that exercise physiology was not around when the GST legislation was drawn up. We are an allied health profession that has come, if you like, after more established professions. We meet all the requirements that the ATO has set in terms of what health services are recognised as professional health services. We are continuing to engage with various parliamentarians. I have a meeting next week with one of your senators in Canberra on that issue.

Mr BERKMAN: We can only trust that that will continue to progress in good faith.

CHAIR: That is a good point, member for Maiwar. There are 459 residential aged-care facilities in the private sector in Queensland. Did you dial down to the estimated cost of providing access to wellness and enablement in those residential aged-care facilities in Queensland? Did you dial down figures to the broader—

Ms Evans: No, we have not done that research to date. We can certainly highlight evidence of best practice in Queensland. We could refer members to a residential facility outside Redcliffe called BallyCara, where currently they employ six exercise physiologists in a gym suitable for not only residents but also people in the community. We have models of best practice that we can refer you to. In terms of the cost, it is very difficult to estimate that.

CHAIR: It might be good for us to look at that if you can provide it to the committee on notice. We have 16 residential aged-care facilities and certainly the committee has visited some of those. There are activities going on in those spaces. However, we have also been to some of the broader private sectors where that might not occur, where you are not getting people active and they are just staying in their rooms. The impetus there is for the private sector to employ people to get people active.

Ms Hobson-Powell: Absolutely. The issue is around exercise physiologists not being covered under ACFI, as well. It is then on the aged-care settings to work out how they are going to fund those models. It is thinking about are they using Medicare? Is it just going to be private payments that occur? A lot of them just think it is not in ACFI, so therefore we cannot provide the service.

CHAIR: ACFI sits under the Commonwealth funding that has responsibility for aged care?

Ms Hobson-Powell: Correct. The review came out that that was a glaring omission that needs to be fixed, but until the Commonwealth changes their aged-care funding that is a potential barrier. It is good to see that some of these facilities are coming up with models of care that sort of think outside that traditional funding model.

CHAIR: I am sure, with the work of the royal commission and the work that we are doing, we want to land on strong recommendations going forward. We thank you for your input on that.

Mr O'ROURKE: In regards to the vision for wellness services into aged care, have there been any studies around the cost savings, that is, if you are focusing on this part it will reduce ongoing costs?

Ms Hobson-Powell: There is a university in New South Wales that does more of that preventive health work and certainly we can get the data on that for you. Most of the work that we have done is on people who have actually been diagnosed and, therefore, the use of exercise is part of their treatment models, which is in the Deloitte report that we just spoke about. There has not been much in that prevention element going into aged care at this point.

Mr McARDLE: As a baby boomer, as pointed out by the chair, I am keen to understand this. Exercise is critical and there is no question about that. However, you must have the right diet as well, otherwise the exercise becomes less effective or not effective at all. What would you say to this committee in relation to a healthy diet being part of the aged care regime to achieve the exercise outcomes we are talking about?

Ms Evans: If our colleagues from the Dieticians Association of Australia were here, they would be echoing those comments. Certainly we do not claim to have that expertise.

Mr McARDLE: I accept that.

Ms Evans: They certainly have developed guidelines and they have made submissions to the royal commission, as well. We could take it on notice and also get their submission to you, if that would be helpful?

Mr McARDLE: Mr Chair, I would appreciate it if we could get that document. You talk about physical activity in relation to a physical response. However, mentally it is also critical; is that not the case?

Ms Hobson-Powell: Absolutely. There is lots of research to show the brain function and activity through CT scans after you undertake physical activity. It certainly has an absolute role in mental connectivity and social inclusion. It helps with your moods, as well. Particularly in aged care, it is one of those side factors that is important with physical activity. It is not just going to help the people physically but also certainly it is going to help with their mental and emotional wellbeing to be participating, and then there are ongoing benefits.

Mr McARDLE: That leads to communication and socialisation. In our society it is so critical to us to be part of the community and for the community to accept us as being part of it, as well.

Ms Hobson-Powell: Absolutely.

Ms Evans: Exercise can also aid in helping people with behavioural challenges. It can actually help reduce their dependence on medication.

Mr McARDLE: Do you have any idea of the aged-care providers that actually provide exercise as part of a daily or weekly routine for residents of their particular aged-care facilities?

Ms Evans: We could only do that anecdotally. That may be something that you can talk about with our colleagues from LASA, who are behind us, when they appear.

Mr McARDLE: It would be good to get information on that, as well. You talk about 30 minutes of physical activity on five days or more. Are you talking about moderate exercise or are you talking about high-impact exercise? What sort of activity are we talking about, exactly?

Ms Hobson-Powell: Those guidelines are around moderate physical activity. It is basically just elevating your heart rate. We use the walk and talk model. For most everyday Australians to understand what that is, they can go for a walk and still maintain a conversation. They are elevating the heart rate. Particularly in aged care, it is not telling them that they are going to go to the gym to lift weights all the time, but it is getting out and doing some walking or doing some gardening if their residential care facilities have gardens. It is other activities that they can be doing, as well.

Mr McARDLE: It need not be what I would call 'exercise', that is, a walk; it might be gardening?

Ms Evans: It could be incidental. It could be walking to a bus. It could be vacuuming the house. It could be a whole range of things.

Mr McARDLE: Let us talk about aged care, because often aged-care residents are fairly immobile. What exercise are we talking about there? Are we talking about light weights on arms and maybe even legs as well? Can you give me an idea?

Ms Hobson-Powell: Absolutely. They can be doing some band exercises. They can be doing some weight exercises. If they are in a wheelchair, they can even be going out in their wheelchairs and pushing themselves around. A few of the places have pools now, so it can be getting in and doing some aqua activities. The point is actually getting them to exercise. I will talk about my father who has dementia and is in an aged-care facility. He used to walk twice a day, in the morning and at night. He goes into an aged-care facility. They put him on medications. They put in alarms so that he does not wander. He is now wheelchair bound. They do not look at trying to increase physical activity. They actually want them to stop getting out and moving. It is a change model around how they look after their patients, as well.

Mr McARDLE: Have you or anybody else done a study that has looked at by how much the exercise activity prolongs a person's life in aged care?

Ms Hobson-Powell: We might have to take that on notice. In Sydney, there is a researcher, Maria Fiatarone Singh, who is a gerontologist and does a lot of work in this space. There is certainly research to show improving health outcomes and also their quality of life. Whether it actually extends that, we will take on notice.

CHAIR: When I first saw Exercise & Sports Science Australia was appearing as a stakeholder, I wondered about the angle from which you would be coming. Thank you for your excellent work and great research, and for your contribution today. We will call our next witnesses.

EDITH, Ms Chris, State Manager, Leading Aged Services Australia

GREEN, Dr Marjorie, National Seniors Australia Policy Advisory Group

HICKS, Mr Tim, General Manager Policy and Advocacy, Leading Aged Services Australia (via teleconference)

SOMERWIL, Ms Vera, Chair, National Seniors Australia Policy Advisory Group

TUCKER-EVANS, Mr Mark, Queensland Chief Executive, Council of the Aging Queensland

WYNNE, Dr Michael, Aged Care Crisis Inc.

CHAIR: Tim, would you like to make an opening statement?

Mr Hicks: I will make a brief opening statement, if you would not mind. Given the breadth of the issues that are covered by the terms of reference, I will keep it fairly short and general. I want to start by saying that aged care is an issue of national importance, just as much as health and education. Nobody ever disagrees with this statement, but the reality of the challenges currently facing the sector tells us that the message has not truly been heard. There are a number of inconvenient and unacceptable truths that we need to confront about our aged-care system. In particular, it is unacceptable that we have nearly 130,000 people waiting years to access the home care that they have been assessed to need. It is unacceptable that funding is not linked to the cost of delivering care. In a recent survey of our members, we found that 80 per cent of them said that the funding that they received constrained their ability to deliver the care that their clients need and expect.

The regulator's own survey shows that about nine in 10 people have a positive sentiment towards the care they receive in residential care, but this does not excuse or diminish the failures of care that we have seen. These are things that need to be addressed. It is unacceptable that we have a dedicated and committed workforce that cannot receive the pay and training that they deserve, because how we fund the aged-care system does not reflect the value of their contribution and the contribution of the sector to our society.

This inquiry, the royal commission and other processes provide important opportunities to confront and address these and other issues. This is something that the sector overwhelmingly embraces. We should all be on the same side here and that side is the side that wants Australia to have an aged-care system that reflects the wealth of love and compassion that we each feel towards our own family as they age. Thank you.

CHAIR: Excellent, Tim. That was a well-articulated statement. Thank you very much for that. At the very core, it is about people. Chris, from a state perspective, did you want to add anything?

Ms Edith: Certainly. To give a little bit of background information—I know you have our submission about LASA—we are the national association for providers of aged services across residential care, home care and retirement living. Our membership is made up of not-for-profit, faith based, private and some government operated organisations, particularly here in Queensland. In Queensland, we have a total of 162 member organisations. Roughly about half-and-half are residential and home care, but more and more these days we are moving to a very integrated model of care that might move across various spectrums. Certainly, many providers in Queensland and nationally are looking at models of care that provide ageing in place. Also, I was very pleased to hear earlier from ESSA about the wellness and reablement approach. LASA's approach at the moment is we are focused on ageing well, not aged care, and we are really looking at a future focus that will bring that wellness and reablement into much more of an integrated aged-services system.

We certainly support many of the organisations out there that are looking at those wellness and reablement programs. I was interested to hear about BallyCara before. I know that they are doing some amazing things, but I can certainly provide names of other providers in Queensland that are also integrating wellbeing, exercise and food into their day-to-day services.

I also acknowledge the point—and agree with the point, in particular in residential care—that the current ACFI funding model does not necessarily support a wellness or reablement model. It can be very difficult for many of our providers that are facing those financial constraints and that are finding it difficult to provide the level of care that our consumers and aged services would want. However, in Brisbane

saying that, I am personally aware of many of our organisations and services in Queensland that provide those services even if they are not getting funding for it. They have taken the viewpoint that it is much more important to have that wellbeing approach.

The other thing that I think is important to focus on is that this is also happening in the home-care sector. There are a number of our home-care providers, including Commonwealth Home Support, that are, again, not necessarily funded for these types of activities but they are providing them on a day-to-day basis and very much coming from a strength based position, not so much as a need for aged services. There are many interesting models out there as well including, I should add, the Brisbane North Primary Health Network and the work that they are doing currently with their active@home model, which is very much based on a reablement model. We really encourage those areas. Obviously, we would like to see a much stronger multipronged approach so that that wellness and reablement focus is integrated into the funding models at both residential and home care.

CHAIR: Thank you, Chris and Tim. We will come back to you. We will hear opening statements from other panel members. We are handing out the media release that you put out recently about financial pressures on aged-care providers that is impacting older Australians. I will come back to you and ask you to talk to that statement. Some of that information is very concerning. I welcome Mark Tucker-Evans from the Council on the Ageing Queensland.

Mr Tucker-Evans: Thank you very much. I, too, would like to acknowledge the traditional owners of the land on which we are meeting and their elders past, present and emerging. Council on the Ageing Queensland has been in existence since 1957. It started as the old people's welfare council in 1957. We are a peak consumer organisation and whilst we, in fact, auspiced Aged Care Queensland, which was the organisation that preceded Leading Age Services Australia, we come very much from the consumer perspective.

We believe that the aged-care system is unnecessarily complex, that many Queenslanders do not understand what services are available to them and that it is likely that many Queenslanders who would be eligible for aged-care support do not apply, because they do not understand how to navigate the system. Currently, COTA Queensland, together with other COTAs across Australia and other organisations have funding from the federal government to run a trial around aged-care navigation systems pilots. I would have to say that any system that needs a navigator to navigate it needs to be redesigned. It really needs to be redesigned from the consumer perspective.

We have an ageing population in Australia. In Queensland, currently, we have over 800,000 Queenslanders over the age of 65. Many of those are in regional and remote areas where accessing aged care is quite difficult and, in some cases, impossible. What we would like to see is an aged-care system that is properly funded, that enables people to access the services that they need with a minimum of three months delay. We hear from our consumers that in some cases it is a two-year delay before they can get services.

We also believe that palliative care is largely focused on the very end of life and it should be extended to meet the needs of consumers to help them manage their pain. It needs to be thought to be beyond cancer, which is where most people think the palliative care is focused. In terms of end of life, we commend the government for funding the Office of Advance Care Planning and for funding hospital and health services to have aged-care planning facilitators within their facilities, but that funding has now ceased. One of the things that is required is that not only clinicians but also the community needs to have education around end-of-life care planning.

We believe that consumer groups such as COTA and Health Consumers Queensland should be active in that area because, if you are having those discussions in the hospital facility setting, it is absolutely the wrong place to have them. We advocate that those discussions around how we want to end our lives are about quality of life and a quality death. That should be happening much earlier.

This brings me to voluntary assisted dying. We have certainly seen through surveys that we have undertaken over the past 10 years that there has been a shift in the community's view on this. Whilst COTA still has a neutral view on this, unquestionably from the surveys that we have taken most recently 80 per cent of the community are now in favour of voluntary assisted dying, provided that there are appropriate safeguards in place.

CHAIR: Thank you, Mr Tucker-Evans. I appreciate that you have commented on all three. I think health literacy is vital. It is the first time that I have heard that the Office of Advance Care Planning has ceased funding. Thank you for informing us of that.

Mr Tucker-Evans: The office is still funded to the tune of \$6 million over a period—

CHAIR: Sorry, six?

Mr Tucker-Evans: Six million dollars, but the funding that has gone to the hospital and health services for aged-care planners in the hospitals has now ceased. It is important to have not only the Office of Advance Care Planning, which we work with as an organisation, but also to have those other people in place at the moment of care and discussion.

CHAIR: Yes. We keep hearing of people not having an advance care plan. It is at a time of crisis, when no-one knows the wishes of the loved one, that decisions need to be made. I have said it and I will say it again: I congratulate AMA Queensland and any other organisations that are out there pushing to get better education for people to plan well ahead. We seem to leave it very late in the piece.

Mr Tucker-Evans: It is pleasing to see that over the last couple of years there has been an uptake of advance care plans. There still needs to be much more community education around this issue.

CHAIR: Thank you very much. Health literacy is very important. We will come back to you for questions. I welcome Ms Vera Somerwil from the National Seniors Australia Policy Advisory Group. You have Dr Marjorie Green with you. Welcome.

Ms Somerwil: We represent the National Seniors policy group because we are advising our group, National Seniors. We are an independent organisation. We have about 120,000 members throughout Australia, but we have the largest number in Queensland. We get our policy advice from them and we take it to the organisation.

For the inquiry into aged care, end-of-life and palliative care, we have looked at it in three sections. According to the evidence that we see from the royal commission—our executive officer from National Seniors has already presented evidence there—and the feedback raised by National Seniors members, the next of kin and all people who are involved are finding that lots to do with the aged-care system is actually substandard. More often than not, this is the result of inadequately trained staff and an insufficient staff. There is not enough time to attend to the social needs of the individual. They seem to be forgotten lately. As the carer of a person in an aged-care facility for eight years, I can assure you that I have witnessed the shortcuts taken by staff and the lack of respect for the elderly.

As you have already been told, waiting times for home care are specifically not meeting the needs of older people in Queensland. We understand that approximately 127,000 people were not receiving the appropriate level of care as at the end of December 2018. It appears the standards of care are not being met in a number of residential settings. However, they are being met in some.

New aged-care quality and accreditation came into effect and this shows a shift towards process standards that require providers to assess individuals' needs rather than their own needs. They are required to deliver on the individual's needs. The demand for aged-care services in Queensland will increase—and it will increase with the future baby boomers coming on board. We are now aware that these people have complex diseases and they are going to require complex care in nursing homes.

The incidence of dementia in residential care is about 52 per cent now. Seniors are telling us that they struggle if they have to find a residential care facility for their elder person now. We know they go through agony trying to find a place to put their resident. There are more often difficulties with care in rural and remote areas. I think that has already been brought to your attention. The skill mix of staff needs to be appropriate for different settings within aged care. Very frail and demented patients require greater nursing care than a resident with low-care needs—there is a difference you know—for activities of daily living such as feeding, bathing, dressing, toileting and social activities.

There is no requirement for providers to show evidence that the money received from governments is used in the provision of individual care. Providers only need to meet the standards set out in the aged-care quality standards. With the increasing frailty of aged-care consumers, staff should have basic knowledge of how to look after people who have dementia, and I am afraid they do not.

I turn to end-of-life and palliative care. Palliative care services need to meet the unique needs of individuals. They require a range of practitioners and models of care within service settings that are not currently provided in many settings, as we have already heard. It is unlikely that palliative care and end-of-life services are meeting the needs of Queenslanders in particular. This will differ for many reasons and the reasons should be assessed on a case-by-case basis. Services do not appear to be well integrated with the hospital and health services in Queensland. I think we just heard that evidence.

As the population of over 65s increases, this will have a significant effect on palliative and end-of-life services. The need for specialist palliative care staff will increase. The delivery of palliative care and end-of-life services can be improved by promoting best practice. This should be achieved through objective analysis of existing service models to ensure that only the best practice models are promoted.

There are many challenges around the delivery of palliative care for Aboriginal and Torres Strait Islander communities. It is the same for everybody. However, we have to pay more attention to their social mores. We understand they should return to country if possible. There are Aboriginal and Torres Strait Islander organisations that do look after their cares.

The priorities for the future are more staff, more data collection, more service planning, better practice models and workforce planning. We are basing our views on voluntary assisted dying on our surveys. We did a national survey and then we did a statewide survey. The statewide survey showed that 65 per cent of our members say that there needs to be another option for dying. There needs to be something in place for voluntary assisted dying. We agree very much with the Victorian model that has been produced and is now in operation. We do not agree with it totally. However, we have made that clear in our submission. We expect that Queensland, being a forward-moving state, will move forward and start thinking about this seriously. We need to have a model of care for people who wish to die without going through the agony of palliative care without getting proper medication for the end.

CHAIR: Thank you very much, Ms Somerwil. You have articulated very well some common themes we are hearing. I see a strong alliance between those at the table now—that is, sending a clear message around the awful situation of 127,000 Queenslanders still waiting to access their home care package. We thank you for your commentary and for your survey in relation to VAD. The committee has been tasked with another piece of work, that is, to look at the Health Transparency Bill, which looks to increase nursing hours in our state-run facilities and puts the impetus on the 459 private sector providers to publicly notify their staff-to-patient ratios. Do you think that would be a good step forward? We are yet to explore it. We have a bit of work to do.

Ms Somerwil: We have petitioned for a few years for nursing ratios in aged care. We were very pleased to find out that this may finally happen. We hope that the private facilities take this on board and implement the same thing. We realise it is much more difficult with private facilities, but we are very pleased that this has happened with Aged Care Queensland.

CHAIR: We look forward to your submission on our next piece of work. We will now move to Dr Michael Wynne from Aged Care Crisis Inc.

Dr Wynne: As I indicated to the committee yesterday, Aged Care Crisis is an advocacy group that collects information about aged care, analyses it and advocates for change. My own interest is in dysfunctional systems. Very often these are driven by dedicated and enthusiastic people who believe in what they are doing and are proud of their accomplishments. Systems with a mission are not very receptive to criticism, and this makes dealing with these sorts of situations quite difficult.

We have had 21 years of this sort of reform that we have been going through. It clearly has not worked. I think it is clear that it is not going to work. It has been getting steadily worse. I make the other point that a system that depends on regulation for its legitimacy—and we are always being told that we have a well-regulated system and that is why it is working—is a failed system and is not working properly. Changes that focus only on more regulation are misguided and any benefit is likely to be temporary. We are pressing for changes in the structure of aged care that address the perverse incentives and the patterns of thinking that make them legitimate.

This inquiry is examining palliative care. The most important issue there is adequate staffing to provide that care. I want to look briefly at why we are in this position. It is a bit of an elephant in the room that does not come up at committee inquiries. When aged care was turned into a competitive market in 1997, the bulk of funding was coming from government and therefore was relatively fixed. Profitability comes from competing to reduce costs. About 70 per cent of the cost of aged care is staffing. Government, at that time, was very keen on fostering competition and it abolished all financial accountability and all staffing requirements. Soon after that we had workplace representatives, the unions, complaining about poor staffing and inadequate care. They resisted staff reductions.

As a consequence, the sector was not as profitable as large investors expected it to be. For instance, DCA was not doing as well as they expected and they had invested a lot of money. The big banks and private equity held off and did not invest. In 2005 the government encouraged investors by passing the WorkChoices legislation. Private equity and investment bankers were soon scrambling to buy aged-care organisations. In 2007 a study done by Melbourne university documented the decline in staffing. A policy of competitive corporate consolidation in 2014 increased pressure on staffing. I think almost every inquiry has shown staffing problems.

The perverse incentive created by the need to keep staffing levels low in order to be competitive I think has been the elephant in the room at every inquiry. No-one wants to talk about that. There are also major cultural conflicts between the caring culture and the culture of competitive markets that makes the sector unpopular for trained nurses. That leads to a high turnover. I tend to think of the aged-care system as an Alice through the looking glass system, because everything seems to be the opposite of what we knew before it was introduced. These policies have really failed in other countries and they knew about them.

I am not going to go through all that, but I would like to talk about the fact that caring for the vulnerable in our community is one of the things that we do in order to give expression to our values, to learn to be altruistic, to build social capital and to become a union. As a community the involvement in that sort of thing is very important for building social capital. If you want insight into that I point out that Professor Michael Fine has written a very good submission to the royal commission about home care and asks for some of the reforms to be reduced because they are having such a big impact on the volunteer sector and the social capital that has been built up in the community around this. We are seeing now many franchising groups and other very profit focused entities entering home care.

This is not to advocate for a socialist system, but to press for one where we use our knowledge to develop the sort of markets that work in the sector. Some category errors were made in applying this sort of market to the sector. We really think we should try to fix that. We should start with the road map that points in the right direction, because it is not an easy change to move ahead with.

CHAIR: Thank you very much, Dr Wynne. I enjoyed your contribution yesterday as well. Perhaps there is a profit-before-people mentality from the corporates that operate some of the larger residential aged-care facilities. Is that a view that you would share?

Dr Wynne: Yes, I think that is so. It is the pattern of thinking that they have. They see it that way and that dominates. There are all sorts of psychological and social strategies that people use in order to justify the things they do. When there is not anything counter to that, then these things happen.

If you go back to what Adam Smith—the founding father of economics—says about the role of markets, it is that governments should not get into bed with the market. There are two conditions that are necessary for a market to work effectively. One is an effective customer. In health and aged care we do not have an effective customer. We have very vulnerable people. The other thing is that the community that is involved is actively involved and sets the limits of acceptable conduct. That is really what we are pushing for—creating a community context where the community has a considerable say in who and how the system operates and the way care is provided so that they are able to provide a check on the market. That releases the staff. When they are under pressure from the managers and big business, they really have to conform. If they have a community that is arguing and confronting the managers all the time—this happens in health care with the medical professions—then you can check that side of the market.

CHAIR: Thank you, Dr Wynne. I will go back to LASA for commentary on that media release. The committee has been down on the Gold Coast for the last few days looking at Earle Haven and the complexities around the contracts, the subcontractors, HelpStreet, People Care and the owner, which resulted in 70 vulnerable people having to be relocated. LASA has put out a media release. Tim or Chris, can you talk to the key findings in relation to a survey that you have recently done?

Mr Hicks: Thanks. I will talk to that. I should also note that I have a little bit of difficulty hearing the other panel members. I can hear committee members perfectly fine, but I did not catch what most of the other panel members said. I am noting that in terms of their contributions.

With that survey we did following Earle Haven and a range of other stories that we had been hearing through our membership regarding the risk of failure—people who had been approached by other services looking for somebody to take over and who were unable to do so—we thought that it was important to provide some quantification of the size of that problem and some of the impacts that it might have. We know from the government's own data that a significant proportion of residential aged-care services are making a loss and are under significant financial pressure. The purpose of this survey was to understand the consequences of that in a little more detail.

One of the key points is that conditions have become worse—I do not think that surprises anyone—and that they are expected to get worse in the next 12 months if nothing substantial changes in the policy environment. Already we have four out of five organisations agreeing that funding constrains their ability to deliver the care that their clients expect. Some of the descriptions of what that means include constraining their ability to offer choice around meal options, limiting the staff skills that they are able to employ and creating an excessive workload that results in staff burnout.

If conditions do not improve, we had 15 per cent—and this is at a provider level, I should say, so some of these organisations are residential care and home care—saying that it was likely or very likely that they would have to close services in the next 12 months. We had 41 per cent saying that it was likely or very likely that they would have to reduce direct care staff. Fifty-two per cent said that it was likely or very likely that they would have to reduce non-care direct service staff. Fifty-five per cent said that it was likely or very likely that they would have to reduce back office staff and around 60 per cent said that it was likely or very likely that they would have to reduce investment despite the enormous growth in the number of older Australians needing care.

We also asked providers whether they had been approached by other services asking to take over those services or their clients in the last 12 months. Thirty-two per cent of respondents said that they had been approached. Only 13 per cent had actually said yes. The problems that they identified were 70 per cent financial risks and 66 per cent quality problems.

I think that illustrates—the key message out of that—is that, whilst there are long-term structural issues that we need to address in the industry, we also need to pay attention to the short term. While the royal commission and other inquiries are underway, we need to put the sector on a stable footing so that they can continue to deliver care to the people who are in their services right now.

CHAIR: Thank you very much for that, Tim. In our travels we have heard from private providers on a range of issues about funding that they have received. Some have indicated that they will receive a portion of money per day per patient that is significantly away from the actual cost of delivering care, paying for facility maintenance and nursing staff. Some figures were around \$180 a day were received but the actual cost is around \$240 a day. Do you have any comment to make on that?

Mr Hicks: That is absolutely consistent with what our members tell us and, frankly, it is what the sector has been telling the government for a long time. One of the structural problems with residential aged-care funding is that there is not a link between increases in costs, like wages, and the amount of funding that the government provides. This is something that the Productivity Commission identified as a problem way back in 1999 or the early 2000s. They said that it was a deliberate choice by the government to encourage productivity—and productivity is important, because we want to make sure that we are getting the most care for the dollars that we spend—but, given the other constraints facing the sector, the inability to vary their prices or their service bundle, the lack of a link between cost and funding was always going to drive risks and I think that is part of what we are seeing today.

CHAIR: Further to that, some of the information shared with us was that, over the past five or six years, there has been if not a percentage increase that matches CPI, which is nowhere near it, they have had a one to 1.5 per cent increase annually, or none at all. Is that something that you would be familiar with as well?

Mr Hicks: That is absolutely a concern. Cost drivers are more complex than just wages. The mix of residents and various other factors affect the service cost. There are ways that services can improve efficiencies and that varies from one service to another, but there is a very high level of award reliance within the aged-care sector and a lot of enterprise bargaining agreements are award linked. When the minimum wage and award wages are going up by three per cent and have been for several years, but the indexation of subsidies is just over one per cent—between one per cent and 1.5 per cent or, in fact, in one year it was frozen at zero—that is going to have obvious consequences for either the finances of the sector or the services that they deliver.

I should make a comment here about profit and surplus. I come from an economics background. The way that economists look at these things is that you have two inputs into the delivery of a service. You have labour and you have capital. Capital can be lots of different things. It can be intellectual property; it can be physical capital. The surplus of an organisation, whether that is profit if they are a for-profit organisation or a not-for-profit organisation, is what they receive to pay for the capital that they need to deliver their services. The wages that staff receive is what the industry pays for the labour input. Both of those things, I think we all agree, are manifestly inadequate at the moment.

CHAIR: I suspect I will get a lot of head nodding from the people in front of me right now, but I pose the question of how do we fix this. This would be an immediate injection of funding? Someone said earlier—I think it was Mark Tucker-Evans—about reducing the wait time of those 127,000 people to three months instead of three years, so that people get their funding packages far quicker. Yes, I am getting some nods.

Dr Wynne: Can I make a comment on that?

CHAIR: Yes.

Dr Wynne: I would just like to go back to perhaps what is a slightly comparable situation in the USA. In the 1990s, there was a lot of rorting and they had a large amount of money and there was an enormous amount of consolidation. With that increased stream they borrowed an awful lot of money. When the government cut back on that funding, they almost became bankrupt because they had those loans to service. A lot of them went into chapter 11 bankruptcy. The government was prosecuting them for fraud and it basically had to step back and re-fund them. They were virtually in a position to extort the government into having to re-fund them.

I think we need to look at what happened in 2014-15 when there was a lot of money put into aged care with the bonds and additional funding. There was also what was called maximising—a lot of money taken out—and the government cut back. I do not know enough about the finances of this and how much borrowing there was and how much of this deficiency has been a factor in what is happening. Our position is that we do not know anything because there is no transparency. Until we know where the money is going, we should be very wary about putting in money. We need transparency. If we look at the data that we are getting, there is not any data in aged care. We know that we have a 40 per cent to 80 per cent incidence of malnutrition, whereas the international figure is about 20 per cent. We are not performing well by international standards by any extent.

CHAIR: Thank you, Dr Wynne.

Dr Wynne: We need money—obviously so—but I think we need transparency.

CHAIR: Thank you very much. That was well articulated. I open up to questions from the committee.

Mr BERKMAN: Thank you so much for being here. This is quite a panel of peak bodies and experts. I want to touch firstly on the LASA survey and the media release before moving on. If we can read between the lines of what the respondents have said and extrapolate beyond the current point in time—obviously, we have been looking at Earle Haven for the last couple of days and that is a fairly specific circumstance around the subcontracting of the provision of care services—these results suggest to me that we are going to see more of those kinds of circumstances emerging if something really drastic is not done very soon. Does LASA or any of the other panellists have observations on that assertion or possibility?

Ms Edith: If I could make a comment? Certainly, I have listened to the Earle Haven hearings that you had on the Wednesday but also read that information. LASA, like everyone else, was horrified about what happened with Earle Haven and People Care. However, I believe that it was quite a different situation. It was very much a contractual issue between People Care and HelpStreet. It may or may not reflect the similar issues and the funding issues that our providers are facing, but I believe that it was a separate issue and it was something between HelpStreet and People Care. People Care is the approved provider. Under the Aged Care Act, they are ultimately responsible for what happened in that home. There seemed to be a number of failings that happened by that approved provider. While I understand that it, obviously, was extremely difficult and there was the response from Queensland Health and the Ambulance Service, yes, there will be continuing issues for our providers but I believe that one was quite distinct.

Mr BERKMAN: Rather an extreme circumstance?

Ms Edith: Yes.

Mr BERKMAN: They are really striking figures—15 per cent of respondents saying that it is likely or very likely that they would have to withdraw services if conditions do not improve in the next 12 months. That is a real concern for me. While I have you all here, I want to zoom out a little bit if I can and refer to some of the observations that we have heard from Dr Wynne this morning and look more broadly at the reliance on markets for the provision of what is clearly an essential service for our ageing population and the neoliberal political and economic underpinnings of that at the moment. Do any of you have observations as a reflection of what Dr Wynne said this morning? What does the commodification of care mean and that conflict between a market that is set up to pursue profit when, in fact, we are dealing with fundamental needs, essential services and care for a growing proportion of our population? I will just throw that to all of you at once.

Dr Green: Home care, I think, has been the modification that we have been moving towards. Home care is very good in the right circumstances. However, you do have to look at where the money is going. You find that a lot of the providers are taking up to 50 per cent of that money for administration. I do not have a background in business, but that seems to me to be an awful lot of money for them to be taking just for doing the case management. In many cases the families could do that management themselves without the administration. That might help a little bit, but you have to look at elder abuse and families taking the money—those sorts of things. There are pros and cons that have to be taken into consideration.

It seems to me, being an elderly person myself, that most elderly people, if they are able, would prefer to stay in their own homes, but they do need a lot of support to do that in some cases. When they have lost mobility or maybe dementia is starting to set in, they need almost 24-hour care. That is one pathway that could be taken, in my opinion.

Mr Tucker-Evans: I think one of the good things that has come out of the aged-care reforms is in fact the focus on the consumer and trying to meet the consumers' needs. The terminology is 'consumer directed care'. It is putting the control in the hands of the consumer. As Marjorie has said, the vast majority of older people do want to continue living in their own homes. We need to work through a system that not only recognises the importance of families and friends in the care process but also ensures that we have services that are meeting those needs where the consumer wants them.

It is about that integration with the healthcare system. This is where I think some of the issues arise. We have the federal government funding the aged-care system. We have the state government funding the hospital and health services. Often we have residents of aged-care facilities who are transported to hospital unnecessarily when in fact the residential aged-care facility is now their home. It is about how we coordinate and integrate those services.

Dr Wynne: We have not paid that much attention to home care, but it is an issue. I think the problem with consumer directed care is that it gives the person a sense of control over their lives. That is an advantage, but it does not seem to have improved the standard of care. In fact, both in the UK and here it has been more expensive. It has taken more money out of care. In the UK it has resulted in a very unequal system, and I think the same is happening here. We are short of money and it needs to be rationed in a sense. You have to spread it out to where it is most needed. Consumer directed care does not seem to work particularly well in that regard.

If you look at the UK you will find that at least two of the people who were involved in that process have come out against it and have been very strongly criticising it. Simon, the chap in charge of the Centre for Welfare Reform in the UK, has been very critical of it. He was originally involved in running it. His criticism was that it ought to be a community activity and not be too tightly controlled. In other words, the community should be controlling it and handling it, not the administration.

The other guy who has been writing about this is Slasberg. He is critical of the fact that it has not been working properly. Some people have a lot of money; other people do not have anything. I think we are seeing the same happening with consumer directed care here. I know Michael Fine is quite keen on keeping the block funding system going because that is handled by local people, and it is distributed to where the need is greatest. What seems to be happening with consumer directed care is that some people are getting money and not using it all, whereas other people are not getting any.

I think we need to be a little cautious about the direction in which this has been going. I appreciate the reason for consumer directed care, but I think there are issues that suggest that it is not working as well as perhaps it should.

Mr Tucker-Evans: Chair, I think it comes back to your point about health literacy. We need well-informed consumers to manage their own health. I, too, am an ageing person. I think from that point of view we do want to be in control of our lives for as long as possible, but we do need support to be able to do that.

Dr Wynne: Choice and control is a driving force for market, but I just make the point that in the UK again a lot of people do not exercise that. By taking it through community you are not taking people's choice and control away. You are providing it within a context where there are relationships and you can be guided in the choice that you make. I do not think the two things are incompatible.

Mr BERKMAN: I would like to ask more, but I will back away now.

CHAIR: Thank you, member for Maiwar. In the interests of time, I must move to the deputy chair for questions.

Mr McARDLE: First of all, Chris, you mentioned that you can give us names of other aged-care services or homes that do provide a wellness exercise regime. Can you take that on notice and get back to the committee to provide those details, if you don't mind?

Ms Edith: Absolutely, yes. I would like to make a comment in relation to the home care providers. There has been a lot of work done recently by the Australian government to increase transparency around the fees and charges that are being held. Again, I think we also have home care providers facing unprecedented financial strain at the moment with the cost of providing care and case management. Again, we know that many, many of our members and home care providers are

out there providing case management extensively to consumers who may even be saying that they can self-direct their own home care package, whereas in fact the additional care and services that they are providing quite often to these vulnerable people have an increased cost. There is still that increased cost for home care providers. I would also say that for the majority of the providers the profit margin is not there to make a profit; it is really there to provide the care.

Mr McARDLE: I want to look at two statements. One is contained in the National Seniors paper, which says—

The population of Queensland is expected to increase from 4.8 million in 2016 to 9.5 million in 2066. The proportion aged 65 years and older will increase from 14.7 per cent of the population to between 23.8 and 25.8 per cent over this period.

A quarter of us are going to be by that time over 65 years of age. The QNU in a submission to the committee identifies a study in 2017 which says—

The proportion of those aged-care residents requiring high levels of care has dramatically increased from 13 per cent in 2009 to 61 per cent in 2016.

We are dealing with a completely different dynamic now as opposed to 30-odd years ago. It just strikes me that we are looking at a system that may have functioned at a level higher than it is doing today, but we are not looking at new models of care. My concern is—and remember Einstein's idea—that if you think you are going to get a different result by doing the same thing over and over again you are the one who is crazy.

When we look at engaging by putting more money in—and certainly I agree with the packages coming online much quicker—I do not think that that model is going to work in the future. I think this committee should be looking at innovative, new, progressive models of care, because I do not think the current system extending into the future will do anything else but collapse. I point to Bupa, which has just made the headlines. Also, Aged Care Crisis in the media release makes it quite clear that to remove their registration as an approved provider would be 'catastrophic'. Can I get some comment from anybody on what do we need to do to move from what is deemed a broken system now to a new model of care that we have to have? What do we need to do?

Mr Tucker-Evans: There is some work that is currently being done in the Metro North Hospital and Health Service area, along with the Brisbane North PHN that is looking for alternative models of care. Chris mentioned in her statements the work that the Brisbane North PHN, which is an Australian government funded organisation, is doing in terms of staying healthy at home. It is working with other organisations, including COTA Queensland, to make sure that there is a different model of care. It is that reablement model that some of us have spoken about. There is also work being done in partnership between the HHSs and the PHNs in looking at different models of care. I absolutely agree with you, Mr Deputy Chair, in that we cannot continue to do the same because the proportion of the population that will need aged-care services is increasing.

Mr McARDLE: I apologise for interrupting you, but can somebody give the committee details of what that work is, because I do not know that we have it here at this point in time?

Mr Tucker-Evans: I can certainly provide some of that, but Queensland Health or Metro North HHS would be able to do that.

Ms Somerwil: Can I suggest that you look at what we have suggested in our submission. There are models available proposing that there are different ways of looking at aged-care services. We are using the model from Hogeweyk in the Netherlands and also Denmark where they have different ways of looking after older people. We realise that this works in very well with hospital services in the state, but they are different models that are being produced overseas. The University of Tasmania has its own model there. They have introduced a model of aged care which is under trial now. They are looking at introducing a new model of care for older people in aged care, so there are other places to look at.

CHAIR: We are all moving to Tasmania.

Ms Edith: Providers out there in the community at the moment are looking at alternative models of aged care. There has been a big focus now on ageing in place and people choosing and preferring to stay at home. Also, one of the other issues with people staying at home is that you can have increased social isolation. We need a multipronged approach at the community, state and federal level where aged-care services become more of a seamless process through good financial planning and good health care—wellness and reablement models promoting what people can do from that strength based approach. That, I think, will assist people transitioning into healthy ageing.

I think we forget sometimes that the good stories are that we are living longer. We are living better than we were in the past. I was at the Brisbane North aged-care forum yesterday. We had consumers there who are in their nineties who are still actively involved in society. I think we need to keep having those conversations promoting those good stories as well.

Mr McARDLE: Dr Wynne, that goes back to your comment yesterday. Community involvement actually includes the residents of aged-care services. They should be consulted on an ongoing basis and have some sort of authority—I use a broader term than that—as to what takes place inside the organisation. Would you agree with that?

Dr Wynne: Yes, definitely. We are never going to have enough money to do everything we would like to do. That means that to some extent you are going to have to do some sort of rationing. A purely market system is always going to be accused of rationing for profit and often will do, otherwise they will not survive. This is one of the other reasons why you need community to be involved so that they have some say over the way the care is rationed and what is provided and what is not provided. Otherwise you are going to have a community who gets very angry about it again.

Mr McARDLE: Dr Wynne, you referred to profits before people being the mentality. That might be my precis of your comments. That seems to be a global approach in that our society is more directed towards the individual making a profit than the care of the community. Would you agree with that?

Dr Wynne: I think it is very directed towards profit at the moment. We all think in terms of markets now. Basically, as I said, the neoliberal policy really was frightened of community. It pushed community aside. As a result we do not have that restraining community anymore. Civil society is poorly equipped to deal with the sorts of things we are suggesting it should. It has to be built up to do that. There are so many failures across the system. There are many areas where vulnerable people have been exploited and I think that is the problem that we are facing. Aged care is only part of that.

Mr McARDLE: The culture needs to change.

Dr Wynne: Yes.

Mr McARDLE: Can I go back to LASA for a second. The media release you put out and that was referred to by Mr Hicks had an attachment with a breakdown of how the sector looked at itself. Mr Hicks, you said 32 per cent of providers were approached to take on another service or its clients in the last 12 months, but only 13 per cent agreed to those requests. The line after that reads that if another service closes in a region that they operate in, 84 per cent of providers were willing to take on consumers and 87 per cent were willing to take on staff who had lost their jobs. I cannot reconcile those two statements.

Mr Hicks: The difference there is that it is one thing to take on clients and put them into your service or, indeed, to take on staff; it is another thing to take on an entire organisation as a going concern and resolve whatever structural issues that organisation is facing. I think that explains much of the difference in those figures. Partly it is also, I think, a reflection of the fact that in an emergency people will step up and do what they have to do.

Mr McARDLE: Thank you for that. My final question is this: going back to the QNMU submission, they make the comment that between the 2009 and 2016 period the proportion of qualified nurses fell dramatically, with the RN cohort reducing by 33 per cent and the non-nursing qualified staff increasing proportionally. What we are going to have is a workforce that, on those figures, is not as highly skilled as an RN or an EN. We also have real problems getting qualified staff to go to places like Longreach. How do we overcome that issue, because if we accept that we are going to require more and more high care, we are not going to have the trained staff, on those figures at least, to provide that ongoing care. How do we overcome that?

Mr Hicks: I think part of it is that there are different parts of care. Some parts of care require clinical expertise, some parts of care just require compassion and a willingness to help and work with older Australians. I probably should say that even those components do require an element of training and we see part of the solution as being a more highly trained workforce for the sector. Of course, as we expect people to have more training that is going to come at a cost, both for the training itself and because more qualified people will expect better pay.

On the issue of rural and remote, we can also get smarter and in many ways we need to get smarter because we are not going to be able to meet the needs of our ageing population just by doing more of what we have always done. There are solutions around telehealth to ensure that people in rural areas can access qualified staff. That is not just a registered nurse; it might be a gerontologist or somebody else. They can get access to that expertise remotely when they need it, even if there is not a registered nurse in the building, say, overnight. There are things that we can look into. The sector is already, in fact, looking into these sorts of solutions.

It is interesting, just to give another observation, that one of the comments we have heard from a couple of members is that metropolitan services actually learn a lot from the services that are operating in rural and remote areas, because the rural and remote guys have had to learn to do more with less. There are opportunities for improvements and efficiencies. We just need to provide the headroom for the sector to actually work on those issues.

Dr Green: Could I also make a comment about the staffing mix. Particularly again in residential care, I think the important thing to realise is that the majority of care and services provided on a daily basis are in relation to the quality of life and social support; it is not necessarily clinical care. We need a staffing mix that really is able to respond to the individual needs of those residents. That includes mixes of well-trained personal care staff and allied health, as well as registered nurses or other registered staff. There really is the recognition that the mix of staffing is what is important for those particular residents. For example, while we have people coming into residential aged care at a much older age and much frailer, we are also having another cohort of people in residential care at the moment who may be living with cognitive decline or alcohol and other drug related illnesses. They can still be very active and very fit, so they need a different model to somebody who perhaps needs stronger clinical care. We need to keep acknowledging that mix of staff.

Mr Tucker-Evans: I would support that too and we need to ensure that allied health staff are able to work to their full scope of skills.

CHAIR: I know we have gone over time. I am seeking a view or an opinion on one final thing. We have talked about transparency, we have talked about funding and we have talked about people accessing home care packages and a range of other needs in a timely fashion. Ought not the committee consider perhaps establishing an aged-care commissioner in Queensland to better follow the money, make sure that people receive timely packages and a range of other roles? Do you think that might be something that the committee ought to consider going forward?

Ms Somerwil: National Seniors would agree, because there needs to be some accountability with funding.

Mr Tucker-Evans: COTA would also agree. I think that in Queensland, because of its geography and demographic mix, the services cannot be designed from Canberra and I think that there needs to be somebody who actually takes an overview.

CHAIR: Tim, on the phone?

Mr Hicks: Would Queensland benefit from having a commissioner? It is always useful to have more people providing scrutiny in an important area like this. The challenge that we get, of course, is that once you start getting overlapping jurisdictions that can create its own gaps. One of the other points that I would make is that there are advocacy services available for older Australians that are provided through the Older Persons Advocacy Network. One of the things that the committee should consider in determining whether or not a statutory commissioner is needed or is appropriate would be whether those resources would be better directed to providing more funding for services like OPAN.

CHAIR: The committee thanks you. The committee is now far better informed. We could keep you here all day. Thank you for your advocacy for older Australians. Thank you for your views on all parts of our broad inquiry and your time here today.

CURTIS, Ms Anne, Engagement Consultant, Health Consumers Queensland

FOX, Ms Melissa, Chief Executive Officer, Health Consumers Queensland

HARDY, Dr Fotina, Queensland Branch, Australian Association of Social Workers

KNIGHT, Ms Ros, Australian Psychological Society

CHAIR: Thank you all for being here. I will ask you each to make an opening statement.

Dr Hardy: Thank you so much for having us here today. I would like to start by acknowledging the traditional owners on whose lands we are meeting today. As a member of the professional body representing social work in Australia, I thank the committee for inviting me here today on behalf of our social work members here in Queensland. Our written submission highlighted the key areas and issues we felt were pertinent to this inquiry and was based on consultation with social workers practising in health, aged care and palliative care. In my statement today I will emphasise some key principles and provide a snapshot of how we hope the outcomes of this inquiry can make a real positive difference in the lives of Queenslanders, because that is what we are all here about.

Our views on aged care, palliative and end-of-life care are informed by a rights based framework that supports the diverse and wideranging groups of individuals that this inquiry is covering. We really wanted to focus on aged care in our statement. We have seen through the royal commission and through last night's news media that what we are doing is not enough and it is not good enough. Missing in the current aged-care system is an explicit and fully implemented rights based framework that has at its heart meeting the rights and needs of the individual. The current model of care is inextricably linked with funding models that can prioritise organisational imperatives over individuals, with the result being a loss of dignity and quality of life for many Queenslanders. Our focus is particularly on the limitations to supporting people's psychosocial needs and wellbeing, along with equitable access to services and care. Limits to staffing numbers, as we have heard, and their qualifications to provide psychosocial support create inequities to receiving the quality of support and care people need and deserve.

Social work is an important part of the multidisciplinary team that provides specialised support and services to older people, their carers, families and community. Yet social workers are not a core member of many services providing support to older people, particularly in aged-care facilities. We cannot overstate the importance of equitable attention to the social determinants of health with regards to emotional, psychological and social wellbeing, which includes access to services.

To illustrate how the current system could be altered to improve outcomes for people, we would like to share a story with you. I will indulge you in a very short case study. This is about Frank; it is not his real name, but it is based on an amalgam of real-life people social workers we have spoken with have supported. We hope that this gives you a stronger understanding of why we are advocating for the important need for increased equity of services, a rights based framework that includes an understanding of dignity of life and of risk, and the importance of social workers being part of a service model of care in the community and aged-care facilities.

Let us meet Frank who is aged 78. He lives alone in a two-bedroom unit where he has lived for the past 15 years. His wife died 15 years ago. He has a son who lives in Townsville, but they do not talk much. Frank loves sitting on his small patio and watching the comings and goings on his street, walking the short distance to his local shops most mornings and playing cards with his neighbours every Wednesday afternoon. One day Frank is admitted to hospital after a fall when no-one was around. He broke his arm and cut his cheek. While in hospital the medical team did their tests. They explored his dizzy spells and his general fatigue. They reviewed his medication. They talked about all the things that he needs to do. They also assessed to see if he could manage independently at home alone with his broken arm.

More than anything, Frank wants to go home. As Frank's length of stay in hospital increases, his function declines. Even though he has access to a whole range of different Queensland initiatives like Eat Walk Engage, which focuses on a collaborative model of improved care, he becomes agitated and confused by his unfamiliar environment, the changing staff and the delay in his desire to go home. He feels lonely and isolated from his community. He becomes despondent and uncommunicative. Frank meets Alice, his hospital social worker, who gets to know him well, his preferences and wishes, and attempts to advocate on his behalf to go home as soon as possible with a transition care package. However, they need to wait for him to become medically stable, which takes a few more days. He is assessed by the aged-care assessment team for a transitional care package and he is assessed as level 3-4.

Frank has another fall in hospital and becomes even more deconditioned, which is something that can happen when people are in hospital for long periods of time because they lose independence and confidence in their abilities. The team no longer feels Frank's discharge plan is adequate and believes he should not return home without supervision, despite his clear desire to do so and his understanding of the risks identified by the medical team. He is insistent, but then Alice looks at how quickly he can access transitional care packages and she is advised that it can take between one to two years at the very minimum, as we have already heard.

The only other option is respite care, because Frank's son has advised that he cannot care for his dad. This involves organising an EPOA, as Frank needs that before entering residential aged care, his will and the complex financial details of selling the house and all that kind of stuff. This has to be negotiated between Frank and his son really quickly. Frank talks about feeling disempowered as he has to make important decisions in a relatively quick period of time so that he does not continue to take up a bed in hospital, whilst also trying to work through years of issues with his son.

Frank enters the first available facility. He does not have the opportunity to visit first and make a decision. He arrives late in the evening as he had to wait for the ambulance to transport him. His belongings from home have not yet been moved in. He arrives in a room devoid of familiarity. He becomes despondent. While there, Frank becomes increasingly isolated, lonely and depressed. His connections with his friends and neighbours are cut. No-one really has been able to tell to him about what has happened. The staff in the facility are caring, but they are busy and they are focused on his medical needs and keeping him supported through group activities. He is missing psychosocial support to focus on his emotional wellbeing, his grief and loss associated with the transition and significant life changes. Frank ends up being prescribed antidepressants, and his health and wellbeing decline further. This story is not unique; it occurs every day.

We ask you to consider a different reality—a reality where Frank has access to a different model of care. It is a model that redistributes services to community resources, so that it allows hospital healthcare to prioritise the acutely unwell. It focuses on preparation, prevention and community engagement frameworks seeking to minimise isolation, raise social connectivity and put health professionals like social workers in the home. It moves frontline services away from avoidable hospital admissions. It promotes autonomy and the right to make the decision to return home, even if the medical team is concerned for your wellbeing, that is, it treats people like thinking adults who can make informed decisions about themselves and has the community backup to support them. Despite its best intentions, it minimises risk averse practice. When someone does enter aged care, it has appropriately qualified and experienced staff such as social workers to support the significant transition and the associated grief and loss suffered. Above all, the model should be truly person-centred, which means focusing on the dignity and worth of older Australians who have the right to be treated with respect and compassion.

If such a model were in place when Frank came to hospital, he would have been discharged home with support scaffolded around him from a multidisciplinary team of health professionals focused on his health, wellbeing and psychosocial care needs. Such a model is necessary if we are to achieve our aim of ensuring the dignity, autonomy and quality of life of people, which in the long term also has great economic benefits. It is the right thing to do. Thank you.

CHAIR: Thank you very much, Dr Hardy. Your case study was well articulated. You mentioned Townsville, which is where I am from. It is not an unusual situation. In my former career of transporting people to residential aged-care facilities, I have seen that and it is overwhelming. I think that case coordination or a co-ordinated level of care is needed and perhaps a whole-of-government approach in that health space. I also note, importantly, on page 8 of your submission, that 37 per cent of people aged 65 and over speak another language, which is evidence of the culturally and linguistically diverse backgrounds of the population in our great state of Queensland. If Frank speaks another language, his case becomes altogether an even more distressing situation. Support around our diverse community is also equally important.

Dr Hardy: Absolutely. It is such a problem when you have people, whether they are in hospital or in aged care, whom people do not understand and so they cannot communicate. Their needs are not met—absolutely not met—and that is a real problem.

CHAIR: When people are sent straight to hospital for acute care by medical and nursing staff—and you articulated this well—we sometimes forget the role that social workers play in navigating the system. In the nation there are 11,000 social workers. How many are there in Queensland?

Dr Hardy: We have over 2,000 members. Not all social workers in Queensland are members, so there are more than that.

CHAIR: I thank you for the work that you and social workers do in this state. It is perhaps sometimes a forgotten role, but it is equally as important as the first line of care. Thank you for your submission and your commentary today. I welcome Melissa Fox from Health Consumers Queensland.

Ms Fox: Thank you, and thank you to Dr Hardy. It is a bit of a challenge to speak after that moving case study. I think that it showed really clearly that the system needs to change. Thank you for the opportunity to speak again to the committee. It is always a pleasure. I start by acknowledging the traditional owners of the land on which we are gathered and pay my respects to their elders past, present and emerging.

As you know, Health Consumers Queensland is the peak organisation representing the interests of consumers and carers. We are focused on consumer engagement and support to help develop a health system that meets the needs of Queenslanders. In addition, we listen carefully to what we hear from our members in our statewide network around the subjects and issues that are of most interest to them and on which they would like to see action. We have welcomed the opportunity to engage deeply beyond our network on these issues. We commend the department for resourcing the work that we will describe today. There has been intensive engagement with over 400 Queenslanders to inform the work of the department, yourselves and our organisations.

Along with COTA Queensland, Palliative Care Queensland and Carers Queensland, partnered with Clinical Excellence Queensland within the Department of Health, we undertake consultation with consumers and carers on what matters to them in relation to ageing, end-of-life care and dying. I now hand over to Anne Curtis, an engagement consultant on specific projects with Health Consumers Queensland, who has developed our methodology around these consultation mechanisms and led this work for us.

Ms Curtis: Thank you, Melissa. Our aim in this project was to reach a significant number of consumers, carers and community members with varying levels of health literacy and those who are not engaged with health services to inform on what they identify as priorities in relation to ageing, end-of-life care and dying. We wanted a process that was inclusive by hearing the voice of people, including rural and remote residents, Aboriginal and Torres Strait Islanders, those who are culturally and linguistically diverse, those who are hard to reach and LGBTIQ people.

To enable this, the first phase of the consultation involved recruiting 20 consumers and carers to host kitchen-table discussions in their own communities. Kitchen-table discussions enabled people to be consulted in a safe, informal and friendly environment, so being in that environment it was very hands off from us and health professionals. Each host was provided with the same set of five questions and each would invite up to 10 participants to attend a 90-minute discussion in a location and at a time that worked for them. The 20 consumer and carer hosts consulted with 183 community members in 12 rural, remote and regional locations across Queensland and eight Brisbane locations over a two-week period in March this year. We presented the outcomes of the kitchen-table discussions to Clinical Excellence Queensland in April. We understand that was also passed on to this committee. Our submission to the inquiry was based on the feedback from those discussions.

We then conducted a second phase of consultation that involved facilitation of 16 focus groups across the state, again with consumers and carers. Twelve were facilitated in rural, remote and regional locations and four in Brisbane, with one session specifically for people who identify as Forgotten Australians. This time we reached an additional 200 people, which included the voice of a group of Mackay High School students who also wanted to answer the questions. The outcomes of this consultation resulted in a second report to Clinical Excellence Queensland, as well as a graphic representation of the key messages. We understand this has also recently been provided to the committee.

The many messages we heard throughout the consultations—and there were many, but I have cut this down—as people age or towards the end of life, they want to stay at home with the support and resources to be cared for in the home. They want to remain independent for as long as they can. They asked for access to quality and timely care and support, and also access to care packages, which was identified by some as an issue, with some commenting that their loved ones had died before they had received a package. If they cannot remain at home, they do not want to go into large aged-care facilities. They would like to remain in their community, in care homes containing up to six or eight beds. Rural and remote people do not want to leave their communities.

People who identify as Forgotten Australians are fearful of being re-institutionalised into residential aged-care homes. The hard to reach, the disadvantaged and those without family to care for them felt that they had no choice but to go into residential aged-care homes.

There is a real need for better, more simplified and accessible information and knowledge as to what services, options and choices are available for care. People talked a lot about the need to understand what choices and services are available. Navigation and service coordination are also issues facing patients and families. There were multiple requests for the introduction of a nurse navigator role to support patients and families to navigate end-of-life and palliative care access, information, choices and support services.

In relation to palliative care, they asked for increased palliative care services and the number of trained palliative care staff within hospitals and aged-care facilities, and to provide care in the home. These requests were statewide consistent messages, with many suggesting that there needs to be easier access to palliative care, more education and understanding of what palliative care is, better and more accessible information and improved forward planning. Another identified area of concern for consumers in relation to palliative care is the perceived lack of coordination between their treating specialists when someone is palliative. An issue for family members was that, due to this lack of coordination, patients with multiple specialists or care providers were receiving different information and treatment, resulting in confusion and distress. Families indicated they have to advocate for their loved ones to ensure their care is coordinated.

We did not specifically ask a question about voluntary assisted dying. However, throughout the consultation it was consistently brought up by the consumers and carers. There was strong vocal support for the introduction of VAD. Much of the conversation in regard to voluntary assisted dying was about the right to a dignified death and having the right to choose how, where and when they die. In addition, in that choice they want dignity to be maintained. For others, it was important to bring their family member home to die, not have them end their life in a hospital or aged-care facility. Many spoke about the need to legalise voluntary assisted dying and having the option available to them. Others supported it with the right safeguards in place.

There is acknowledgement that advance care planning needs to be acted on earlier. However, many people indicated that they struggled to know where to access information and the complexity of the forms, including advance health directives and enduring powers of attorney. Many people feel that we need to have the conversation about dying with family, friends and the community, and even start the conversation in schools. On multiple occasions people came to speak about the impact of their family members' advance health directives being overturned or not requested by treating clinicians. Communication between service providers and patients' families was highlighted as an issue.

Many people spoke about the lack of communication experienced by them, whether from medical professionals, aged-care home staff and support service staff, and/or the provider. They asked that they be involved, listened to and communicated with as the primary carer. Access to transport was a concern for many people, particularly those in rural and regional areas. For others, the lack of available transport leads to their isolation from community and family, and this was identified as a real issue for people in remote areas. All through this process we have heard the voice of over 400 Queenslanders who are very clear on what matters to them in relation to ageing, end-of-life care and dying. As much as there were many positive stories shared, the greater proportion came to be listened to and shared their challenges with the care received by their loved ones. The participants felt that this was an opportunity to share their desire to see systemic change concerning ageing, end-of-life care and dying.

Ms Fox: If I can just finish, briefly. It has been an incredible opportunity for our organisations to hear from so many Queenslanders on these important issues. I would like to thank everyone who did take part in our consultations for speaking about what can be upsetting and difficult issues. Health Consumers Queensland and the other organisations that partnered on this project believe there is a need for the aged-care system and the health system to accelerate and upscale the work that is already being done, in some cases in partnership with consumers, carers and families, to redevelop and re-think aged care, end-of-life and palliative care services in Queensland to better meet the needs of our communities. Rather than rationing, it is about making the better use of our resources to ensure that the care that is delivered is consumer centred, safe, efficient, value based care and as close to home as possible.

CHAIR: Thank you very much, Ms Fox and Ms Curtis, for your contributions today and for the work of Health Consumers Queensland. I feel like we have followed each other around the state.

Ms Curtis: I feel the same.

CHAIR: You have touched on some very important points that we have heard. The committee has travelled, starting in Far North Queensland. I come from the regions myself. We have met with Indigenous groups in Mossman, Cairns, Mount Isa, Palm Island and Townsville, just in that Far North Brisbane

catchment alone. Consistent themes were heard from Indigenous and Torres Strait Islander communities about their wishes not to go into a tertiary hospital but to die on country surrounded by family, and the need to start having the conversation early. Health literacy is vital. It is also the complexity that you have highlighted with the advance healthcare directives being burdensome and overly heavy to navigate. Queensland Health has a statement of choices and we are looking at other jurisdictions in terms of how they can make it easier to understand, which is so important. It is through organisations such as Health Consumers Queensland—and I have said it publicly before with AMAQ—that 50 per cent of 50-year-olds have their advance healthcare directives completed early. I am probably repeating myself, but we tend to leave it until a time of crisis. It is an incredibly complex thing to do in terms of respecting people's wishes. I want to thank you on the record. I do not know how we can do that better, unless you have some models of advance healthcare directives from other jurisdictions that the committee might find useful to consider going forward. That is one aspect that I thought was important. I will let you think about that and then we will come to questions. Welcome, Ms Knight.

Ms Knight: Thank you for the opportunity to present on behalf of the Australian Psychological Society. Like my colleagues to the right, I would like to acknowledge the traditional custodians of the lands and pay my respects to the elders past, present and emerging. I would add to that an acknowledgement that, for many Aboriginal and Torres Strait Islander people, the need to maintain or return to country towards the end of their lives is very important.

I know that the committee has our submission. I start by saying that I agree with all of my colleagues on the right. We speak to some of those issues in our submission, so I will skip over those now and come directly to the psychologically relevant ones. We also are about to submit our submission to the Royal Commission into Aged Care, Quality and Safety, which contains much more depth on some issues. If you would like that to be forwarded to you, we are happy to supply that as well.

CHAIR: Yes, that would be great.

Ms Knight: For those who do not know, the Australian Psychological Society represents 24,000 out of 30,000 psychologists around Australia, of which 4,000 live in Queensland. I note also that only 46 psychologists in Queensland consider them specialists in this area. That comes to my first main point, which is that psychology's involvement in ageing, aged care, palliative care and other areas has been very difficult to get established. We would see that the main psychological issues in very broad terms are around suffering, fear of suffering, experiencing suffering, control, the ability to make your own decisions and the ability to decide what will happen to you towards the end of your life. If I can speak to where psychology fits into those broad churches, we have a lot to contribute that just might help to tailor things to an individual, thereby saving money and improving their life quality for whatever time period remains for them.

I will touch on a few areas where we have the capacity really to help in these domains. First of all, diagnosis of disorders. Clinical neuropsychologists, of course, specialise in diagnosing dementia and separating out dementia from depression, other delirium and other issues that can occur. However, getting an assessment is really difficult when somebody is entering that end-of-life phase. It is not covered by Medicare, so even if they are in their own home sorting out exactly what is going on and what medication, if any, would be appropriate can be quite expensive and, therefore, is underutilised. In aged care in particular, it is about sorting out who is depressed, who is anxious and moving away from the assumption that, 'Of course they're depressed and anxious; they're old', and that that should be okay. We need to help them to work out and to deal constructively with their feelings around being at this part in their life, and to identify when it has become a psychopathology issue that should be addressed using not just medication—which of course the committee would know is often the go-to—but rather therapeutic techniques like CBT or supportive therapies to help the person manage those feelings that they experience. Of course, we are experts in behavioural management and therefore for the concomitant behaviours that occur, as people's cognitive functioning and mood decline, we can help staff with setting up behavioural plans rather than, again, use of medications and other things, to help them function better in the scenarios in which they find themselves.

Clearly, last but not least, helping assess decision-making capacity is one of the biggest fraught issues in this area. The Australian Psychological Society holds a broad view of a person's ability to make decisions. I want to be clear about that. However, it is about helping people to establish on what basis they can make decisions, perhaps being a little more granular than a yes or a no. An elderly person can make a decision to spend \$800 in a particular way they want, but maybe not to sell their house. It is trying to get to decision-making at a much more individualised, granular level that works

for both the safety of the community and also the safety of the person concerned and their right to control. We would also add that we could provide supervision debriefing for staff and workshops for carers and families about what is going on. We can help assist conversations around death and dying, and therefore we can be an adjunct to the workforce at that secondary level, as well as the direct client service.

Again, one more level up, we could assist with policy development, best practice care for terminally ill and the broader scope of what government wants to do around that. We would emphasise the importance of research and translation of research into practice, as well. I am very encouraged by the consumer research, because we see that as being absolutely crucial. As noted by the previous group sitting here, they have the right to have a view of what happens to them, so they should be the loudest voice in this conversation.

Other than that, like I said, a lot has probably already been said and it is in our submission. I just note in terms of voluntary assisted dying that the Australian Psychological Society, like most international societies, does not hold a view on whether it should or should not exist. We acknowledge that it is a very complex issue and, therefore, we do not hold a view on that. What we hold a view on is what should happen should it come into existence, again around assessment of competence to make decisions and the impact of mental illness, which is not as big as people think it is in that decision to take advantage of voluntary dying. We want to make sure that coercion is not possible, that there are management plans for conscientious objectors and that there is care for practitioners and training and everything else that is rolled out appropriately, so that the workforce is able to manage the burden of that. In terms of initial points, that is where I will leave it.

CHAIR: Thank you, Ms Knight. You have touched on a couple of points around the establishment of potential legislation with voluntary assisted dying, so I think you have covered that. If it were to be introduced, would the society consider that counselling should be mandatory or optional?

Ms Knight: We would consider it to be optional, the rationale being that we do not necessarily think mental illness is always a driving factor. Again, as we would treat any other adult in society, we would allow those around them, as well as themselves, to consider whether they need to be reviewed for mental illness or cognitive impairment impact.

CHAIR: We keep hearing consistent themes around people with dementia. As with an ageing population, we know there is plenty of data out there to say dementia is a chronic disease and it will continue to be until a cure is found as they lack capacity and the disease progresses. We were at Redlands residential aged-care facility the other day and they were talking about level 5 to 7 dementia patients who are in high care as they had lost capacity. Their views or family views on early diagnosis were that we should consider having some kind of option in an advanced health care directive or a legal framework around voluntary assisted dying. What are your views on that?

Ms Knight: Broadly, the society would always come back to the right of the person to make decisions. Therefore, once that decision-making goes to somebody else, their capacity to make a decision would be important. Dementia is a difficult one because it is a balance. We ask, what would the person have told us before their dementia progressed? Would they have said they wanted voluntary euthanasia if they had that option or not? Have they change their mind along the way and can we adequately account for that? It means that, again, we would probably want to look at care around the issue rather than be prescriptive at this point.

CHAIR: Are there any other views from Health Consumers Queensland or social workers on that? It is a bit of a complex one.

Ms Fox: It applies, doesn't it, to younger people. When we were considering the consultation around these issues, we wanted to make sure we were not just looking at palliative care for older people and care at the end of life but also considering every age group. There are many circumstances that could fall into this category. It comes down to considering what are the existing laws around capacity and how can you take into consideration, as you said, people's wishes before they lost capacity or have impaired capacity.

Ms Hardy: Like the Australian Psychological Association, the ASW has diverse views on this, so we do not have an actual position on it. With Victoria legislating voluntary assisted dying, the ASW has developed an ethical framework to support social workers, because our view is that we need a really strong framework around how we ensure the process of making decisions, the process of supporting people, choice and all of that kind of stuff. It is really embedded in an ethical framework. That is the way that we are managing that and every member would have a different opinion on that.

CHAIR: Thank you. My final question before I open up to other members is to Ms Knight. The committee has heard of psychotropic drugs being used and your cohort of psychologists assessing older Australians perhaps in residential aged-care facilities. I will use the Earle Haven example. Whilst we cannot identify some things that were revealed in private session, we are hearing of people who have been moved now being far more alert and interactive with their family. Do you have any views on the use of chemical restraints?

Ms Knight: Yes, the society takes a fairly strong view that, were there to be more therapy options available within nursing homes across-the-board, the use of psychotropic medication would decrease markedly and that would be for the better. It is not easy to have somebody assessed in a nursing home by a psychologist at all. There is no funding for it.

CHAIR: That is the other thing I noted here. It does not come under a Medicare rebate.

Ms Knight: Not at the moment. Obviously, we are pushing for that, but whether we will be successful is another thing. While I have sympathy for those running the aged-care facilities when they have limited access to resources, I think as a model it is fraught and it is not in the client's best interests to be using psychotropic medication as behavioural management, mood management and everything else when often there are very good reasons they are feeling the way they are feeling or what they are doing. Like everybody else, that should be addressed.

CHAIR: Thank you very much for your commentary. I will open it up to questions from other members of the committee.

Ms PEASE: Thank you very much for coming in. One of the issues that I have been thinking about is that we often hear from family members and organisations but we are not hearing the voices of the people whom we are talking about. Dr Hardy, you have mentioned that in your submission and also in regard to your friend, the 71-year-old from Townsville. Could you give me some ideas about how we can better hear the voices of those people? It is not just elderly people, might I add. I had a very dear friend who passed away from cancer. One of the things that she hated most was she lost control. The disease took away her control and everyone else was making decisions for her about what was going to happen. How can we do better?

Dr Hardy: I think the work that you are doing is one really excellent way of doing that—of being able to go and talk to the people themselves and finding ways to access their voices. We do not do that very often. We have stories that we hear from the work that we are doing with older people in aged care and in other places. I would say that that would be the way to do it and also engaging in more research around that. The research becomes tricky because we then have high risks in terms of ethics and all of that kind of stuff. We silence the voices of the people whom we need to be listening to. We also disregard them, because they are older. Having recently lost my mother-in-law, who had Alzheimer's, and finding her notes that she had written along her journey that talked of her struggles and trying to cope with what is this thing that is going on, they are gems that give us insight. We need to go out there and talk to people.

Mr BERKMAN: I am particularly interested in the APS perspective on one component of the Victorian scheme, which is this prohibition on a medical professional raising voluntary assisted dying with a patient. You have gone into some detail in your submission around coercion. Do you have a view? We have heard others give evidence about the risks around that kind of prohibition in that it creates a really difficult tension between providing useful information for a patient yet at the same time protecting against a medical coercion, I suppose may be one way of describing the way it is framed. Do you have a view on how that could or should feature in a scheme, or if it just needs to be out altogether?

Ms Knight: It is a very fraught area—the whole coercion area. Whether you are coercing somebody to do it or not to do it is very difficult. In terms of medical doctors raising it, what I would understand from that is the level of authority and power they have with their comments and suggestions. Unlike your husband, if your doctor says to you, 'Have you considered assisted dying?' it comes with an almost implicit sense of, 'Perhaps this is something that you should be thinking about.' I can completely understand why it is prohibited, because you want to protect both the doctor and the patient from that sense of taking that authority too far. Even though it is not intended, that could easily become so.

Mr BERKMAN: Can I ask you from a health consumer's perspective? It has been described that it sets up a dance. That was the way one of the witnesses earlier described it. It might be clearly something that a patient is interested in, but it cannot be raised by a medico. From a consumer's perspective, what would you say to that?

Ms Fox: I was not aware of that component of the legislation. That was my first thought. For some time conversations in Queensland around care at the end of life—not voluntary assisted dying, but care at the end of life—have been about the importance of community members, health professionals, families, consumers themselves taking responsibility for having these conversations. We know that the challenge comes at the end of somebody's life where there can be a difference of opinion, or a lack of those previous conversations with family members. My initial thought on this issue is that for a health professional to be able to raise all options for somebody in a very considered, careful, protective framework is really important to support people to make informed decisions.

Mr O'ROURKE: My question is to Ms Knight. One of the aged-care facilities in Rockhampton employs a psychologist for several hours a week. Are you aware of any other locations around the state where the aged-care facility directly employs a psychologist?

Ms Knight: Off the top of my head, no, but I can find out and come back for you, if you want.

CHAIR: We will take that one on notice.

Dr Hardy: I can also confirm that I know of a couple of aged-care facilities where they would routinely bring in either psychologists or mental health accredited social workers through the new PHN funding to provide psychological and psychosocial support, to people with depression in particular. There are a number of facilities.

Ms Knight: It is a bit different from being employed, though. I live in New South Wales and I have tried in my day job to get psychologists into nursing homes. What you can do when you are on the ground permanently versus just being brought in to do 'X' and then back out again is quite different. I will happily find you the figures.

Mr O'ROURKE: Thank you.

CHAIR: I thought we could all move to Rockhampton, because he seems to have it covered.

Mr McARDLE: Thank you, ladies, for being here. Again, the usual cohort of intellectual capacity is here. Ms Fox and Ms Curtis, there is only one question that I want to ask. On page 3 you list from one to 13 the themes that emerged from feedback. Are they ranked in that order for a reason?

Ms Curtis: Yes. It was based on how many times we have heard the same feedback. The kitchen table discussion report was an 83-page report with all the raw data in it. I went through it with the support of a staff member from COTA Queensland and Palliative Care Queensland. We went through very carefully every single feedback that we had from those 20 kitchen table discussions and ranked it in the way that it showed up.

Mr McARDLE: The number of occasions it was raised?

Ms Curtis: Yes.

Mr McARDLE: Therefore, it got a point, shall we say.

Ms Curtis: Yes. That is why staying at home was right up there at the front. It was interesting because palliative care was No. 8 in the kitchen table discussion report whereas voluntary assisted dying was No. 4, yet when I did the focus groups it had turned around slightly. Palliative care came up higher and voluntary assisted dying was not far behind that.

Mr McARDLE: I am keen to look at that raw data. Can you table that document, if we are allowed to do so—if not today then certainly take it on notice to table that?

Ms Curtis: We believe that it was provided to you, but we have it. We can table it, yes—both reports again.

Mr McARDLE: I move—

CHAIR: Seconded.

Mr McARDLE: Thank you very much. Ms Knight, how many psychologists practise in Queensland?

Ms Knight: Five thousand, eight hundred.

Mr McARDLE: I assume they are predominantly based in the major capital areas such as Brisbane, the Gold Coast, the Sunshine Coast and up the eastern seaboard. There would not be a great number in what I would call regional, rural and remote areas; would that be correct?

Ms Knight: Yes, that would be correct.

Mr McARDLE: You say on page 4 that depression in palliative care patients is a major issue and you also say that anxiety and delirium are also major components of anybody who is in a palliative state. In the Oregon studies into VAD there is a listing of the causes or reasons people access VAD

in that state. It talks about the top three being, roughly speaking, the loss of enjoyment of life, being a burden and not being able to partake in traditional family activities, or words to that effect. You then get down to pain and suffering. Does the depression, anxiety and delirium have an impact on the patient coming to those top three reasons for accessing VAD?

Ms Knight: I do not have the statistics off the top of my head on that one at all. Therefore, I can take that question and come back to you. We do not think that those states are as important as people often think they are in accessing VAD—as in depression and anxiety per se.

Mr McARDLE: If you could take it on notice, that would be great.

Ms Knight: Yes.

Mr McARDLE: The reason I make that comment is that you make the point that it is 'often under-diagnosed in palliative populations, with clinicians believing that depression is appropriate/"normal" in advanced disease and palliative situations'. That is a worrying comment, because it means that the clinicians—and I am using the term in a broad sense—do not recognise the potential impact on the patient and their full processes if they think it is normal.

Ms Knight: Absolutely. As I said earlier, the suggestion of it being normal means that they do not try to intervene to change it much either.

Mr McARDLE: Correct.

Ms Knight: It is absolutely a worrying way of seeing the world. We would expect that people would have adjustment issues from moving, to going into palliative care and to addressing end-of-life questions, but that does not mean that they have to be depressed in a clinical sense or anxious in a clinical sense.

Mr McARDLE: No. My point is this: if you do not recognise the factor, you do not understand the impact.

Ms Knight: Sure.

Mr McARDLE: That is my question.

Ms Knight: Sure. That is back to the decision-making. Is that where you are going?

Mr McARDLE: Correct.

Ms Knight: Yes, absolutely. We know the questionnaires, for example, are not well administered in aged-care facilities. It would potentially lead people to draw conclusions that were, in fact, erroneous.

Mr McARDLE: The committee has been given a draft bill prepared by professors who are at QUT but not on behalf of QUT. One of the things is an assessment of free will or lack of coercion. Is it important that that assessment be undertaken by a social worker or a psychologist and not a GP? Is there an expertise that should be brought to bear in relation to what is a society fraught with elder abuse in all its types and also your statement here about depression? Should that be assessed by somebody outside, the family GP to begin with or a GP in general?

Ms Knight: The family GP, obviously, is an important source of information and you would not want to lose that gold. It is part of the process of understanding whether coercion is occurring or depression has been present for a long time, et cetera. The fundamental is, yes, I think there needs to be somebody who has the expertise to assess both the mental illness components and cognitive impairments that might exist, but also somebody who can look at the level of family functioning and coercion—a range of things. Please do not hear me saying that families are coercive all the time.

Yes, I do think it needs to be people with expertise. Psychologists are definitely well placed for the mental illness and cognitive impairment side of things. Social workers would obviously have a role to play there too, in terms of more of the coercion side of things, assessment, recognition of rights and other things.

Dr Hardy: I would agree. I think that what social work could provide is more the holistic psychosocial assessment. Having a bit of a team of people with the expertise and knowledge to be able to provide that assessment is important. As with many things, it is about a multidisciplinary team being able to work together to do that. I think that makes sense.

Mr McARDLE: My final point is a comment. If you have an outsider who is qualified, you have an independent individual. Whether you are a doctor, psychologist or member of parliament, once you get close to a person or to an organisation you can lose objectivity, not by design but by outcome of engagement. Would that be right?

Ms Knight: Yes, and for some very serious decisions, of course, somebody who is much more objective but open to getting as much information as is available—appropriately funded to do it in a team based setting and everything else—would be better. We could imagine in aged-care facilities that even psychologists and social workers employed after a while would feel a sense of pressure in terms of statistics around things.

Ms Fox: Chair, could I respond to your question about the statement of choices and other examples around the country?

CHAIR: Yes.

Ms Fox: I am happy to reach out to equivalents of myself around the country to find out, in their opinion, what other templates exist that are consumer friendly. We would obviously want whatever is used to support the three key messages that we heard in our consultations, which were: support us, involve us and empower us. I am aware that the statement of choices was designed with consumers and its continued implementation and rollout is supported by consumer representatives.

It is not only about what template is used, it is also about, as you would have heard, how that is accessible right across the system from primary care to hospitals to aged-care facilities to ambulance services, to make sure that everyone who is providing care knows about that person's wishes. As I said, it is about those early conversations so that we do not end up in a situation where a document such as the statement of choices, which is not legally binding, comes into conflict when there is an issue around a family member maybe not being in line with the wishes of that person. Obviously, the statement of choices is more consumer friendly than something like an AHD.

CHAIR: No doubt. We have heard that to date. I think advances in technology, like the Viewer that Queensland Health has introduced, where documents are uploaded for the use of responding health practitioners, be they ambulance or others, is a good tool going forward. There is more work to be done in rolling that out.

Ms Curtis: I just wanted to say that the most consumer friendly advance health directive that I have actually seen is the New Zealand model?

CHAIR: Yes, we are currently looking at the New Zealand model. They have done a fair bit of work on that. The committee has received that particular document. We will now take a short break.

Proceedings suspended from 11.48 am to 12.13 pm.

CAMPBELL, Mr Chris, Queensland President, Pharmaceutical Society of Australia

LOCK, Mr Mark, Queensland State Manager, Pharmaceutical Society of Australia

TWOMEY, Mr Trent, President, Pharmacy Guild of Australia

CHAIR: Welcome, gentlemen. Mr Twomey, would you like to make an opening statement?

Mr Twomey: Thank you, Mr Chair and members of the committee. It is always an honour to be presenting before you. Community pharmacy in the state of Queensland has a lot to offer in terms of relieving the pressure and solving the problems that exist in the provision of aged care to Queenslanders. I know the remit of this particular hearing is broader than just aged care. I am happy to take questions on those other aspects, but the majority of my report, which I believe you have—I have extra copies if you need me to table more—will focus around solving those issues in aged care.

First and foremost, the reforms that we are suggesting and have suggested in our submission require no money and no further financial investment on behalf of the state of Queensland. What we are asking the state to do, through things that are exclusively within their regulatory and legislative remit to do but also through their role on the COAG Health Council to help drive reform at a federated level, is basically unlock the full scope of practice of the community pharmacy network within the state of Queensland.

The specific areas I would like to talk to or that we have provided information on in our report are around the issues of medication continuance and medication safety. Those proposed changes that we have put forward through the Chief Health Officer and the Minister for Health regarding the now passed, I believe, Medicines and Poisons Bill but the pending passage of the associated regulations are the real-time monitoring which exists in some parts of the federation but not yet in the great state of Queensland and the recommendations of the inquiry into the establishment of a pharmacy council and transfer of ownership in Queensland, which is a report of this committee. The last point is around the great work that the pharmacy network is doing in the area of immunisations and increasing herd immunity in the state of Queensland. How would you like to handle this, Chair? Would you like me to table the report as read and take questions, which I am happy to?

CHAIR: We might do that. Leave is granted for the report to be tabled. We will come back to you on that. I will allow the Pharmaceutical Society of Australia to make an opening statement as well. I wanted to concentrate on the digital prescribing platform that is available as it relates to aged care. The committee has heard of the 34,000 transports by the Queensland Ambulance Service of residential aged-care residents to and from hospital. What we would like to examine is ways of keeping people in their facilities by offering a better level of care. Pharmacy will play a role in that. I want to explore the linkage between the GP writing the script and the provision of the medication. I am sure you can talk to that. We might come back to that.

Mr Twomey: I am happy to.

Mr Lock: I would like to thank the committee for inviting the Pharmaceutical Society of Australia, the peak body for pharmacists in Australia, to appear today at the public hearing. The *Medicine safety: take care* report released by PSA this year revealed alarming statistics associated with medication related problems in transitions of care, aged care and community settings. It showed that 98 per cent of residents in aged-care facilities have at least one medicine related problem, with an average 3.2 problems per person. It also revealed that over half were exposed to at least one inappropriate medicine. Disappointingly, pharmacists who possess the unique medicines and medication management expertise are not routinely included in the delivery of healthcare services in aged-care facilities. The pharmacist workforce is underpinned by a robust standards framework and has a strong desire and commitment to deliver services to improve the quality use of medicines by all Queenslanders but particularly those considered to be vulnerable population groups, such as aged care and palliative and end-of-life care. Pharmacists must be recognised as a core member of the healthcare team and all settings wherever a medicine is being used or considered as a component of a patient's health management plan.

Generally in the aged-care setting a facility would contract a community pharmacy to deliver a range of pharmacy services, with the type and frequency of these services varying from facility to facility based on the needs of that facility and its residents. However, activities designed to improve the quality use of medicines are generally not prioritised by aged-care facilities and as such contracts between the pharmacies and the facilities tend to be limited to the dispensing and delivery of medicines and responding to medicine related queries on an ad hoc basis.

Based on what pharmacists have experienced, that focus that aged-care facilities give to medication management issues are primarily in the context of their need to comply with accreditation standards. There appears to be a lack of awareness by facility leaders of the benefits of pharmacist delivered quality use of medicine services on the care of residents as well as the operation of a facility.

Medication management issues are a frequent cause of noncompliance in aged-care quality agency standards. In the aged-care complaints commissioner's annual report for 2017-18, there were 4,315 complaints Australia-wide about residential aged care, which accounted for 75 per cent of all the complaints. The most common issues raised in complaints about residential aged care were about medication administration and management.

PSA, as the peak professional body representing the 6,000 pharmacists in Queensland, has been strongly advocating for a service delivery model that generally embeds pharmacists into aged-care settings. It is the PSA's firm view that this is an opportune time to consider the model of embedding pharmacists in aged-care facilities to expand this across all aged-care facilities within Queensland to ensure improved medication safety and provide residents with greater access to timely, equitable, efficient and effective medication management services.

The role of a pharmacist in the aged-care setting was detailed in our submission to the committee, as were the benefits of investing in aged-care pharmacists. Other health practitioners, including general practitioners, have also indicated their support for the benefits of including pharmacists in the aged-care team but acknowledge structural and financial barriers prevent this from occurring regularly. The current funding for pharmacists to provide the quality use of medicine services to facilities is completely inadequate at \$60 per facility per quarter plus \$6 per patient per quarter. For a facility with 100 residents, that equates to about three hours of pharmacist time per month for the facility.

Recently PSA released clinical governance principles to support the design and delivery of pharmacist services underpinned by safety and quality. PSA's principles framework is relevant to all settings where pharmacy services are delivered, including aged care. The framework of principles builds on the work of the Australian Commission on Safety and Quality in Health Care and is promoted as the key mechanism to ensure pharmacist delivered services provide the best possible care to individuals.

PSA's recent submission to the Royal Commission into Aged Care Quality and Safety goes into further detail about what I have mentioned. Of note in our submission is the support to embed pharmacists in aged-care facilities from the Chief Medical Officer of the Australian government, Professor Brendan Murphy, provided at a hearing of the royal commission. A proposal to embed pharmacists into aged-care facilities as a national program has been presented by PSA to the federal health minister and is included in PSA's submission to the royal commission. PSA welcomes the opportunity to work with the Queensland government to embed pharmacists within all aged-care facilities in Queensland. Queensland has the opportunity to be leaders in health care by utilising the over 6,000 strong pharmacist workforce in the state to ensure the health and wellbeing of ageing Queenslanders. PSA encourages the committee to consider this recommendation for the benefit of all Queensland residents in aged-care facilities. Thank you for giving us the opportunity to make this opening statement. For the committee's reference, I would like to table the two documents that I referred to today—the PSA's royal commission submission as well as the PSA's clinical governance principles.

CHAIR: Is leave granted? Leave is granted. Thank you, Mr Lock, for your opening statement and for the work of the PSA, and the guild. I know we have done considerable work with both the PSA and the guild with regard to previous work of the committee. I talked about the pharmacist's role in preventing hospital admissions. You quoted the pilot study of the University of Canberra around reducing potential hospital admissions. You state that pharmacists' advice resulted in the prevention of 85 potential incidences of adverse drug reactions and a number of other things. I will come back to you in a minute.

I want to go back to the digital prescribing platform. I would like to have some more discussion around the issue we found with Earle Haven. It was reported that 70 per cent of residents were on psychotropic drugs. There have been other findings post their removal and having to find housing for those residents. A lot of the evidence at our committee hearings yesterday was taken in private so we cannot identify that. We now have some residents who are a lot more alert and for whom a range of medications have ceased, which is interesting. I want to come back to your comment that 40 per cent or 50 per cent of residents could be receiving potentially inappropriate medication, which is on

page 3 of your submission, and talk to that. Mr Twomey, could you talk to what a digital prescribing platform might look like and the benefits to the aged-care sector in Queensland if this were to be introduced?

Mr Twomey: I am more than happy to talk about digital prescribing and platforms and the transition of care from inpatients to outpatients from hospitals to aged care. There are a couple of points. The guild also has some quite strong views on the quality use of medicines in residential aged-care facilities and the use of—I would never be one to verbal the chair—chemical restraint and how a full scope of practice pharmacist workforce would be able to deprescribe. That is something that a pharmacist is empowered to do in other OECD countries but is not empowered to do under the Queensland law. At the moment we could be aware of such things happening but be powerless to prevent it.

CHAIR: Can you cite those other countries?

Mr Twomey: The United Kingdom, Canada, France and various states of the United States. At the moment we have the power to do reviews, but we do not have the power to deprescribe even when we can see something wrong.

CHAIR: There is a clear benefit in looking at this?

Mr Twomey: Absolutely. I am more than happy to come back to that. I did not want to deviate because there are a lot of important issues. Specifically on digital platforms, we saw the evolution of the My Health Record recently. It had a bit of controversy, but by and large it has the bipartisan support of the states and territories, as it should. The role of the My Health Record is to first and foremost empower the consumer, empower the patient, and ensure there is greater visibility by all of the people playing a role in their primary and acute healthcare team, and the pharmacist is foremost as one of those players.

You are correct in raising digital prescribing, and right to do so. The federal Minister for Health has announced that the first digital prescriptions will go live next month—October. When he says 'digital prescriptions', I do not know whether he means one or two or millions because there are 290 million prescriptions in Australia a year. Nonetheless, the framework will be available from next month, but it will take many years for that to become the entrenched way of prescribing.

Having a bit of paper to communicate between a prescriber and dispenser to provide the right medicine at the right time in the right dosage to a patient is quite archaic in the 21st century with the digital tools we have available to us. If a patient is an inpatient in a hospital, public or private, there is a medication chart. The hospital pharmacy department will dispense off that chart. The chart could be paper or the chart could be digital depending on which hospital you visit. Nonetheless, it is a live document that communicates the intentions of the prescriber or prescribers to the dispenser.

That clarity, that simplicity, that tool does not exist when someone exits a hospital and goes into either a residential aged-care facility or if they are choosing to age at home. I should use this point to highlight that most Queenslanders choose to age at home or are forced to age at home if there is no bed available. I know your questions are specifically about residential aged-care facilities, but they are just as pertinent or if not more so for people who are ageing at home.

What the My Health Record has the functionality to enable is a live medication chart, so the pharmacist and the prescriber—the dispenser and the prescriber—can communicate between the two of them from a single source of truth. That removes the burden from the patient to be able to chase up bits of paper which say, 'You can have a box 28 tablets with three repeats or a box of 90 tablets with two repeats.'

Unfortunately, the majority of people in this space are on five medications or more; that is what the evidence shows. Some of those are prescription, some of those are non-prescription, but none of them come with the same number of repeats and the same size packets. Inevitably, when we are trying to pack the medication for the patients we serve, they run out of something—every time. That creates a blockage because the patient has to return to their prescriber before we can complete that order. The technology exists. The problem is it is not mandated.

In the fifth community pharmacy agreement—it is a five-year agreement funded by the Commonwealth; we are in the last year of the sixth community pharmacy agreement—there was an agreement between the AMA, the RACGP and the Pharmacy Guild of Australia on what this digital prescribing chart would look like. Unfortunately, it was never made mandatory in residential aged-care facilities. The simplest thing to fix this problem would be to mandate the use of it in facilities. That would solve most of the grief that patients experience in having to chase up repeat prescriptions. I hope that answers your question.

CHAIR: That will help us greatly in going forward. I will move to the Pharmaceutical Society of Australia. You might unpack the use of psychotropic drugs, or chemical restraints as it is referred to. You quoted 40 per cent to 50 per cent of residents in your submission. What study was undertaken to come to that conclusion and are you able to provide that?

Mr Lock: That information is included in our *Medicine safety: take care* report. That is also included as one of the appendixes within the royal commission submission. It does detail the different medications that were dispensed long term—so anything greater than eight weeks—in particular benzodiazepines and the antipsychotic medications.

CHAIR: Would you say it is a common practice?

Mr Campbell: Currently there is funding for two-yearly residential medication management reviews. If the guidelines tell us eight weeks but we are waiting two years before a medication review, and as per Trent's point, we can only make recommendations when we notice an at-risk medication or someone who has been on a psychotropic or benzodiazepine for longer than recommended. Part of our submission looks at ensuring that pharmacists are there more than just the three hours per month. These medication issues are happening. We know that 98 per cent do have that. We know that on average there are 3.2 medication related issues per patient. That cannot continue. We know from looking at the pilots where they have embedded that it is about the continuous access. We are lucky that the community have wonderful access to pharmacy, but they are being denied in residential aged-care facilities. It is an opportune thing.

CHAIR: I think you have hit the nail on the head.

Mr Twomey: Just to support my colleagues, embedded in the guild's submission is a copy of our response to the inquiry of the Pharmacy Board of Australia into non-medical prescribing. Under the AHPRA framework, guidelines were released for non-medical prescribing which the nursing board, the Optometry Board, the Pharmacy Board et cetera could respond to in terms of looking at what public benefit there could be in removing regulatory red tape to empower those workforces to prescribe. The reason I keep coming back to prescribing is because deprescribing is just the other side of the coin to prescribing. You have to empower a health practitioner to prescribe in order to give them the authority to deprescribe. There are three different models: structured, supervised and autonomous. The guild's paper talks to autonomous prescribing as the preferred way forward and references some of those countries that we mentioned before. That is within the remit. Even though there is a COAG health ministerial round council, it does not permit the Queensland government to act independently to empower the pharmacy workforce in Queensland to do that, as our great state did with pharmacist immunisation.

The last point I would like to highlight, which is not within the power remit of the Queensland government but is something you could forward to your federal colleagues, is the delinking of the provision of a residential medication review from the dispensing of medication programs. For example, there are 5,700 pharmacies in Australia. There are 1,140 in Queensland and many of those have, as my colleague said, contracts to supply medications, to dispense medications and packs, to residential aged-care facilities. There is \$16.8 million a year federally funded to provide these residential medication reviews. They are done on any given month by only 194 to 206 pharmacists out of the 32,000 in Australia. I cannot give you exact figures of how many of those 200-odd are in Queensland, but we represent roughly 20 per cent of the workforce.

I do not think it is too long a bow for me to say that 20 per cent of 200, so there are 40 Queensland pharmacists out of the 6,000 that are providing residential medication reviews. I will repeat that: there are 6,000 pharmacists in Australia, most of which are practising through 1,140 pharmacies, and only 40 of those are providing residential medication reviews. The way to fix this is to, yes, advocate to your federal colleagues to invest more money in an underfunded program but, more importantly, to fix the business rules that link the residential medication review to the pharmacist and the pharmacy that is supplying the medicine, because otherwise we have this problem where there are not enough pharmacists. We do not even know if those pharmacists are distributed throughout the state of Queensland or if they all live in Fortitude Valley and just fly-in fly-out, propagating further workforce problems. There is one thing that is within your remit and one thing for which you might have to lean on your federal colleagues a bit.

CHAIR: Before I move to questions, for the benefit of the people watching, can you talk about the risks of polypharmacy to aged-care residents? Quite often we will see them in a stupor, so to say, lying in their beds. What are the risks of polypharmacy? You were not here this morning, but we heard from Health Consumers Queensland and a range of other stakeholders that we want people to be active. There is a cost saving to the state when people are active in our aged-care cohort. Talk to us about the risks of polypharmacy.

Mr Campbell: To follow on from what Trent mentioned, the majority are on more than five medications. As soon as they take eight medications, there is a 100 per cent chance there will be an interaction between those. If we look at the residential aged-care facilities, we know that those medication related issues are there. From an impact perspective, we have data from our medicine safety report that looks at what the costs of medication related issues are: 250,000 hospital admissions at a cost of \$1.2 billion. If we look specifically at an individual, Aaron, I think your case—and I had not heard of that—was almost like forced deprescribing where we saw an improvement in patient outcomes because of that forced deprescribing that we can enable a pharmacist to help to support.

CHAIR: In terms of those 250,000 hospital admissions, do we have that data in that report?

Mr Lock: That is in that medicine safety report.

CHAIR: That is incredibly concerning. Do you have anything to add to that?

Mr Twomey: I think the fracturing of the system where you have the review of the medications done by a different practitioner to that which provides the medications is a fundamental problem. This is all about consumer empowerment. This is all about safety; this is about using digital technologies to help empower and help increase coordination. Having a FIFO workforce of pharmacists that is underfunded, under-resourced and does not have that relationship with the local community pharmacy that knows the patient and provides the medication to the patient each week is not a solution to the problem. Yes, we need more money, but what we need more than money is ensuring that the system is more coordinated. Linking the residential medication review process so it is the same pharmacist as that which is dispensing and supplying is one step to address that concern.

Mr Campbell: Also, if we have that continuity within the aged-care facility so we are not just serendipitously saying, 'We have landed on a time when that medication might be prescribed,' or, 'Here is the opportunity to deprescribe,' and we do that in a timely fashion, that is where we will get the outcomes. If we wait two years for the review or wait for the serendipitous delivery of the medication where it may or may not be picked up, it is not funded that they pick that up. It is the continuity.

Mr Twomey: I will give you a specific example. If someone is ageing in a facility, they will probably see their GP once a week or once a fortnight when she comes and does a ward round of the nursing home, saying 'Hi, how are you all going?' They will see their pharmacist when they go to the pharmacy because the funding mechanism to allow the pharmacist to come and do the ward round just like the GP does is not given to the local community pharmacy. The local community pharmacy dispenses prescriptions, packs them all up, checks to make sure they are right, gives them to their technician and then the technician runs them down and hands them to the nurse. The real solution is to link those funds to that pharmacy so that pharmacists can get out of that dispensary and go and do the ward rounds and go and visit the patients just like the GP does. At the moment it is someone from Fortitude Valley flying up to Innisfail and going around—and the person could be asleep while they check the chart—and then going home. That is not good quality use of medicines.

CHAIR: I agree. That is a good segue before I go to fellow members for other questions. I am going to reach into my portable 'pharmacy' to get an antihistamine. The tablet I am taking is to stop a runny nose. I will open up to other questions now.

Mr BERKMAN: Very quickly, I want to touch on a point that I think you have both made in submissions around voluntary assisted dying and accessing medications. I think both the Pharmacy Guild and the Pharmaceutical Society have indicated that you think conscientious objection for pharmacists must be a part of any scheme for VAD. I am curious to interrogate whether there could or should be any exceptions to that for extremely remote regional communities in Queensland. Obviously, we have far greater challenges with remoteness of some parts of our state than Victoria, for example, which does have that protection. Do you have a view on that which you could share?

Mr Twomey: Sure. It is all about the consumer first and foremost, and all Queenslanders should have access to the same level of care that they choose. If this legislation does pass and this does become an option for consumers, the Pharmacy Guild of Australia thinks that it is the choice of the consumer to do this. We do not have a position on it. Community pharmacies are the most accessible form of primary health care in the state bar none. There is a community pharmacy in the Torres Strait: in Bamaga, Cooktown, Weipa and Karumba. There is no private general practice in any of those areas, and that physical land mass I have just articulated is larger than the state of Victoria.

Just like when the emergency contraceptive was introduced—and there are some conscientious objectors—the vast minority of pharmacists who cannot for whatever religious or ethical reasons provide that have an obligation to refer that patient to someone else where they can get it in

a timely, affordable and accessible way. My pharmacies provide the emergency contraceptive; all of my pharmacies do. There is a group in my area that does not for religious reasons, so they refer. We get phone calls. I do not practise as often as I used to, but we would get phone calls asking, 'Have you got it? I'm sending someone down.' That is a good duty of care. I think the same needs to happen in this particular area.

I think your question goes to those remote communities where there might not be another option and there is only one pharmacy, and that is fine. Most of my pharmacies are in Cairns. One of my pharmacies is a compounding pharmacy, for example. We compound specialty medications that the normal pharmacy would not have. We provide an outreach service through those other pharmacies for those services because they do not have the scale to do that. I think pharmacists are highly professional; I know they are highly professional. If they do not feel they can play a role, I have no doubt that they will ensure, whether it is through the public community controlled health organisation or reaching out to another pharmacist, they can provide some form of remote care; they will ensure their professional duty of care is executed. That was a poor choice of words.

Mr Lock: To reiterate Trent's point, the obligation of pharmacists to refer on to other practitioners for the service is bound in the code of ethics that pharmacists are required to practise by, which they declare as part of their registration as a pharmacist. That is a requirement.

Mr Twomey: I hope that answers your question.

Mr BERKMAN: Absolutely. Thank you.

Ms PEASE: Thank you very much for coming in. Whilst we have been travelling with this committee we have spoken to a lot of different people about a lot of different things and one of the issues that has been raised with us is access to end-of-life medication in remote areas and sometimes the difficulty for people to access that because it is not required all the time, it is out of date, it is expensive. Do you have any suggestions as to how to improve on that? I might get the PSA to comment first.

Mr Lock: Currently there is some work being done in the Adelaide region with regard to that. It is a trial on educating both general practitioners and pharmacists in that area to help increase the access to palliative care services and medication in the community so that people can be at home for this. They recently have been getting good results from that and they have extended that trial for another 12 months to see it continue on and build from it, so there is some work happening in that area with some good results.

Mr Campbell: Part of that is a commitment by the community pharmacy to always stock the medications that may be required.

Ms PEASE: One of the issues that we heard was that they were out of date. You might be able to shed some light on that because it was actually up around North Queensland that we heard that information.

Mr Twomey: I did not realise that we had voluntary assisted dying in Far North Queensland.

Ms PEASE: No, end-of-life and palliative care medication. I am referring to the medication that you give them through the drivers at the end of life.

Mr Twomey: The issue here is whether or not they are or are not covered by the Pharmaceutical Benefits Scheme. If the drugs are—and let us make the assumption that they are and they are not private medications—the community service obligation, the CSO, requires and enables all medications to be available within 24 hours. That is a pretty world-class system. You cannot expect small businesses in remote locations to keep every single drug on the Pharmaceutical Benefits Scheme unless you want to pay for it. If you want to pay for an imprest and have everything sitting there in case they need to use it, we could not afford it as taxpayers, as a community. The 24 hours, the CSO, is world leading and it means any of those pharmacies can make sure that anything on the Pharmaceutical Benefits Scheme they can have within 24 hours. Inside that I think is where the problem you are alluding to is.

Ms PEASE: Certainly if you are lying there in terrible pain, 24 hours is a very long time.

Mr Twomey: It is a very long time. I do not have a solution other than if the Queensland government wants to pay to have an imprest that sits in Queensland Health facilities that we can draw on. It is quite difficult for the private sector to model and know. We do that to the very best of our ability. The computer systems we have are quite sophisticated. They map the supply and demand, but there are tens of thousands of drugs on the Pharmaceutical Benefits Scheme.

Ms PEASE: Going back to the trial that you are undertaking, this is in South Australia?

Mr Campbell: It is PHN funded.

Ms PEASE: What is that looking like? How is that going to address that issue?

Mr Lock: It is about increasing the awareness. A lot of the palliative care services have been driven by the hospital system and the specialists and the supply of medication being through the hospital system. They are trying to increase it in the community with more patients wanting palliative care in the home versus palliative care in the hospital system. It is about increasing that awareness and education for the prescribers as well as the suppliers about particular medications, the need for them, when they are going to be needed.

Ms PEASE: The shelf life, access to it, all of that?

Mr Campbell: There are unique medications that a prescriber might decide on—and Trent would be acutely aware of this—that may be through a non-CSO wholesaler. Twenty-four hours would be wonderful if it just so happens that that high-dose morphine is available or the midazolam is available through it, but we have scenarios where they are a non-CSO wholesaler. This is a federal issue that we have with non-CSO wholesalers when we do not have that same turnaround time, but I get your point that sometimes we need it within that hour for a syringe driver to continue to provide that pain relief.

Ms PEASE: We have heard that.

Mr Campbell: It is a big issue.

Mr Twomey: These medications are S8, so they are schedule 8 medications, and we raised this with all of you when we had the pharmacy inquiry about the ability to transfer drugs and share stock between pharmacies, and it is not there. If those reforms in the new medicines act come into being, that will go somewhat towards addressing some of these issues because we could, instead of having to order it from the wholesaler, ring the pharmacy down the road and see if we can get it transferred. We can have more of a hub and spoke type model. We do these things in the S4 space. We do everything we can to get the medications that patients need when they need them.

CHAIR: There are thousands of community pharmacists doing the good job that they are doing. No doubt they would hear from consumers about drugs they think should be on the PBS that they cannot get access to. Do you have any commentary?

Mr Campbell: The main one that we are seeing is actually immunisation through a pharmacy, if they are able to get that funded. That is the biggest feedback I get, particularly over-65 access to high-dose or adjuvant influenza vaccinations. They currently have to pay privately. To look at that as one example, it is \$70 for an over-65 patient in Queensland whereas if you go down to Victoria it is provided through the National Immunisation Program.

Mr Twomey: The NIP is federally funded, but it is state administered. In Western Australia, Victoria and the ACT those governments have chosen to make their national immunisation stockpile, funded by the feds, available not just through general practice and community controlled health but also through community pharmacies. The state of Queensland has enabled the pharmacy workforce to deliver these vaccinations, but it is completely private. In terms of the publicly funded ones, they still have to make an appointment and go and see their general practitioner whereas they come and see us 18 times a year and they see their GP six. It is a lot more convenient for them.

Mr Campbell: It is about improving access. With regard to the fact that they are not supplied under the National Immunisation Program, there were scenarios where we could not physically receive the stock, particularly looking at the year we had this year with influenza. That is probably the biggest feedback we are getting from our members around access—something that we could change.

Ms PEASE: I want to acknowledge the great work of community pharmacists. Both of my parents went through palliative care and passed away not quite at home but nearly and we were supported tremendously by our local pharmacies. They do a great job. We are very, very fortunate to have lots of great community pharmacies in my electorate.

CHAIR: We note Cate's Chemist in Townsville have become parliamentary junkies; they follow us around to all of our inquiries now. It has been good to get feedback locally on the ground and from your organisations.

Mr McARDLE: I have a comment, no questions. I applaud you as a body continuing to morph into a more community focused organisation. I think medicine as a whole has to change direction dramatically to cope with what we are going to see by way of an ageing population. I think the hands across the table approach, working in conjunction, is pivotal to solving some of the concerns and questions we have of an ageing population and an aged-care crisis and also potentially the future issues that will arise as we develop better technologies and better medical outcomes as well. Although that is a blessing, it is also a curse to a certain extent.

Mr Twomey: Thank you, Deputy Chair. We always like, as a profession, to bring solutions rather than bring problems and often ones that, as I said at the outset, do not require investment of funds on behalf of the taxpayer just to reform a system.

Mr McARDLE: Always a wonderful goal.

CHAIR: We have a supplementary question from the member for Rockhampton.

Mr O'ROURKE: This is directed to Mr Campbell and Mr Lock. In your submission you recommend that the Queensland government allocates funding to embed pharmacists in public aged-care facilities. Do you have any suggestions how we could do that into the private sector just so that we have equal access for clients?

Mr Lock: It would be around how the facilities like to allocate the funds that they are given for providing services within the aged-care facility. The trial data from the ACT could help in terms of how it would look embedding it in multiple facilities, not just the Queensland Health ones.

Mr Campbell: It is also the expectation and the skill of the workforce. You start by embedding that in publicly funded facilities and you demonstrate the value and benefit to the private sector: they are getting less medication related issues, less cost associated with that. The other thing would be to look at enabling those pharmacists to be able to do more when they are there. If you were looking to prescribing or deprescribing opportunities that they could have, then a facility would see that as a much more useful use of that workforce. It is multifactorial. You need to demonstrate that there is an expectation that a pharmacist would be embedded into an aged-care facility and then allow them to do the work that our competency standards and our scope of practice demonstrates.

Mr Twomey: I have to say I have skirted around this issue because this is one area where the Pharmacy Guild of Australia and Pharmaceutical Society of Australia are not aligned. The guild does not support the embedding of pharmacists in residential aged-care facilities because we believe it fractures the quality use of medicines rather than strengthens it. We believe that the patients value the relationship with their local general practitioner and value the relationship with their local community pharmacist. We believe that if resources are to be invested they need to be invested to strengthen that relationship and not fracture it. As a dispenser, I have to review everything I do every time I hand out a medication. I cannot say I am just supplying it and somebody else in another setting is doing the review function. I cannot abdicate my responsibility when I hand out a medicine for the safety and use of that medicine. I have to take full responsibility for that.

We feel that with the finite funds that are available in a system they need to be strengthening the local community pharmacy sector and empowering that local pharmacist so that he has the relationship with them to do the good job and the good work they do. With regard to just having somebody working on a Tuesday morning for three hours, as we know, patients have adverse medication events or have changes 24 hours a day, seven days a week, so we cannot say, 'Well, just wait until next Tuesday morning and we will fix that problem for you then.' You need to be able to contact your local pharmacy, have it fixed that day and have something delivered and corrected. I respect that we have a different opinion, but that is just the one where we do not agree.

Mr Campbell: We want the same outcome: improved quality use of medicines in aged-care facilities.

CHAIR: I think that wraps it up nicely. It is okay to have different positions. Thank you very much for your contributions.

DOUGLAS, Dr Carol, Australian and New Zealand Society of Palliative Medicine

GOOD, Dr Phillip, Australian and New Zealand Society of Palliative Medicine

CHAIR: Welcome. Palliative care is a very important part of our inquiry, so I invite you to make a statement before we move to questions.

Dr Douglas: Together with my colleague, Phillip Good, I am appearing before the committee today to represent the Australian and New Zealand Society of Palliative Medicine. I was the president of ANZSPM from 2015 to 2017 and Phillip was the president from 2008 to 2011. We are both palliative medicine specialists working in Brisbane. The Australian and New Zealand Society of Palliative Medicine is, as you would have read in the written submission, a not-for-profit medical society for medical practitioners who provide care for people with life-limiting illness in Australia and New Zealand. ANZSPM wishes to acknowledge the traditional owners of the land on which both the committee is meeting and from where I am speaking today and, as such, we pay our respects to elders past, present and future.

In our presentation to the committee today we would like to focus our remarks on the critical points which are outlined in our written submission. Firstly, we would like to highlight what we view as non-negotiable optimal palliative care options essential to support all people in exercising their choice and preferences at the end of life. One myth is that palliative care involves only the last days and weeks of life, but to support people with a chronic and progressive illness involves, for many people, support over a considerable period of months to years of life.

People also need timely, flexible and responsive access to interdisciplinary clinicians who have the necessary expertise to assess and address the symptoms and emotional and psychological needs that are occurring at a given point in time, and also clinicians who proactively consider and plan for future scenarios—a major role of palliative medicine specialists—to minimise negative impacts before they occur. Due to the increasing success of treatment choices, there is increasing clinical complexity at the end of life and also, in many cases, people have more than one illness that requires specialist clinical expertise and an interdisciplinary team.

Good palliative care includes people being informed about their condition and supports their involvement in shared decision-making and communication of preferences for care. This requires a health workforce equipped with the respect, confidence and communication skills to have these conversations. To achieve this end, we need a whole-of-health, whole-of-social-services and whole-of-community response, and we know there are substantive deficiencies in all of these areas. Indeed, many people are subject to cumulative deficiencies in the system as they traverse primary, community, acute and residential aged care or fall between the cracks due to the postcode in which they live, the time of day they present to hospital, the clinical diagnosis with which they present or the lack of knowledge or communication skills of the clinician with whom they happen to meet.

Additionally, a person may be hindered in seeking palliative services due to their misunderstanding or fear or that of the family about what palliative care is. The analogy would be having a heart attack and not being offered evidence based options of a coronary artery bypass or primary angioplasty as either there was not a clinician with skills to do the procedures or no-one referred you to discuss these options. Our recommendations that specifically address these deficits are: firstly, community awareness is critical to address misconceptions and fears about dying and also facilitates better awareness of the extent of choice and engagement possible in decision-making at the end of life.

We need to think about how we can remedy the shortages in the specialist palliative care workforce within sustainable service models. We need to enable earlier integration of palliative care clinical specialist services in all healthcare settings—and I make reference to the integration of palliative care into other disciplines to form supportive care models and the integration of specialist palliative care into multidisciplinary team meetings in major acute facilities that determine ceilings of care and advance care planning. We need to be able to expand palliative care programs so access is equitable by location, setting and time to include after-hours access. We need to mandate minimum competencies in end-of-life care and communication skills for tertiary education and vocational training for all healthcare professionals in Queensland.

To summarise, we know that palliative care, and more specifically access to palliative medicine specialists and medical teams who have specific palliative care expertise that is timely, responsive and tailored to the individual wishes and preferences, makes a real difference, supporting people to live well until the end of their lives. We argue that the pressing priority to provide optimal end-of-life choices requires people to have timely access to high-quality palliative care which is currently not the case for many who receive too little too late or no palliative care at all.

CHAIR: Thank you very much, Dr Douglas. Dr Good, do you wish to make any statements at this point?

Dr Good: No.

CHAIR: Firstly, thank you for reflecting the views of the Australian and New Zealand group representing palliative medicine. In our travels to date—and this is not taking away from the excellent work that we see; I have seen it personally—we have heard that access to good palliative care is something that is needed throughout Queensland, particularly in rural and remote regional Queensland and you did touch on that. It is a vast state and it is difficult to put any services in those areas, let alone specialised palliative care, which is a specialty in itself.

We have also heard from palliative care specialists directly that there is sometimes a gap, albeit sometimes a small gap, where even the best palliative care and the best intention of giving it does not relieve the pain and suffering of a person. We must have regard to the people who have come before us including, as I have referred to publicly, Dr Will Cairns in Townsville who has 40 years experience and the many palliative care nurses and patients. Their position is that we should have choice in providing access to a voluntary assisted dying scheme. That is, I know, different from page 12 of your submission and your recommendation around voluntary assisted dying, which is to refrain from legislative change.

Of course we need to have regard to every person who has come before us. It is a difficult issue to navigate and there are divergent views. I do not for a second take away from the important work that palliative care specialists and palliative care nurses do in our society, but when we hear from those actually giving drugs we must have regard to them. I take on board your position. Of course, the committee will ultimately have to make a decision going forward.

I do not know whether you can talk to part of your membership that might have a different view. When we speak to Will Cairns, we have to listen to the specialists as well. I know that you are specialists in your own right.

Dr Good: You raise very good points. I think what is clear in ANZSPM's viewpoint is that they do not see voluntary assisted dying as part of palliative care practice. I think that is very clear. There is a fair bit of consensus around that from that point of view. The viewpoint of individual members about voluntary assisted dying would reflect the diversity of viewpoints in society. We are a society that has members. No society is going to have a 100 per cent viewpoint on anything in particular. As I have talked about here before, I think a lot of the issues around legislation are societal issues rather than medical or health issues. In that sense, we are all individuals in a society and everyone is going to have some divergent viewpoints on that.

I think the important thing to state from the point of view of our society is that whatever the state of legislation is—whether voluntary assisted dying is legislated or not legislated—as doctors we all have a commitment to good care of the patients. It needs to be very important and clear that, if people do not agree with legislation coming in or not, that does not affect your medical practice. We all feel the same about an idea of non-abandonment of patients. We are not judgemental of patients.

It is not that much different from what happens now, in fact. It is not uncommon for us to encounter at different times in a patient's trajectory the patient expressing wishes of an early death. That does not stop you looking after a patient. It does not stop you from giving good care to a patient. Our role as a palliative medicine specialist society is that we need to aim to provide the best care we can give whatever patient choices are.

Palliative medicine is one of the areas where that happens a bit better than in a lot of other areas of medicine. In general, we think of ourselves as pretty non-judgemental. I will give an example. We have patients who may get a cancer diagnosis. There will be a variety of times when the patient decides that they want to take mainstream medical approaches to that and at other times that they want to take non-mainstream medical approaches to that. No matter which way people choose, from a palliative medicine point of view you are still there to support the patient with their symptoms and to support the family. I think that would be our response. It is really important that, whatever happens, we continue to provide as good care as we can and support for patients.

Dr Douglas: Based on practice, we often hear the description of patients being in unbearable pain or having unbearable suffering. I would say that the experience of palliative medicine specialists is that the person who is expressing a wish to die earlier often is doing so due to a suffering that is in anticipation of what might occur—the loss of dignity, the reliance on others to provide them care eventually.

It would be a very unusual circumstance today—and I cannot comment; we have just been listening to the previous submissions and there are clearly people who do not have timely access to symptom control, but in my experience of patients who have proceeded in various circumstances

over the years to seek an early death it has not been about uncontrolled symptoms. I think that is a very important point to make. The will to live in progressive disease fluctuates constantly. The will to die or the wish to die fluctuates constantly. As Dr Good has pointed out, the ability to have the language and communication to have those conversations with your patients often in their despair and when they are suffering can change their ability to manage. We are not coercive. We are not persuasive, but it is very interesting when you see patients day to day, especially in an inpatient setting, how one day they can be despairing and the next day they are actually enjoying or feeling more comfortable with the position they are in.

I also want to say that when you practice in this area and you are very close to it, our experience is that people want to live as long as possible. One of our major roles is trying to advocate regarding life-prolonging treatments or what are suggested to be life-prolonging treatments. I think it is very important to see that humanity in general want to live longer—people want to live longer. It is a minority of people who, because of the perceived or anticipated suffering, are very clear that they want to shorten their lives when they have particular diagnoses.

CHAIR: A starting point is perhaps the budget announcement of \$17 million for regional and remote palliative care services. I think it is a good starting point. It tells me that others are watching the work that we are doing and having regard to the information that you have submitted, that Palliative Care Queensland have submitted and that other stakeholders have submitted. I think there is more work to do, but it is a good starting point in this journey. I thank you for your contributions. I now move to other questions.

Mr BERKMAN: Can you explain for the committee how the society arrives at its position? Obviously we are talking about voluntary assisted dying. How does the membership contribute to that? How is a consensus or a final position arrived at?

Dr Douglas: I am happy to answer that because that was some of the work that was undertaken in the time that I was the president. We surveyed all of our members across Australia and New Zealand, and 76 per cent of the doctors were opposed to the introduction of law. In the minority, about half described themselves as neutral and a minority were in favour. As Dr Good pointed out, that was a reflection of the individuals' views, but as a society we needed to reach a position on this based on a consensus view. That is how it was reached, and it was very carefully carried out. Is that what you are after?

Mr BERKMAN: Yes, absolutely. I am happy to hand over to others.

Mr O'ROURKE: Throughout some of the meetings that we have had we have heard some really harrowing stories about people wasting away in extreme pain and suffering. Other people have turned around and said, 'It is just that the doctors are not prescribing the right drugs to ease the pain.' There would be times when you cannot manage the pain; is that right?

Dr Good: Pain is a funny word, in a sense. There is a broad sense of what pain is. I think pain is a word used sometimes instead of suffering. If you are talking about this idea of pain as suffering and can we get rid of everyone's suffering, of course, nothing can get rid of everyone's suffering. Suffering is a broad existential concept. Pain is one part of that from a physical point of view.

What we can say is that it is very rare in our practice that people express to us a want to shorten their life because of pain. That is the first thing. The second thing is that, where voluntary assisted dying is introduced, it is very, very rare that it is asked for because of pain and it is very, very, very rare that it is ever used because of pain. We have to be careful about this mismatch between saying, 'Because some people are having terrible pain and suffering,' which I am not disagreeing with—it happens; it is there—'therefore, we need voluntary assisted dying to fix this problem.' That is a simplistic response to a complex problem.

A number of things have been presented that are harrowing circumstances, in submissions and things like that. One of the things that I deal with a lot and as a committee you need to think about from a societal point of view is: is the legislation being introduced going to fix the issues that are being presented? They are two very different things. There are lots of presentations around wasting, as you are describing. I have read lots of submissions around dementia and people dying. I was asked here about terminal sedation. In many ways, many of those examples would never fit any legislation for voluntary assisted dying that is currently available in the world or is currently proposed anywhere in the world.

All we can say from our viewpoint is that, obviously, what we are trying to do every day is to help people's pain and suffering. That is what we are trying to do. Are we like anyone and do it perfectly? Of course we do not do it perfectly. Do we always get it perfectly right? To think that

voluntary assisted dying is somehow going to fix that issue is very naive, because even when it is introduced it is very rarely used for that. Even when it is introduced, like every medical procedure, it has adverse effects and does not always work as we would like.

As I was saying, we try every day to help people with pain and suffering. One of the things that we would advocate is to try to improve palliative care services for every person in Queensland. That is what we are advocating in terms of trying to increase the number of palliative medicine specialists and increase the access to palliative care. That is where we are advocating. One of the things that we need to make very clear is that we think doing that will make a bigger difference to more people in Queensland than will other things proposed.

Ms PEASE: Thank you very much for coming in and for your great work in the community. I know how hard you all work and it is a very difficult job. You have relayed many of the things that I wanted to talk about. There have been harrowing tales from family members. I am going to go further to what my colleague was saying about being sedated or starved to death and the terribleness of that for the people—their carers and loved ones—watching that; that we do not treat our animals that way and, if we did, we would be charged criminally for that. I know that you have given an explanation and talked about how you can give things for suffering and pain. But how can you answer those people? How can we respond to people who have witnessed a loved one lying there, starving to death and crying out? I would love to hear how you would respond to that. No doubt, you would see people like that every day. They are starving, wanting to die. The only way that they feel they can achieve that is by stopping food.

Dr Douglas: Could I start? My experience is in acute—my most recent few decades is in the acute setting. You are asking us to respond to what you are talking about. In fact, what you are talking about is a very broad medical system that is caring for people at the end of life. If you are asking us to respond, I think it is really about what can we do as a society, what can we do to improve the care of any patient who is approaching the end of life and is cared for by a multiplicity of different clinicians? From our perspective, when we receive a referral for such a patient we employ all of our knowledge and our skills and our compassion and come to the bedside. We try to engage that patient and family in a discussion about what is going to improve the situation. Perhaps it is because—and it is because—our training gives us particular skills and the experience that we have to recognise that suffering.

I can tell you in my day-to-day work that there are patients whose suffering is not recognised. Very often the clinical imperative is to improve the metabolic parameters, to look for signs of improvement that we would say is not an overall improvement of that person with a lack of recognition of the suffering. Part of what we have to do in palliative medicine is to engender those skills more broadly within the medical profession, within the nursing profession, so that they can address what is important to the patient.

If you are asking us what we can do, we address the person-centred suffering. We have to understand the underlying clinical conditions so that we understand the way the patient is being managed. It is incredibly distressing to hear anecdotal accounts of what happens in facilities anywhere—whether it is in community facilities or in hospital facilities. Very often we are put in a position to respond to that and when we look at what has happened over a period of days or weeks it is very difficult to read and to understand and to go to those meetings and try to meet those patients or bereaved people who are dealing with their bereavement and the grief from what they saw.

It is very easy retrospectively to say, 'This should have occurred,' but this is about the broader medical system and trying to improve the understanding around end of life. Unfortunately, end of life is sometimes not even recognised. I can walk into a room and see a person is dying and they are still connected up to A, B, C, and D and it is not helping them at all. How do we respond? We respond with our compassion, a strong evidence based approach to the way we manage the symptoms, how we care for that patient and how we care for that family with a view to how is that family going to cope after that person has died.

There is no panacea to this, but I think, certainly, with what is facing us in society and the tsunami of work that is coming towards us, this is going to become an increasing issue. How we are going to manage it is we have to embed at least fundamental skills in other disciplines.

Ms PEASE: Thank you, Dr Douglas. I understand what you are saying. I am trying to get an understanding, because those are the stories that we have heard.

Dr Douglas: But it is not the responsibility—we are not always there. We are only there in a minority—

Ms PEASE: I understand that, but what I am trying to understand is, if you were there, how could you respond to those families who are watching this happen? That is what I am trying to grapple with—from what we have heard and what these family members have seen—to be able to understand your position. We have to come at this with an open mind and be fair and listen to everyone's stories and journeys, and we hear such harrowing tales. These people cannot go back to work. They have suffered PTSD. As a family member, they have not been supported or cared for whilst they have watched their loved ones starve to death or die a terrible and horrific death. I know that, in hindsight, you might not have personally been there but, as an organisation, you have taken this position. That is what I am trying to understand; how to justify that position.

Dr Douglas: Going forward, I think what is going to be critical is the workforce in Queensland—the specialist workforce—because it is the cornerstone of improving end-of-life care in this state. You have heard the directors group, which we are members of, talking about what are the changes that have to occur in the system to allow for improved care. I think that has to be listened to. I know there are huge gaps in Queensland where there is a lack or paucity of specialist palliative care. Calls are received every day in metropolitan areas from practices, from hospitals, from doctors who need support with really complex care.

Ms PEASE: Thank you very much.

Dr Douglas: Thank you.

Mr McARDLE: Thank you, doctors, for being here today. Dr Douglas, one of the things you said was that the knowledge of palliative care is very sparse and the capacity of palliative care is more so. The member for Lytton outlined that we have heard a number of people talk about their personal experiences in relation to a loved one passing, but we do not understand how many of those people who were passing did not have access to palliative care or did not have access to what I would say would have been quality palliative care. I think that is your point, is it not? There needs to be an increase in workforce and in funding so that those people who are regional, rural and remote or in the south-east corner get that access. That may reduce the number of incidents we hear of people who go through—and I accept—horrific situations. Could you comment upon that?

Dr Douglas: There have been some foundational changes in Queensland. We have a palliative medicine training program with a view to improving or increasing the number of palliative medicine specialists. What we have not been able to attract interest in is increasing the number of specialists. In other words, you need the government to say, 'We need to fund further positions in palliative medicine across the state.' We have regional areas that are funding for one full-time palliative medicine specialist and they are unable to hold on to that particular individual or person. Therefore, there is not the capacity until you build the number of specialists in an area, to train in that area and build the capacity of palliative care and palliative medicine.

The other part about it is that you may have a palliative care service there, but you need the treating teams to refer the patients—general practitioners who feel that they are working outside of their scope or who need additional support and need to refer. It is the access—

Mr McARDLE: Correct, the access to and treatment by.

Dr Douglas: And treatment by, yes.

Mr McARDLE: We were on the Gold Coast on Tuesday with a very similar hearing. We had before us two medical directors of the Gold Coast HHS. One was in palliative care. He said that the 2018 FTE figures for palliative care in the HHS were 25.1 and they were broken down into a variety of specialities. I then asked him what that figure represented in relation to a time at which it covered the population adequately and he said 1992. Does that surprise you?

Dr Douglas: Not at all, because I have looked very carefully at the workforce across Queensland as part of my role. I think in an earlier submission you took my work where I had looked at the number of palliative medicine specialists in the state in respect of what we needed to grow to in order to reach a benchmark. That does not surprise me at all.

Mr McARDLE: The other point that I have heard from different HHSs is that funding is allocated to the HHS, or allotted, but in a number of HHSs there is no necessity to spend the money on palliative care; it can be moved. It can, therefore, be spent in the acute setting, shall we say, not in palliative care. If we are going to have a regime that delivers a long-term benefit, would you agree—and your submission indicates this is the case—that we need a system approach to palliative care that requires integration of HHSs and PHNs but, more importantly, a robust financial model that makes all accountable for how they spend the funding?

Dr Douglas: Yes, there has been an historic difficulty in understanding how the funding has flowed from Queensland Health to the HHSs—who makes that decision, what it is based on and where that money goes. Additionally, there has not been an increase over time based on per capita, or whatever they are doing. Also, historically, there was a national partnership agreement that came out a few years ago that money was to flow to rehabilitation services and palliative care. I can say categorically that at that time a significant amount of that funding went to rehabilitation services and, in my personal experience, nothing came to the palliative care services in my area. That is absolutely accurate.

Dr Good: I absolutely agree with the need for accountability. I think it should be turned around. Rather than saying, 'You have this much money for palliative care, therefore, you should spend it,' HHSs are given minimum standards of what they need to provide and they need to show that they are providing that service. The emphasis is then on the HHS to report back that they are providing that service so that there is accountability. That is what you are saying: that money is being provided but there is no accountability of that money being spent in that area.

Mr McARDLE: Correct. The other point goes back to my colleague's questions in relation to events relayed to us by family members. I do not mean to disparage this for one second. I do not think we know enough about the physical process of dying. That is an important concept. More importantly, it is important that we understand the process. We have heard that the person who is passing is not aware of a lot of the symptoms that a third person may observe. I am not saying that is right or not, but trying to understand the process of a person passing, I think, is equally important for the committee so that we can then reflect upon events that we have been informed of without for one second diminishing the emotional impact of the third party observing a loved one passing away.

Dr Good: I think that is a really important point. Going back to the member for Lytton's question, one of the really emotional things, and something that we deal with every day, is this idea of food and fluid at the end of life. That is two things. The third thing is breathing patterns that people have at end of life. There is a lot of literature around food and fluid and this term that you use of 'starvation'. It is a term that you have to be really careful about using. There is a very big difference between feeling hungry and not being provided with food and not feeling hungry and not being provided with food. Probably almost every single day of my clinical life I get asked about food and fluids at end of life. The answer to the question you are asking and the answer to the question that was asked before is that we have to be really careful about what the person is experiencing. In my experience, patients, as part of the dying process, or an illness process, get less appetite. Often for the patient themselves, that is not as disturbing as it is for the family.

Likewise, you described this idea of wasting, or cachexia, which is disturbing for everyone. It is disturbing for the person in a sense of, 'I'm seeing my body change' but, from a physical point of view, it is not so disturbing for them. In terms of the thing that goes on about breathing at the end of dying, there are a number of breathing patterns that people experience. For the most part we think that people are unaware of their own breathing patterns, and they are often reflex breathing patterns, but for someone who has not seen them before to watch them can be quite disturbing. A really good example of that is this idea of a thing called secretions, or respiratory secretions—that gurgling breathing that people describe. It is known anecdotally as death rattle. I have heard it many times but, in hearing it, I still find it on a level disturbing, because it sounds like someone is drowning. That is how on an emotional level I understand it, I see it and I experience it. I know, though, that on an intellectual level the person is not aware of it. In all of my experience of seeing patients I have only ever had one patient ask me, 'Is what I am having the death rattle?' They were right. They were having the death rattle and it was not disturbing them.

For most patients, a lot of what is happening at end of life—dying—is reflex events of the body, which is not disturbing that person. For us watching, it can be everything from peaceful to very disturbing. Explaining to people what is happening at the end of life and a good understanding of what could be upsetting or disturbing the person and what is not disturbing makes a big difference. A lot of our work as palliative medicine specialists is often to just go in and explain, 'What is happening here now would not be disturbing the person, because they are unaware of it' versus, 'This person seems to be disturbed and they need more medication to try to make them more settled.'

Dr Douglas: If I could just make one further comment, it goes back to the question by the member for Lytton regarding starvation and the fluids. When we go in and have that careful discussion with the patient and family, we often make decisions that are not medically based and continue fluids. We may turn them down so that the patient does not overload. That is often so that the family feels more comfortable that the patient, despite the dying process, is going to continue to have fluids. I think that is the difference often between just stopping something because it is not seen to be clinically

relevant and going in and negotiating. We have the same thing with food as well, especially with some ethnic groups where it is very distressing for them if they are told, 'Do not feed the patient.' It becomes a compromise to make sure that they are able to do what is important to them culturally, but it does not put the patient at much further risk. It makes them feel more comfortable about the way the patient is being cared for.

Mr McARDLE: I think we all agree that we are not for one second diminishing the grief and the grieving of a family member. Let us assume that VAD becomes law in this state. The draft bill by the QUT professors indicates that a medical practitioner can be involved in that process. That is a very wide definition under the relevant legislation. It can include a GP. My concern is that a GP may well know the individual. Without attacking GPs, are they the right person to be involved in that process given the intimate knowledge required, I would have thought, to make a proper assessment, let alone bringing in outsiders—psychologists and the like—to make a thorough assessment of the person's not just free will but their medical status as well? If you cannot answer, I accept that.

Dr Good: There are various models around the world. It is hard to know what people would consider to be the best model for that. One thing to say is what you are talking about is this idea of autonomous choice and the idea of the decision-making of the individual with the people around them, including families but also general practitioners or other medical staff and healthcare staff. That is a very western ideal. I am not sure in practice many of us would ever see an individual too often making an individual choice without any reference to a broader community or society.

Mr McARDLE: Thank you.

Mr BERKMAN: I want to preface my question by saying that I accept completely that VAD is not part of palliative care and that we need a massive increase in funding for palliative care for it to be done right everywhere. I ask this question in the context of evidence that we have heard that oftentimes medicines for VAD are accessed but not used—that is, we have identified that there are some gaps in terms of the existential suffering that people face at the end of their lives. The evidence that we have heard is that simply having that option available to people alleviates that to an extent. I am interested in your personal experience. Have you seen that that kind of choice, including VAD, can play an important role in addressing existential suffering?

Dr Douglas: If you are interested in a very limited experience, yes, I have had patients who have accessed medication through the web—however they do it—and yet have not acted on that. It is a poor analogy, but I often think of people who need to have a temazepam in the bedside drawer if they are not sleeping but seldom use it. The evidence from Oregon is that something like 75 per cent of the prescriptions that are provided in a year, which has not increased dramatically since the law was introduced there, are used eventually. It is a very low number—about 125 or 130 and about 70 or 80, from the data per year, use the medication. There is certainly a number of people who hold on to the medication and continue to live and continue to be supported. I think that it tells us a lot about the fluctuating will to live and the fluctuating will to die.

What exactly is existential distress? What feeds into existential distress? As Dr Good alluded to, when you are practising palliative medicine those sorts of requests are happening all the time. Often, the opening gambit from a patient is, 'Okay, are you going to be the one who is going to give me the needle?' We address that. We have the skills to untangle or tease through what is driving those thoughts and help them with that. Very often they will come back to us with far less distress about what the future might look like. Not understanding what is going to happen in your disease, not understanding how we can anticipate what the problems are going to be as you go along, drives distress. Poor communication, a lack of understanding about where they sit with the condition—'Am I going to die this week? Next month? Next year?'—and sitting with someone who honestly tells them, 'This is how I see it. This is how I see the length of your life,' gives them the ability to plan, to start thinking about the issues that are important and what their end-of-life care might look like. I think that is fundamentally how we address that existential distress. Everyone has existential distress to a greater or lesser extent.

Mr BERKMAN: Thank you.

CHAIR: I thank you both for your contributions today. It has greatly assisted the committee going forward. We will break for 17 minutes and resume at two o'clock.

Proceedings suspended from 1.43 pm to 2.02 pm.

O'FLYNN, Ms Michelle, Director, Queensland Advocacy Incorporated

ROWE, Mr Geoff, Chief Executive Officer, Aged and Disability Advocacy Australia

CHAIR: Would you like to make an opening statement?

Ms O'Flynn: Yes, thank you very much. First, I would like to respectfully acknowledge the Turrbal people, the traditional owners of the land on which this event is taking place, to pay my respects to elders past and present of the Turrbal Nation and to extend that respect to other Aboriginal people present. By paying respect to the first peoples on whose land we gather, we acknowledge the loss of lands, cultures and treasures, knowing the consequences for people, communities and nations. Given the common goals of our work, we bear this in mind as we meet today. In reference to today's inquiry, I acknowledge that far too many people with disability have experienced a threat to their very existence by well-meaning but unknowing members of community and some of the medical profession. This is without doubt experienced more harshly and with greater frequency by our first people.

It is important that those who seek voluntary assisted suicide have a greater understanding that their wish to die because of fear poses a great threat to vulnerable people with disability. We are here today in the shadow of the world of euthanasia, which was created by Nazis. It was first used to murder children with disability to end their misery, before turning upon adults with disability and mental illness, and then upscaling to eliminate Europe's Jewish population. Today's modern medical professionals are not Nazis, but the premise of ending misery is still a foundation for killing people. People with disabilities are always on top of that list.

Our submission explains in part the societal devaluation and patriarchal responses to disability and how this has meant that people are constantly fighting for their lives, for their rights to basic health care, to be born and most of all not to be killed either in utero, during life or at any time that they may present in hospital. I have heard many parents tell me that, whenever they have attended hospital with their loved one with disability for very routine medical treatments, death making has been offered to them to relieve them of their burden. The crux for seeking voluntary assisted suicide, as mentioned by the presenters before me, is that pain and suffering is not usually what leads people to seek to end their lives; it is about the fear of becoming a burden.

The submission brings together the trends that individually threaten the lives of people with disability, but that have not been examined in detail when considering the rise in demand for assisted suicide. One of the most recent trends in Australia is the death pod, designed by Philip Nitschke. It is a portable machine that allows users to administer their own death in a matter of minutes. Although users are supposed to pass an artificial-intelligence powered test to determine their capacity, the details of the test are not specified and it is very unlikely that it would offer authentic supported decision-making. The expedience of this kind of death making has increased the risk for abuse and is a subtle means of coercion or even blatant misrepresentation and trickery, which could be used to terminate the lives of vulnerable people, including children, the elderly or disabled members of our community.

As mentioned before, in the state of Oregon where assisted suicide first became legal the main end-of-life concerns for people considering assisted suicide were, in fact, not about inadequate pain control or concern about physical pain. Those were not even in the top five reasons for seeking it. It was about burden of care. There is the story of Brittany Maynard who sought assisted suicide through Oregon and got it. She was a returned veteran. Another person had exactly the same diagnosis for terminal brain cancer. He said that if that had been available to him at the time he may have taken that opportunity. However, as it was, he sought other treatment and extended his life for three years more than his prognosis. Through the support of family and those around him, he resolved to fight efforts to legalise assisted suicide, because it gave him time to think more on it. He dedicated the last years of his life, as the president of Patients Right Forum, to working on behalf of patients to oppose legalising assisted suicide. His family say that they dedicated the last years of his life this way because they recognised the death with dignity movement for what it was, that is, a well-funded rebranding of euthanasia offering nothing but a message of hopelessness.

Canada is such a wonderful place, but its liberal laws on death making are under scrutiny as the lobbyists have sought to undermine the proof of capacity as a protection when making those decisions. It was considering advance requests so that people could seal their fate before losing capacity, but it actually meant that people were refusing treatment that they needed and thus experiencing more pain and were fast tracking their death making. It also created a loss of opportunity or a right to change their mind once they lost their ability to communicate effectively about any change.

Canada's laws required the government to commission an independent study focussed on whether the law should be expanded to include three types of patients: those who want to make advanced requests, patients whose sole purpose for seeking a physician assisted death is mental illness and mature minors. I know that that has been considered here. The Queensland Council of Civil Liberties, for example, has suggested that 12-year-olds are mature enough to be able to make those decisions.

More and more reasons are emerging to kill people who are not heard, including the rapidly expanding scenario in Canada and some western European countries whereby a person dies by euthanasia with a legalised lethal injection that he or she has requested, and the body is then operated on to retrieve organs for donation. Euthanising patients for their organs is gaining frightening traction. 'Donation after death' is the term. That is a very mixed scenario to get into, but certainly it does seem that it would fast-track people who may consider voluntary assisted dying and the coercion that could be used with the increasing need for organ donation. The speed with which we are headed towards death making is truly frightening, despite the many voices that say it cannot come soon enough.

CHAIR: Thank you, Ms O'Flynn. We will move straight to Geoff Rowe from Aged and Disability Advocacy Australia.

Mr Rowe: Thank you for the opportunity to present to this inquiry this afternoon and for the opportunity to attend yesterday's investigative hearing to talk about Earle Haven. I will take our submission to this inquiry as read. It has raised a number of issues, primarily around aged care and some issues around palliative care. We have indicated that, as an organisation, we do not have a view on voluntary assisted dying at this stage.

There are probably three main issues that I want to touch on in my opening statement. Primarily, they stem from the lack of human rights within the aged-care environment. I want to raise with the committee our concerns about the interface between the health system and the aged-care system in Queensland. It is not working. We are seeing a fast-tracking of older people in the hospital system directly into aged care, and that is occurring against their will. It is also occurring because of the lack of home care places available through the Commonwealth Home Care Program, noting that there are currently 127,000 Australians on the waiting list for that and there are vacant beds in aged care. We are seeing people being fast-tracked into aged care. We also are very much aware that, when aged-care providers find someone who has behaviour difficulties or issues, they will admit them to hospital, backfill their bed and refuse to take them back into their system. Therefore, the conflicts between the aged care and health systems are on the part of both parties.

We believe that some of that could be resolved in part by allowing older people within the aged-care system access to the main care health services that are available to the rest of the community. I am talking about mental health services, allied health services, and aids and equipment. As I outlined yesterday, we are quite disturbed at the increase in the use particularly of chemical restraint in aged care, which is often seen as the first resort rather than the last resort. The lack of access to mental health, psychology and counselling services means that service providers frequently opt towards chemical control rather than just dealing with the health issues or trauma at hand.

Finally, I would encourage the committee to support the aged-care workforce strategy. There has been a lot of work done on that in recent years and you will have heard to date in your hearings about the lack of trained staff and appropriate staff in aged care. Aged care is not seen as sexy. I think we can change that. Certainly it has been mooted that, between aged care and disability, it is being seen as a major future employer. I think there are some real opportunities for all Queenslanders if presented, marketed and supported by the state government to fill some of that void.

CHAIR: Thank you very much, Mr Rowe, and thank you for your contribution on the Gold Coast, as well. I think you have referred to points that we have already heard today around the use of chemical restraints and a number of other concerns in the aged-care sector. We do thank you for that. I have been reading through Ms O'Flynn's submission and I take some issue with the references to Ward 10B and abuse in child youth detention centres. Taking a leaf out of the member for Lytton's book, I find the words around the Nazi holocaust and how that war was strategised as particularly offensive, to think that the work we are doing in the modern age is reflective of what happened then. Going forward, the committee will make a ruling on your evidence today, because to some extent I do not think that is relevant. Are there any questions?

Ms PEASE: I have some questions for Mr Rowe—not really questions but just commenting on the need to develop the workforce and training the workforce appropriately. I agree. I saw a lovely story this morning on ABC News that in New South Wales there is a great initiative about encouraging Brisbane

young people to get involved in the disability care working space. I agree with you; I think we have a great opportunity and there is an opportunity to develop those areas, particularly for young people. Thank you for that.

CHAIR: Are there any other questions?

Mr McARDLE: I do have a couple. Mr Rowe, you made the comment about increasing the workforce and a strategy, and I do apologise: what is the document you are referring to in relation to that strategy?

Mr Rowe: The document is referenced in my submission. There has been some subsequent work undertaken by the Commonwealth around the workforce development project and I am happy to forward that information to you.

Mr McARDLE: If you would not mind doing that, that would be fine. What does the workforce strategy look like in relation to allied health professionals and the like becoming more and more involved in aged care? A very simple question.

Mr Rowe: That is a good question. The strategy that has been developed has focused on the primary care workers within aged care, although it has also involved the allied health industry in consulting and developing that. To support people to live longer in their own home, it means that people need to continue to be mobile and it means that they need modifications made in their homes so that they can continue to live et cetera. The allied health workforce has certainly been flagged as a growing need within that work plan.

Mr McARDLE: Many aged-care facilities have a mix of RNs, AINs and ENs or PCWs at the moment, but there are not that many who have a tail of allied health professionals embedded within them. They might come in every now and then but infrequently.

Mr Rowe: Infrequently, yes.

Mr McARDLE: In terms of the importance of allied health professionals—and that includes diet and exercise as well—can you give an indication from your point of view of the critical nature of the work that they would do in keeping the residents not just healthy physically but mentally as well which would then enable them to join in in relation to their community called the aged-care facility?

Mr Rowe: It is perhaps not the best reference, but the ABC documentary that is currently on, *Old People's Home for 4 Year Olds*, really highlights—

Mr McARDLE: Isn't that brilliant?

Mr Rowe: It is brilliant, yes. My wife is an occupational therapist and watching that she said, 'That's the sort of thing that OTs do and should do.' They were trained to do that when she studied some years ago. I think as aged care has developed, we have lost the involvement of the allied health sector. It has become far more transactional. The relationships that used to happen within aged care do not happen as much. There is talk about reablement—about people being supported and assisted to return to their pre-injury or pre-surgery or pre-fall abilities—but I think the reality is something different. One of the frustrations I suppose, as I said in my opening comments, is that people's ability to access the external health system, once they are in aged care, becomes very difficult. It is almost like they have moved to another country. The doors and opportunities have just been closed on them, and they need to be reopened if people are to have a quality life.

Mr McARDLE: Would you agree that the model we have now existed 30 years ago or even longer?

Mr Rowe: Potentially, yes.

Mr McARDLE: Yes, exactly, but that model is broken—inherently broken to the point that we are seeing the outcomes before the royal commission and the issue with Bupa that is now in the media headlines. Do we now need to move to a consideration of a complete new model? If not complete, then a new model?

Mr Rowe: Certainly I struggle to find a reason to advocate for the current model.

Mr McARDLE: One of the things you raised yesterday—and we did not really get a chance to explore it because the hearing had a particular focus at that point in time—was your call for human rights in relation to aged care. Where would that sit? Would it sit at the federal level or would it sit at the state level, with all of its complications at a state level, and how would you enforce it? Would you volunteer yourself to run the human rights in aged-care facilities?

Mr Rowe: It is a kiss of death. It would be a very exciting thing to do. We do have a Human Rights Act about to be enacted in Queensland and I guess we are optimistic that that will flow on, but there needs to be support. You cannot just have an act on a wall without support for rollout, and Brisbane

rollout means education. Yesterday I mentioned that if we look at the Disability Services Act what underpins it are human rights. If you look at the Aged Care Act, what underpins it is a funding model; it does not talk about human rights. Older people have no rights. We need to change fundamentally the way we approach the delivery of our aged-care services. I go back to my statement: older people should have access to the same resources and the same things that you and I and people younger than us have access to. They are Australians; they are Queenslanders. They should have access to quality health care. They should be allowed to make decisions.

It is the decision-making I suppose I did not particularly touch on yesterday—and this does fall within the state government gamut—but we see time and time again and hear stories of an attorney, so a son or a daughter, going into the aged-care facility and saying, ‘Mum’s not to have any visitors, she’s not to have any phone calls, not to have any spending money and not to go out,’ and the aged-care staff say, ‘Yes, right, you’re the attorney.’ That is not the role of the attorney. There is a complete lack of understanding within Australia about what the role of an attorney is under an enduring power of attorney, so there is abuse happening. There are human rights abuses. Financial abuse is rife. As a society we all pay for the financial abuse of older people because more and more there is an expectation that older people, where they can contribute to the cost of their aged care, will, but if they have had their finances taken by someone else their capacity to contribute is zero and it is us as the taxpayers who need to meet that cost.

Mr McARDLE: Would you agree that the process at the moment removes a resident’s right to have access to the right to decide their own livelihood?

Mr Rowe: As a general statement, yes, that is true. As I tried to say yesterday, the difficulty with the royal commission and hearings of this nature is that the focus is on what is broken and you hear about the services that are broken. There are some services that do fabulous things and some staff who are just doing brilliant things, but it is the ones that are not doing it well you hear about. Whether it is through ignorance I am not sure, but there are human rights abuses happening within our aged-care system every day of the week, and some of them do not need to occur. As I have said, some of the mechanisms that have been put in place to protect people are being used to abuse people, and that is wrong.

Mr McARDLE: Ms O’Flynn, I want to echo the chair’s comments. Having read the opening few paragraphs of your submission, they may hold that point of view. I do not. Whether I support VAD or not is beside the point. I think the line you are trying to draw from an era that was repellent and repugnant is not appropriate for discussion here before this forum. That is only a comment. I take your point of view as your point of view.

Ms O’Flynn: If I may add something with regard to the words and the voices of people with disability, I did ask a committee member with a disability to join me, but they were unable to attend. The reality for many people with disability, despite the fact that it is not dressed up in the horrors of Nazi Germany, is that mercy killings still exist—that family members still kill their family members with disability and get off lightly. Often the conversations are around the commitment and love that that family member has given to the person with a disability and that is the focus rather than whether there was any value to that person’s life, and it is devalued in their death. For many people with disabilities, the foundations that lay behind the horrible things that were done all those years ago are still real and valid now. While I respect that it is confronting and horrifying to think that our modern society still has any connection to those treatments of the past, it is a reality for many people. I have seen parents who have had to fight to have basic health care in hospitals for their loved ones because the person was deemed not worthy, would not feel the pain and, after all, ‘Wouldn’t it be better to let them go?’

CHAIR: Thank you very much, Ms O’Flynn.

Mr BERKMAN: Ms O’Flynn, your submission is very much just focused on one aspect of the broad inquiry that we are conducting, but we have heard plenty of evidence about the very arbitrary cut-offs for people with disability and their access to the NDIS when they are over the age of 65. I just wondered whether there was anything on that that you might like to add for the committee’s benefit.

Ms O’Flynn: I absolutely concur with what Geoff had to say about the aged-care system and the issues of people having autonomy in their lives in aged care is very harshly felt by people and younger people as well with disability who are forced to live in aged-care settings. Despite the constraints upon workers in aged-care settings—and we all acknowledge how under pressure they can be—the reality is that quite often people with disability who have disability support needs are not having those met in aged-care settings. Their health needs are not met, especially if they are people who are non-verbal or who communicate in different ways. Preventable deaths of people with disability occur every day in aged care and in community because there is a lack of understanding, particularly around intellectual impairment. While Geoff and I are here in different aspects of our work, we have much in common.

CHAIR: Thank you, Ms O'Flynn and Mr Rowe. We have an extremely tight time frame. We do appreciate your contributions here today.

THORNTON, Ms Christine, Private capacity (via teleconference)

CHAIR: Good afternoon, Christine. I am Aaron Harper, chair of the committee. We have your submission before us. You bring a firsthand experience with your husband, Troy Thornton, who chose to end his life with assisted suicide in Switzerland.

Ms Thornton: Yes. Thanks for having me.

CHAIR: I ask you to share with us and the people who are listening here today that experience and then we will open up to some questions.

Ms Thornton: Yes, absolutely. I guess he fought the long fight for as long as he actually could. When we started discussing what his choices were, we did a lot of research and found that he was able to do that in Switzerland. The disease was already ending his life. He chose to end his suffering and the incurable quality of life with dignity and respect and, in his words, 'a good death' rather than having to endure the horrible stage that the disease was getting to. He would have ended up in palliative care or full-time care, so we got everything organised. There were a lot of procedures we had to go through—a lot of paperwork, we had to do a lot of interviews. We had to go through a lot for us to be able to go over to Switzerland to start with, but once we were over there it was a really beautiful experience for us to share together. We would have liked to have done it in our own country obviously—we did not want to have to leave our family and friends to fly halfway around the world to be able to do it—but it was exactly how he had planned it. We were able to honour his wishes right to the end.

CHAIR: Thank you, Christine. I have a brief of your submission here. Talk to me about Troy's diagnosis. When was he first diagnosed and what was the diagnosis?

Ms Thornton: Back in 2014 he was diagnosed with degeneration of the back of the brain, the cerebellum, which was basically dissolving. There was no cure. Back in 2014 we were told that that was it. There was nothing we could do and we were told he would have around five years before the disease would eventually take him. It was a very slow process; it slowly attacked the body from being able to walk, talk, breathe, swallow—all the things that we all take for granted.

Last year in July the disease changed to the more aggressive form of the disease, which was multisystem atrophy. As soon as that was diagnosed in July they said, 'It will take you very quickly,' and that is when he said, 'I'm going to choose my own way out.' After being in the emergency services department for over 30 years and experiencing all forms of death from suicide to lots of things anyone can imagine when you are working in that industry, he said, 'I don't want that. I want to make my own choices.' That is how the disease started, but it took hold very quickly.

CHAIR: How old was Troy?

Ms Thornton: Troy was 54. He would have been 55 a couple of weeks ago. He was very active and he loved life. He was a very full character. For him to lose the ability to walk and talk was very hard. There was no quality of life for him.

CHAIR: I can draw some comparisons with him and his 30 years in the emergency department to my previous career. What was his role?

Ms Thornton: He ended up being an operations officer with the CFA at Mornington, just down the road. His dream was to be in that role. He made it to that role and was able to do that role for a couple of years before he had to retire.

CHAIR: Do you have children, Christine?

Ms Thornton: Yes, we have two children. We have a 14-year-old and a 17-year-old.

CHAIR: No doubt there was a broad and difficult conversation with your children—

Ms Thornton: But a very open one. The kids knew exactly—we had many open discussions. Nothing was ever hidden from the kids. We were all very open and honest. We are all at peace now knowing that he did not have to endure any suffering. We went on lots of holidays. We spent a lot of time with friends. Not many people get the chance to say goodbye and tell everyone how much they love them and how much they mean to them. We did not have to, like a lot of people do, sit beside him as he suffered and endured a horrible death. We were able to let him go out in peace.

CHAIR: No doubt you had the discussions about accessing palliative care, but he chose—

Ms Thornton: Absolutely, we talked about all of that. There was no way he wanted to do that. Basically, it ends up attacking—it basically stopped him from swallowing and breathing. We had a couple of times where he actually choked and luckily we were at home to be able to help him swallow what was stuck in his throat. I think it was a worry for him maybe choking on his own saliva or even from something he may eat and then choke. We were worried about coming home and finding him.

CHAIR: That is very rare. Thank you so much for sharing what was a very personal experience for yourself, Troy and the family. I do not think we have had this opportunity to date, despite the thousands of written submissions and people who have come before us. This is a unique situation of access and you are able to talk about the choices that you made. I think that is ultimately what we keep hearing: people are coming to us asking for choice.

Ms Thornton: Not everyone is going to agree, and you do not have to. It should be a choice. If you do not want to ever make that choice, then you never have to. I do not understand why we cannot allow people to make that choice. Until you are in that situation—Troy would never have thought he would make the choice to end his life. However, when you are actually faced with something that is incurable, there is no coming back. The brain is not going to suddenly start growing back. There was nothing at all. There were no mistakes. There was not going to be any new technology. This was it. We put our beautiful animals to sleep because we do not want them suffering, but we do not allow humans to have the same choice. I am not quite sure how we can still be in Australia and not have these options. That is what Troy used to get quite angry about. He did not understand how we do not allow that in this country, when it is supposed to have equal opportunities and rights. He was very passionate about not understanding how we have not made that change here yet.

CHAIR: That is the work we have in front of us. I thank you very much. I am going to open up to other members to ask any questions they may have.

Ms PEASE: Thank you very much for sharing your story and for your strength and your resilience. All the best to your family.

Ms Thornton: Thank you so much.

CHAIR: Christine, thank you so much for your contribution and sharing it with us. The other thing I am reading in here is that you had to fly halfway around the world, leaving your children, and at significant cost, which not everyone might have the opportunity to do.

Ms Thornton: No, not at all. We were lucky enough to be able to do that. I have spoken to a lot of people who actually have similar diseases. For some it has gone too far and they cannot actually leave the country now, so they are stuck in limbo and will have to endure the palliative care and a situation that we did not have to face. Yes, we are very lucky that we were able to do that, because a lot of people could not. It should not be an easy thing to do and there should be lots of boxes that you have to tick. I never disagree with that, because you do not want just anyone accessing it. It should be here.

CHAIR: You said there was a significant cost. Can you give us an idea of cost?

Ms Thornton: All up from going through all the paperwork, all the doctors and all those sorts of things to flying and getting over there, you are talking about \$30,000.

CHAIR: At that stage had the Victorian model been passed? When did this occur?

Ms Thornton: No. It was in February. Troy knew at that stage it would probably come in, but the problem with the new legislation is that it does not actually cover everyone. You still have to have a doctor who will sign off that, without doubt, you will likely pass away within the six months. The problem with a lot of these brain diseases is that no-one can actually tell you; it could be six months, 12 months or 18 months. Even with some cancers doctors are still saying it could be six months, 12 months or 18 months, which means those people will not be entitled to actually use it. There is a lot of work to do with how it has come into Victoria. It still will not cover everyone, but it is a start. We have to at least have it, so we can actually—

CHAIR: I am sorry to interrupt. What recommendation would you give the committee in terms of diagnosis and time frames to be considered?

Ms Thornton: I think you also have to take into consideration the people who actually have terminal diseases for which there is no cure and no hope. They are the ones like Troy who would have missed out from the legislation that is in Victoria. There still have to be two doctors agreeing that without doubt you will pass away.

CHAIR: Just to clarify my point, is there a time frame or a recommendation for the committee for its deliberations going forward? You talked about Victoria having six months.

Ms Thornton: Twelve months would at least allow a few more people to be included in that time frame. Six months is only a short period of time.

CHAIR: Thank you so much for your contribution today. We will end the call now and we will move on to our next witness. Thank you again.

BEALE, Mrs Laurel, Private capacity

SEARS, Ms Kym, Private capacity

CHAIR: Welcome and thank you for being here this afternoon. Would you like to make an opening statement before we move to questions?

Mrs Beale: My submission is about my husband's experience in palliative care and our family's experience watching on.

CHAIR: What is your husband's name, Laurel?

Mrs Beale: I have to refer to my notes as well, if you do not mind. Neil was the love of my life for over 54 years. He suffered a massive stroke at home, resulting in irreversible brain damage with no future quality of life possible. Just after his first scan I did manage to tell him what was happening. I think he understood because he lightly squeezed my hand and he shed a tear, so I knew that he knew what was happening.

The doctor gave us two options: we could either put him into a dementia ward in a nursing home or in palliative care. If I could stop there for a minute: how great would it have been if he had been able to have had one of those final injections and go to God in peace? The family could have said our goodbyes to him and there would have been no more suffering and no loss of dignity, which he did suffer in palliative care. But that is not what happened, because that would have been euthanasia.

We chose palliative care over the nursing home. To be honest, I did not even know what palliative care was. I soon understood that when a person has no future quality of life he could be medically assisted to end his life. He would be kept comfortable with drugs, but the very basics of life—food and water—were withheld until he passed away. Straightaway I thought, 'He's going to be starved to death.'

Palliative care was to become our reality. To be honest, it was soul destroying. It was not a pretty sight for any of the family. We believe that he was still in a little bit of pain. For six days and nights we all sat with Neil while this amazing man slowly let go of life. He was given no food or water, but was given small doses of fentanyl for pain relief and other drugs to dry up his body fluids and to assist with any anxiety he may suffer. From our perspective, as I said, he was basically starving to death.

When I said it was not a pretty sight, we watched him as he had fluid running out of his nose and mouth, which we wiped away dozens of times day and night. When his breathing was laboured we would start counting his breaths per minute. Sometimes it was four, sometimes it was 12, other times it was six. We were constantly checking his urine bag to see if his kidneys were shutting down. By the end of each day we could see his weight—he had a large frame—was falling off him. Our three children took it in turns each night to sit with him to let him know that his family was still with him.

We were assured that Neil was not suffering, but we believed he was in pain because he would frown. When he frowned we asked for more fentanyl. If it was within the time frame he would be given it, but if it was not within his time frame it was denied and he had to wait and suffer—we believe—until he was due for his next dose of fentanyl.

We also felt like criminals asking for more fentanyl because they said that that would be euthanasia. They said it was illegal and that too much fentanyl could be seen as euthanasia and hasten his death. In fact, they were prolonging his death. After six days in palliative care my husband passed away. He was aged 76 and his kidneys failed, obviously through lack of water. My youngest son, who was sitting with him all that night, witnessed his passing away.

My husband did not deserve this and neither did we. I pray that my family do not have to go through that with me in the future. I do not understand why he could not have been given one large dose of fentanyl over one day, instead of dozens of doses over six days which, as I said, prolonged his death. We euthanase our pets, so why not our loved ones as well? Even the worst kind of criminal on death row used to be given a lethal injection. They were not made to suffer. It was just terrible.

You can buy exit kits online to end your life. I know of one particular person who did just that. He went online and got this kit. He had terminal brain cancer and had excruciating pain in his head. There was no more medical assistance available for him, so he got his kit and ended his life with his family around him, without any more pain—and it was just lovely. Surely that alone indicates the dire need for euthanasia. I hope my submission will assist in the legislation moving forward, to assist those who are suffering with pain or with no possible future life, like my husband, to have the legal right to die peacefully, with dignity and on their own terms.

CHAIR: Thank you very much. Thank you for sharing your deeply personal story of Neil's passing. It must be difficult being only a month ago. So, first, I offer our condolences.

Mrs Beale: Thank you.

CHAIR: Thank you for articulating your wishes. Had you and Neil discussed this previously?

Mrs Beale: Many, many times.

CHAIR: Do you think it is something that he would have—

Mrs Beale: He had a health directive. I know we discussed euthanasia because he had early Parkinson's. He was on that medication, which was one of the reasons why I thought he would have been suffering when he was frowning because he would have had terrible withdrawals from the Parkinson's medication. It has to be tapered off over several weeks, not just cut off. That is what he would have been suffering from.

CHAIR: We have had it asked before. Some people are asking for the issue of accessing voluntary assisted dying to be placed—or saying that it ought to be placed—in an advance health directive. You said that Neil had one.

Mrs Beale: Yes. I have done a new one myself and I have put that I want to be euthanased if I am in that position.

CHAIR: That is interesting. Thank you very much. Thank you for sharing. I will open it up to any questions we might have.

Mr McARDLE: Mrs Beale, first of all, I offer my condolences. Neil sounds like a lovely man.

Mrs Beale: He was the love of my life.

Mr McARDLE: Of course he was.

Mrs Beale: We were a very, very close family. That is why the whole family sat there day in and day out.

Mr McARDLE: This is your daughter over here, I take it?

Mrs Beale: That is my daughter, Kym.

Mr McARDLE: Kym, would you like to come to the table as well? I think that is important. Welcome, Kym.

Mrs Beale: She was very, very close to her father.

Mr McARDLE: I offer my condolences to you, Kym, as well. Mrs Beale, I want to talk about what you said at the start. You made the comment that there was a choice between an aged-care facility and palliative care.

Mrs Beale: Correct.

Mr McARDLE: Looking at that now, either one would not have been right, would it?

Mrs Beale: That is correct, yes.

Mr McARDLE: Am I right in believing—if I am wrong, let me know—that the grief you are going through, which has been ongoing for some time, also relates to the choice that you and Neil made at that time?

Mrs Beale: Yes, correct. I am not saying that palliative care for this type of person should be stopped. I believe that euthanasia could be another arm of palliative care.

Mr McARDLE: What you saw Neil go through when he was going through palliative care emphasised to you that your choice with Neil was wrong?

Mrs Beale: I suffer with that.

Mr McARDLE: Exactly. Does that also bring with it a sense of guilt?

Mrs Beale: Yes.

Mr McARDLE: The guilt, I think, extends to you, Kym, as well. You feel guilty about joining your beloved husband and father in the choice that was made; is that right?

Mrs Beale: We had no other option. We watched him go through it—and we did suffer.

Mr McARDLE: Exactly—and you are feeling that guilt even today.

Mrs Beale: Absolutely.

Ms Sears: Guilt and sorrow that there was no other option given to him. Basically we were told that it was irreversible and that nothing could be done. It was on mum's shoulders if she wanted to continue treatment. If they prolong it, then she would be left with having to bathe him, feed him and cook for him, which she was quite fine with but, ultimately, if you knew my dad, he was an extremely proud man.

Mr McARDLE: Yes, of course he was.

Ms Sears: His brother had had a stroke and was wheelchair bound and he had always said he never wanted that for himself. We basically felt that we were handing a death sentence to him. We had no options. There were no options. It was one or the other: watch him die or prolong his death.

Mr McARDLE: What you saw your husband go through, Mrs Beale, during those days is, in your mind now, part of the guilt that you feel for the choice you made?

Mrs Beale: It was, especially when he lost his dignity. He was incontinent from having the stroke. One day a nurse thoughtlessly lifted up the sheet while my grandchildren were there and one of them actually witnessed it. He was embarrassed and humiliated. He was horrified at the thought that pop had this pad on.

Mr McARDLE: Mrs Beale, thank you again for being here. Kym, thank you for coming as well. You are very brave ladies.

CHAIR: Thank you, ladies. Thank you very much for your contribution. I apologise that time is slipping away. I ask Dr Andrew McGee, Mr Mark Thomas, Dr Zelle Hodge and Dr Steve Hambleton to come to the table. In the interests of time, we need to bring you to the table together.

HAMBLETON, Dr Steve, Private capacity

HODGE, Dr Zelle, Private capacity

McGEE, Dr Andrew, Private capacity

THOMAS, Mr Mark, Private capacity

CHAIR: I apologise that we cannot have you appearing before us individually, but I think it is relevant that we bring you together. Are there any opening statements before we move to questions?

Dr Hodge: Thank you for giving me the opportunity to speak to you today. I think there are a lot of concerns with some of the proposed legislation, but in my opening statement I would briefly like to talk about three particular issues. They relate to the vulnerability of the patient with a terminal illness and that vulnerability in their relationship with their loved ones around them, with the doctors who care for them and with the organisations that care for them.

I think we are very much aware—and there have been many examples of this—how people with a terminal illness feel concerned about the burden that they are putting on others. They do not want to be a burden, and I think part of the concern is that from those around them there may be both overt and covert pressure to make a decision to prematurely end their life because they do not wish to be a burden. I call that a benevolent pressure.

Also, sadly, we have the situation—and I think you are probably well aware of this in some of your other inquiries—that sometimes there is what I would describe as a malevolent pressure. I found an article in the *Courier-Mail* on 22 June where they talked about the issues of inheritance and the pressure being put on elderly patients or patients with a terminal illness. I think there is a concern about the covert and overt pressure on the very vulnerable who have a terminal illness.

The second issue is the concern with regard to the relationship with their doctor. Obviously this is an area where I have a particular concern. I have a concern in all of the areas. I have been a doctor for over 45 years. One of the things that you learn very quickly in medicine is that things are not black and white. Everyone is different physically and emotionally. In the practice of medicine there are two things that are absolutely black and white. They are black and white because of the power imbalance between the doctor and the patient. One is that you will not have a sexual relationship with your patient. You will be deregistered. The second is that you will not initiate an action where the primary intent of that action is to end a patient's life. This is the policy of the World Medical Association—the British, American, New Zealand as well as the Australian medical associations. It really is to protect patients because there very obviously is a power imbalance there.

The third area that I would like to flag is with regard to the organisations that look after those with a terminal illness who are extremely vulnerable. I do not want to raise too many concerns, but I am sure that everyone is aware of what happened in Bundaberg over 10 years ago. In Bundaberg the issue that occurred was that the financial drivers of Queensland Health encouraged hospital administrators to support surgery, which should not have been done. I think we would all agree that Queensland is the most decentralised, population wise, of all the states, and the cost associated with providing care for the terminally ill is significant. I would have some concern about the financial drivers around that.

I would like to finish by saying that we have all heard the incredibly sad stories, and our hearts go out to those who have been grief stricken with their loved ones, but I was very interested to hear Stephen Duckett's comments to the committee. He said that he had read all of the personal submissions to the Victorian inquiry and he said that in virtually all of them there was inadequate palliative care. Despite the fact that we know there are some incredibly sad stories, what I would like to ask you, as members of parliament, is this: if this legislation were implemented, there may be support for the autonomy of a few, but the concern is that in the public interest of many the vulnerable with a terminal illness are put at greater risk because of the overt and covert pressures that may occur.

CHAIR: Thank you. We have a few doctors here. I am glad you said that you had 45 years experience. Is that as a general practitioner?

Dr Hodge: As a general practitioner, yes.

CHAIR: You talked to the point of alleviating suffering or first do no harm?

Dr Hodge: Yes. The concern is that it is very difficult to put it in legislation to ensure that no harm is done to the patient, particularly with regard to doctors and the ethics associated with medical practice, which is to do no harm to the patient. There is also the concern about the relationship of relatives and the overt and covert pressure.

CHAIR: Sorry, I will come back to ‘alleviating suffering’. They are my words, not yours. I want to talk about the double effect. I might come back to doctoring around that. Obviously you can give medication to alleviate suffering, which is not meant to hasten death but it can bring on death.

Dr Hodge: That is correct.

CHAIR: Do you or do you not support the idea of future legislation, if possible, around voluntary assisted dying?

Dr Hodge: No, I do not support voluntary assisted dying.

CHAIR: Thank you. We will bring on Dr Steven Hambleton.

Dr Hambleton: Thank you for the opportunity to talk to the committee. I am also a GP, working in Brisbane, with 35 years experience. I am a past state and federal president of the Australian Medical Association. The baseline for deciding whether there should be change in policy is high-quality, accessible palliative care services for those who need them. I do not think we have that. I do not think that we have heard about good palliative care today either. It should be able to relieve suffering for the vast majority of individuals and their carers. We need to take into consideration the carers and draw attention to those physical, emotional, spiritual and social needs.

Even if we ignore the theological issues in relation to the sanctity of human life, changing the culture away from always doing the best for my patient and that everyone is of equal value will inevitably distort attitudes and expectations and will have the most profound negative impacts on the most vulnerable. I served on the Pharmaceutical Benefits Advisory Committee and, on a different parallel, I reflect that sometimes there was a treatment or service that potentially benefited a small minority but, inevitably, harmed a much wider group. On a population basis, I believe that voluntary assisted dying changes the fabric of society and that there will be a net negative outcome. For that reason alone, voluntary assisted dying should not be supported.

On the ABC this week I heard a young woman—and, again, another parallel—speaking about her own suicide attempt, saying that she decided that her family would be better off without her. I would hate to live in a society where the elderly felt compelled to suicide because their family would be better off without them. I further note that I hear a lot about intractable suffering. The committee has heard that in Oregon in the United States it is not intractable suffering that is among the top reasons people decide to take their own life. It is about loss of autonomy, loss of dignity—not intractable suffering. Surely, there are things that we can do to make a difference.

Lastly, there is no such thing as a law that will deliver a perfect outcome in every case. We only have to look at Victoria to note that there are at least 60 protections built in. That is telling me that the law is imperfect and I do not think we can make a perfect law.

CHAIR: Thank you, Dr Hambleton. We all applaud the AMA for its work in trying to educate people—50 per cent by 2050—to get advance healthcare directives. I think that is a good thing.

Dr Hambleton: Thank you.

CHAIR: You started your contribution by saying that palliative care should alleviate suffering for the vast number of people. Do you concur that it should but, because we have heard from palliative care specialists, there is sometimes a gap where it does not?

Dr Hambleton: We heard about a gap today. I think we could have done better. I feel very sorry for that family that we heard the story of. I would have to bow to my palliative care experts. There is a small minority whom we have difficulty with and that we need to do our best for. We are finding better ways and newer ways of doing things. Earlier, we heard that the family believed that the person was suffering. Frankly, that suffering should have been relieved.

CHAIR: Your end point was on suicide. Through not the TV program but the NCIS—the National Coronial Information System—we have received data of seven Queenslanders per month who have been diagnosed with a terminal illness taking their lives.

Dr Hambleton: That really is a failure of the support structures and I guess the value of human life and the confidence that they are not going to suffer. Zelle and I have been GPs for a combined total of 80 years. We have sat with people, at the sides of their beds, easing their passing. We need to give our patients confidence that, one, they are valued and, two, we will do our best and we will look after them and their family and we will try to make sure they do not suffer and neither does their family. I think that message needs to get through. If people are feeling so frustrated that they are taking their own lives prematurely, I think it sends a strong message to us that we have to do better.

CHAIR: Thank you, Dr Hambleton. We appreciate your commentary today. Mark Thomas, welcome.

Mr Thomas: Thank you. Could I just clarify my position? Firstly, as an academic my principal concern is legal theory as it relates to this question. I am also a practising barrister and I have recently witnessed firsthand the operation of the prosecution of people for aiding suicide. I was, in fact, defence council in the last two trials held in Queensland. Also, from a personal perspective, I spent several hours a day for six months beside my mother's bed as she died. There was a point at which I think I singularly recognised that the person, or whatever was in the bed, was no longer recognisable as my mother.

There is a widespread and, albeit, understandable reluctance to use the term 'suicide' when we are looking at this legislation. I do not think that any of the draft bills or legislation use the term. That reluctance obscures an important but critical question in relation to the operation of the criminal justice system. That question is this: is a death within the ambit of the voluntary assisted dying regime a suicide or is it, as some of the proposed legislative language suggests, a supervised medical procedure? Whichever answer you give has profound implications for the bringing of criminal charges against third parties and the lack of clarity in both the proposed legislation and the active legislation—in the aiding suicide provisions of the Criminal Code—risk unintended consequences surrounding the prosecution of related offences in relation to third parties. If, for example, you were to say that it was not a suicide, the entirety of section 311—that is, the aiding suicide provision—evaporates. It is an essential element of any of the offences that are captured by section 311 that there first is to be a suicide.

If a person then were to counsel an individual to participate in a voluntary assisted death, even for the basest of motives—that is, such as accelerating an inheritance—they would not, under those circumstances, be able to be prosecuted under section 311. That would be an undesirable and unintended consequence of the way in which the language has been adopted in the framing of various pieces of legislation.

Conversely, if it remains a suicide for the purposes of law, third parties who participate—and I use, for example, by way of robust discussion, people who have terminal diagnoses but who are not yet with any threshold attracting protections that exist within a regime—are themselves at risk of prosecution. As an example, take someone who has a terminal illness. They have a prognosis of perhaps 12 months. We have heard plenty of people say that prognosis is an inexact science. It would be natural for many people in that situation to begin to seek opinions from those close to them about the possibility of invoking the regime once they became eligible. Any third party who engages with someone who is as yet not eligible, either by being prima facie eligible or by making a first request under the draft bill, may then be subject to a prosecution that relies heavily on prosecutorial discretion. That, as I understand it, is not amenable to any form of review.

The problem then is that the discretion is going to operate in a clouded juridical framework, as is evidenced by difficulties in the two cases that I spoke of where there were extended legal arguments in section 590AA hearings as to what the Crown needs to prove in the context of a section 311 prosecution. That is simply because the language of section 311 is loose. It is not prescriptive in any way.

These issues, I would suggest, are not going to be solved in the next few minutes. They require a minute examination of all the possible or imaginable scenarios in order to fashion legislation that makes it abundantly clear what is and what is not permissible, particularly for the close companions of terminally ill patients. In the absence of the clarity that such an examination might produce, the associates of the terminally ill could be left floundering in a penumbra of legislative uncertainty.

If one of the purposes of any legislation is to create a compassionate and humane environment in which autonomous individuals might approach imminent death, a lack of certainty as to the extent to which their partners and their families or their closest friends can have open conversations about the possibilities that arise by the legislation would seem counterproductive. In fact, it is precisely those conversations that were referred to by Ms Thornton in her recounting of the circumstances of the death in question.

My position is that it is, therefore, incumbent on parliament in drafting legislation of this nature to canvass fully and fearlessly the range of circumstances that might result and determine in advance as far as possible how actions will fit within the criminal justice system and the intersection between proposed legislation and any protections that exist under that and the pre-existing provisions of section 311 of the Criminal Code.

CHAIR: Thank you very much, Mr Thomas. How long have you been practising as a barrister? You said you were a legal academic as well.

Mr Thomas: I do both. I was admitted in 2000 as a barrister of the Supreme Court of Queensland. I also became an academic in 2000. They have been running in parallel. The balance between them is a moveable feast really. It depends. There was a flurry in the last two years revolving around assisted suicide trials.

CHAIR: You are correct in your observation: legal clarity needs to be made around the issue of introducing a voluntary assisted dying scheme in Queensland. What was the experience in Victoria? I am sure it was defined—and I will have to check—as a medical procedure. I am asking for an interpretation of what you would believe a scheme, if introduced, should come under. Should it come under the Health Act to then alleviate some issues around the criminal—

Mr Thomas: I think you create intractable problems. If you characterise a death that occurs within the scheme as envisaged or, as it eventually turns out to operate, as a medical procedure of some form rather than by the more common term of suicide, section 311 is simply not going to have any operation, because it is an essential element that, in order to be prosecuted, you have to prove firstly that there was a suicide. If there is a statutory provision that excludes a death of that nature from being a suicide, section 311 is dead letter law.

The problem then is that there are actions that could be taken by an individual in the lead-up to someone entering into the regime that we would want to see susceptible to prosecution. For example, a close relative who is in the will may want to advance their inheritance and may exert considerable pressure prior to any protections arising under the act. That would ordinarily be caught by section 311(b), counselling suicide, although there is a lot of doubt about how those three subsections interact. If there were no suicide, counselling suicide would be off the table and there would be no apparent mechanism within the criminal justice system for that to be prosecuted.

CHAIR: What was the Victorian experience and legal opinion with the introduction of their law in terms of the definition? Where does it sit?

Mr Thomas: That is something that I would probably have to go and look at and do a little bit more research on. I am quite happy to get back to you with an opinion about that, if you wish.

CHAIR: I think we will get you to take that on notice. It is akin to the interpretation of a law.

Mr Thomas: Yes. I think it is probably indicative that this is a question of statutory interpretation. Section 311, freestanding and without any reference to any VAD plan, is itself still subject to considerable debate as to what the Crown has to prove. There are many things that were raised in those section 590AA hearings that revolved around the use of words that simply do not appear in section 311, most notably the question of intent—what intent did the person have to have and, more particularly, when did they have to have that intent? Those are all open questions and they deserve, if you are going to introduce a system like that, to be fully explored and integrated.

CHAIR: You can help us do that.

Mr Thomas: Integrate a criminal justice system that recognises the subtleties and nuances that exist when those two regimes are going to co-exist.

CHAIR: Thank you very much for your contribution. Yes, we look forward to your research in that area assisting us going forward. I welcome Dr Andrew McGee.

Dr McGee: Thanks for having me here. I am an associate professor at the Australian Centre for Health Law Research at QUT. My expertise is primarily in the area of bioethics. Bioethicists are obviously a different kind of expert from, say, a biologist insofar as laypersons or non-experts are not really meant to take our word for things. It is up to each and every one of us to make our own ethical judgments of course. A bioethicist can never really tell you what to think, but we do spend our professional lives analysing arguments for their quality as well as advancing arguments of our own and we publish peer reviewed research to that end. Our submission—Mark and I submitted together to the inquiry—was based partly on some work that I did with my other colleagues, and many of you will know them, Professor White and Professor Willmot which we published in the New South Wales Law Journal. We sought to look at all of the parliamentary debates that had taken place with the introduction of every single bill ever introduced into Australia, and the first ever bill introduced in Australia was in 1993.

The presupposition of our exercise was that it is parliamentarians ultimately who are responsible for whether voluntary assisted dying will become law. On that basis, we wanted to examine all of the arguments that have been put forward by parliamentarians in the parliamentary debates. When we went through the debates, we found ultimately that there were two broad categories of argument on voluntary assisted dying. There were those arguments that we call arguments concerning personal matters. These are issues of conscience; so for example a number

of parliamentarians said that they did not believe anyone other than God should take a human life. One, for example, said, 'It is my understanding that God has a no-kill policy.' Those of course are matters about which there can be reasonable disagreement in our society. Many of us would not share those beliefs, and it is reasonable for us not to do so. Before I say any more about that, I also want to mention the second category of argument. This category we called arguments concerning public matters. These refer to arguments in which the state does have a legitimate interest, for example the possible impact of legislation on vulnerable populations, vulnerable people, the possibility of a slippery slope et cetera.

The first part of our submission arises from that work we did and it makes an obvious point in a way. It is basically the neoliberal point that if we are going to base our decision on whether to legalise voluntary assisted dying on what we call the personal matter grounds then the default position should always be legalisation, because that then enables everyone to act in accordance with their own conscience. If voluntary assisted dying remained prohibited, for example, then you are holding everyone hostage to that view, but it does not work conversely. If you think about it, the opposite of prohibition is actually legislation that mandates conduct, for example legislation that requires you to wear a seatbelt—that kind of thing where we do not really have any choice. When we legalise voluntary assisted dying we are not really requiring anybody to avail themselves of voluntary assisted dying, so those people who oppose it on personal matter grounds—for example, on the ground that only God should take a life—are free in their own lives not to avail themselves of voluntary assisted dying.

What we tried to argue ultimately is that these arguments should drop out of the debate. There should be far more focus in the parliamentary debates on what we call the public matter issues to do with the impact of voluntary assisted dying on vulnerable people and the possibility that legislation would be progressively broadened in that we would be back in the House every year with an extra category of patient who also wants to avail themselves of assisted dying. The crucial point—and this is the point I would really like to stress today—is that those public matters are actually empirical questions that are amenable to empirical research. There is now a large body of empirical data which does demonstrate—and I should say I am not an empirical researcher; I am a bioethicist—that legislation is not progressively amended. The obvious example there is the Oregon legislation which in 22 years has not changed substantively. The eligibility requirements have remained the same. It is not true that other people who are not terminally ill, for example, can now obtain access to voluntary assisted dying in Oregon.

CHAIR: Dr McGee, in the interests of time, we will have to wrap it up, but we value your contribution. Professors Ben White and Lindy Willmott have given us significant 'light' reading of all the debates across the various jurisdictions and kept us up to date on that. I think you have raised a couple of good points in terms of the personal matters and public matters, but we will have to go to questions.

Mr McARDLE: Dr Hodge and Dr Hambleton, thank you for coming today. Dr Hodge, you were an AMAQ president too, weren't you, at one stage?

Dr Hodge: Yes, I was.

Mr McARDLE: We hear about the gap of people who do not benefit—my word—from palliative care. Is that an argument that in your opinion is being run to validate VAD, or is it a matter that palliative care is not available to the extent that it is needed in this state that validates VAD?

Dr Hodge: I think that palliative care is definitely not available to the extent that it is needed in this state. I also think there is an issue with regard to what people understand about VAD and palliative care, because I know that there have been lots of comments made that 80 per cent of the population support it. I think many people think that VAD or euthanasia, whatever you want to call it, is when you withdraw life support. I think there really is a very great lack of understanding about what palliative care is and I certainly think there is a real funding deficiency. As I said, Queensland is the most decentralised of all the states and we certainly do not want to have a situation where, for people outside the south-east corner—and I think this is the whole public interest which has been raised by Dr McGee—the public interest is protecting the vast majority of people who may be disadvantaged rather than giving autonomy to a few. The only way you can really ensure that that is occurring is if there is adequate funding. The AMA current president talked about how the current commitment is a down payment with regard to palliative care and what is needed. I am very concerned that one should say we should implement voluntary assisted dying in a situation because people have inadequate palliative care. I refer again to Stephen Duckett's really interesting comments that he made to the committee a couple of weeks ago.

Dr Hambleton: The only thing I would add is that, in 35 years of general practice with an ageing population, I cannot think of one of my patients who suffered unnecessarily toward the end of their life with good access to palliative care, and we have good access in Brisbane. Earlier today I heard some elements that were not as good as I would have liked them, so we need good quality palliative care. We need to understand what that means. We need to stop promising people a terrible death, because that is mostly what does not happen. We do need to do better. We do need to do research and we need to make that service available more broadly. Yes, I do think it is part of the reason people are afraid of what happens at the end of their life and what happens when you die, and we do not talk about it as a community. Thank you to the committee for applauding the AMA's Fifty over Fifty campaign to have an advance care directive. I say to my patients, 'The advance care directive's really important, but even more important is talking to your family about it to say, "These are the sorts of things that I would want at the end of my life."' We need to start talking about the end of life like we start talking about the beginning of life. Sometimes there is incontinence, but we wipe babies' bums all the time. It is not such a bad thing.

Mr McARDLE: Doctor, you made the comment that we are terrified of talking about death. That seems to be a hallmark of our society. If we go back 60-odd years, it was simply part of what took place. The Irish now still have the wake; they lay the body out. I am not saying we should do that either, but we are now prone to not talk about death but talk about living forever, and that then blocks a communication.

Dr Hambleton: It does, and in celebrating the end of one's life you do not need to call the police if there has been an expected death and you do not have to call the funeral director immediately. You can spend time with your loved one. All of these messages are very poorly known.

Mr McARDLE: Dr McGee, you make the comment about VAD being 'subject to any concerns or impacts that need protecting from'. Do you have an opinion as to at what point in a person's life a person should have the right to access VAD?

Dr McGee: Yes, I do. I actually believe that a person ought to be terminally ill. It should only be available to terminally ill people, but I would define that to include people who are suffering from neurodegenerative disease.

Mr McARDLE: Let us go a bit further than that, and I will give you an example; I have given it before. If a man is diagnosed with stage 4 prostate cancer, he is going to pass. There is no question about it; it is a matter of when. He may have eight to 10 or 10 to 12 years based upon, as I understand, the studies. Should that man in year two who is still, at least for all intents and purposes, a fit person have access? He has a terminal illness. Psychologically he is suffering intolerable pain. Should he have the right to access it?

Dr McGee: Personally I do not think he should, and that is because in that particular instance you are talking about somebody who might have 12 years left, which is the premise of your question. I think as a matter of public policy you are in a situation there where it is very difficult to distinguish that from suicide. If we are going to make a meaningful difference—if we are going to draw a meaningful distinction—between voluntary assisted dying and assisted suicide this regime has to apply for people who are dying in the true sense.

Mr McARDLE: So you need a definitive time line, otherwise you start to blur between that time line and any time line?

Dr McGee: Leaving aside all the issues about prognosis, prognostication et cetera, yes, I think it needs to apply to people who are genuinely dying. Of course in your example there can be debate about that. There can be a debate about whether that person is actually dying, even though they have 12 years to live, so we could obviously get into some semantic argument about that. In my view, if we are going to talk about this as an assisted dying regime and we are going to distinguish it as a matter of policy from, say, our other policies which are to discourage suicide, then it really should apply only to people who are genuinely dying.

Mr McARDLE: My last observation is that we have heard many people talk about what they have seen as their loved one passes. I get the sense to a large extent it is a personal sense of guilt and a personal sense of grief that feeds the guilt, and it may well be that the person who is passing is not going through what the observer states they think they are going through. Would that be correct?

Dr Hambleton: I think that is a real issue. I think that observing someone is really tough. I think good palliative care is about care of the carers as well, to help them understand what is going on. 'How do you know my dad is not in pain?' 'How do you know my mum is not in pain?' There are physiological measures that we can take. If we believe the person is suffering we should be relieving

it. If we believe that person is actually anxious, we should relieve that anxiety. In a situation where there is true palliative care and a person is dying, there is no value in hydrating that person above providing them with comfort. There is no value in providing nutrition above what would be comfortable, but that needs to be explained properly so everyone around understands the situation.

In the case of dementia, the person is not suffering if their environment is managed properly. If we are looking after people, we are providing them with dignity in the moment. We all have family members who are going through that. It is about their personal dignity in the moment.

CHAIR: To the doctors and Mr Mark Thomas, thank you for your contributions today. In the interests of time we have to call our next witness as we are falling behind time.

COMPTON, Mr Everal, Everal Compton Charitable Trust

CHAIR: Thank you very much for coming today. May we call you Everal?

Mr Compton: My word. People who call me Mr Compton are usually angry with me.

CHAIR: Would you like to make an opening statement before we go to questions?

Mr Compton: First of all, thank you for allocating me time to be here. May I also say how much I admire the work that this panel has done. I am aware that you have travelled many miles to many places to listen to many witnesses. I wonder whether your constituents know where you are at any time. I want you to know that your time in this has been noted.

CHAIR: Thank you. I have a stunt double in Thuringowa!

Mr Compton: May I talk in three roles: one through my charitable trust, which has financed research into longevity for many years and has seen the results of that research; also through my 35 years on the board of National Seniors, 25 years as chairman and consulting with ageing people all over Australia—although I do not speak on behalf of that organisation, I am drawing on that experience; and also as an elder for 62 years of the Presbyterian and Uniting churches to bring a Christian viewpoint to this. I make it clear that I am not speaking on behalf of the Uniting Church, either. Might I address three of the matters that you are looking at?

Briefly, I believe that a revolution is needed in aged care in Australia. The whole of aged care now is designed to provide total services for people at total expense to government and to the people, saying, 'We'll look after you in every way possible in your old age.' I believe that is to the detriment of every older person in Australia. It is important that they be given some worth and some value. They should be told that we have a policy in Australia that we are not going to look after them until they die, but that we are going to enable them to lead a good life at all times. I believe we have to change the whole concept of looking after people all the way to the grave and handling everything, but enable them to do things. Even the most decrepit person has something they can do. I believe that the whole emphasis has to be changed. We should be saying to people, 'You're going to look after yourself as much as you can,' and 'You're going to help other people as much as you can' and 'We're not going to pander to you all of the time.' I believe that government expenditure could be cut by half—that is not the reason for doing it—if we had a policy of enablement.

In relation to palliative care, I believe it is in many ways to the detriment of society. In my role as an elder in the church, I have sat with people as they are dying and I have sat with people as they are waiting to die. Many are under enormous tension, because they were put into palliative care when they did not want to be. They wanted to die, but society, medicine and the whole community said, 'You must have palliative care.' There is every evidence that they have been placed under enormous tension in doing that. I have sat beside people who have said to me, 'Why didn't they let me die when I wanted to?' I believe that considerable research has to be done into the impact of nervous tension on the lives of people put into palliative care. I believe that it is a huge problem that needs to be addressed.

I now turn to assisted dying. I will talk first of all as a Christian. There is a belief amongst many Christians that God decides when people live and when they die, and he decides when they are sick and when they are going to get better. If we have something like assisted dying, we are indeed trespassing on God's territory in trying to take over God's job in deciding whether people live or die. I do not believe in a god who decides who lives or dies, who gets sick or who gets better. In fact, I would cease to be a Christian if that was the case. If we say that, we are saying that God caused five million Jews to be killed by Adolf Hitler, because he is in charge of dying. We are saying that those people in Christchurch died because God wanted them to die. We are saying that the people in the Twin Towers 18 years ago in New York—3,000 of them—died by God's will. I cannot accept that. God does not decide who lives or dies. God gives us the spiritual power to handle anything that life throws up at us, including death. I think we need to get away from the whole concept that we are somehow trespassing on God's territory.

I have also been disturbed in reading some of the evidence around Queensland Christians who have come along and used highly emotive language that I do not think should be in the Christian vocabulary—words like 'suicide', 'manufactured death' and 'murder'—in association with assisted dying. I do not believe that Christians should be in the business of using fear and emotion to win an argument or to settle a social issue. I personally believe that most Christians would reject the emotive language that has been used in the whole issue in order to try to win a debate. The one thing about Christianity is that God gives us a choice in life, in everything that we do. All we are asking for in legislation about assisted dying is to give people a choice. I do not believe that many will take the

choice, but I will be one if my circumstances happen that way. There are people running around the state saying, 'If this legislation passes, we will have doctors and others, even politicians, running around with needles trying to kill people because we have a law that says it is legal.' We are dealing with the right of a small number of people to take this choice.

I have made it clear to my family, in writing and personally, and I have made it clear to all my friends that when I have no quality of life I want out. I have had 88 good years. I think I might have kicked a few good goals in that time. I have had a happy life and I am not going to lie around like a vegetable and wreck what has been a good life, have my family sit beside my bed every day, have the money that I want to give to my grandchildren dissipated away, because I am miserable enough to want an extra three months of life. I cannot see that that is a good Christian attitude in any way at all. If you do not pass—this is not a threat, by the way—legislation about this, I am going to find a way to assist myself to die anyway. I believe it is not hard for an old guy like me to bring on a heart attack or fall out of bed.

Mr McARDLE: Do not do it today.

Mr Compton: No, I will wait till I get out of the room. However, my doctor has told me—and she is a good doctor, a lovely Chinese lady—that if I drink as if it were water two bottles of straight whiskey, no voluntary euthanasia legislation is required. I am dead at that point. My heart cannot cope with that. When I look at it, that's not a bad way to go.

I hope that we can agree that death is a part of life. It is not something to be afraid of. I hope that if I get the chance on my last day on earth, I can get all my friends into the room to have a drink with me and chat about good days and happy days. I hope that we all part happily and that the death that God made part of life is a happy event and not a miserable event. If you pass this legislation, I might invite you all to my death party.

I hope that I can go out like that professor in Perth. He was 104 years old. I actually helped him through National Seniors when they sacked him at 96 because they said he was too old to be a professor. I ran the most scurrilous campaign you have heard of. We got him reinstated. He was not about to die and he was not in a terminal state, but at age 104 with his old body breaking down he had had enough. It was a tragedy that he had to go to Switzerland to end his life. It should have happened here in Australia. He went there. On his last day with his family he went out to see the sights of the place, had a nice feed of fish and chips, which is his favourite feed, sat with his family holding his hand and listened to Beethoven as he pressed the button or whatever he had to do. What a wonderful way for him to die. I hope that all of us—anyone who takes the assisted dying path—can do it in that splendid way.

May I say in closing that I believe that as Christians we have to decide whether we want to operate by dogma and by doctrine or whether we going to operate by compassion. My reading of the life of Jesus Christ is that, insofar as doctrine is concerned, he used to argue in the synagogues all day long about doctrine and tell them it was no good, so let's agree that it is no good. What he did was to go out into the world where people were at the coalface and he showed compassion. He was with them in every part of life that counted. I hope that we can get rid of dogma and doctrine, and that we can all live in an Australian society that is built on compassion and goodwill, and that is a great place to live and a great place to die.

CHAIR: It is not often I am silenced. Everal, well done. What a remarkable gentleman you are. Your energy and passion for this particular debate is well and truly noted. Your contribution in the aged-care sector with National Seniors and everything you have done over all those years has obviously given you the drive and determination to come here today and share your thoughts with us. I do not have any questions. I think you have pretty much said it all. I am going to open it up to any questions.

Mr BERKMAN: I have no questions. I want to make a quick note of thanks for bringing a little colour into an afternoon that has otherwise been contextually tough on a very difficult subject.

Mr McARDLE: Mr Compton—

Mr Compton: Everal.

Mr McARDLE: If I like you! Everal, we go back a number of years now. You made the comment that VAD will be the right of a small number of people. That should not be the reason for putting this legislation into effect; would you agree with that?

Mr Compton: What I said is that it is the right of all people to choose. What I believe is that only a small number will—maybe five per cent of the population—but they have the right to have that choice, the same as the rest of them have the right not to make that choice.

Mr McARDLE: In your mind, does the fact that it is only a small number of people validate the right for the act to exist? I am just asking the question. Do you see that—

Mr Compton: No, I do not know.

Mr McARDLE:—because a small number can access it, is that the basis to make the legislation?

Mr Compton: We do a lot of things in the world for a small number of people. For instance, the number of women affected by domestic violence is less than 10 per cent of the population. It is a terrible scourge, but we pass laws because that should not happen. Therefore, if we say, 'Let us only pass laws by numbers,' we avoid all sorts of things. It is fundamental that people should have that right. It is fundamental that all elements of society, which you might call a minority in society, have legislation that looks after them and gives them rights and otherwise. If we only ever legislate for that which would fix the majority of society, I think we would not have good government in this land.

Mr McARDLE: I would probably take issue with domestic violence being a small group of people.

Mr Compton: I said 10 per cent. I would hope it is not more than one in 10 women getting bashed.

Mr McARDLE: We hope it is zero, but we have a long way to go. We will debate that another time. Do you feel that palliative care should also be much better funded and much better understood together with end-of-life documentation? I want to try to balance the ledger. What I am concerned about is that, whilst assisted suicide or euthanasia or VAD is seen as a potential outcome, if there is real choice that ledger needs to be balanced. You need to put in place a lot more of what we do not have now to give the right to a real choice. Would you agree with that?

Mr Compton: I agree that palliative care and assisted dying go hand in hand. A person should have a right to palliative care, if they want it. It should be their choice and they should not be forced into it. If they do not want palliative care and say, 'I want out,' they have the right to say that. I agree that there should be more funding for palliative care. I believe there has to be funding to help people to understand assisted dying, make a choice about assisted dying and have the medical profession aware of it. I believe that palliative care must not be administered to people who do not want it.

Mr McARDLE: But neither should VAD.

Mr Compton: Palliative care needs to have adequate funding and work correctly.

Mr McARDLE: Let us agree on this then: you say that VAD should be put into effect. It is up to the committee to consider that—

Mr Compton: Yes.

Mr McARDLE: I am saying to you that this committee should also say to the parliament that we need to ensure palliative care and issues around end of life should be equally at the forefront of people's minds. Therefore, you have a playing field that is equal allowing a balanced choice to be made.

Mr Compton: I would go along with that; I agree.

Mr McARDLE: We agree. Everald, I do like you.

Mr Compton: I do not want palliative care to be the only choice that people have.

Mr McARDLE: And I say to you that there are people here who do not want VAD to be the only choice. Therefore, the balance has to be struck between the two.

Mr Compton: We have a choice between them both.

CHAIR: There being no further questions, we are going to take a five-minute break.

Proceedings suspended from 3.48 pm to 4.04 pm.

NEAL, Dr Katrina, Private capacity

CHAIR: Welcome, Dr Neal. Would you like to make an opening statement?

Dr Neal: I am here as a GP, a rather humble GP. I am not a particular academic in anything except GP land. I am a GP who has a special interest in mental health. At some of the places I work I do solely GP mental health work. I left all my notes at home, which is probably a good thing because I think most of them were irrelevant.

I would like to talk about how bringing forward this law on euthanasia may affect the mentally ill. Before I do so, I would like to briefly talk about suffering and the meaning of suffering. I refer to the Christian allegory that was mentioned of the Saviour suffering on the cross and dying on the cross. Whatever you believe or do not believe there is a lesson to be learnt in that. It is that he died willingly on the cross having the power, in this story—whether you believe it or not does not matter—to avoid it. He had the power to run away from it, but he chose to submit himself to the will of the Father. Why that was the will of the Father, I have no idea.

The point is that suffering is not always bad. Sometimes suffering is necessary. Every time I see my grandchildren run on a concrete path, my heart leaps out of my chest thinking they are going fall and scrape their knees badly, which happens often. It hurts me more than them every time. If they do not fall and they do not suffer the consequences of what they do, they do not learn. Suffering is not all bad. As a society we need to learn that suffering can be good and that we do learn by the things we suffer.

I am not going to extend this completely to the idea of dying. The definition of euthanasia is something like having an easy and peaceful death. I wish that upon everybody, me particularly. Everybody has a right to an easy and peaceful death. I do not think it absolutely has to mean that they need to avoid every bit of suffering.

There are people in our society who suffer a lot and they are not allowed to kill themselves. This is where we talk about the mentally ill. Every day in a practice where I talk to people who present, I talk to someone who wants to kill themselves. They are suffering so badly that they want to die. My job as a GP is to help them find some joie de vivre—help them to find a reason for living. After all, most of us I think believe we have no idea why we are here, but we do know that life is a gift. Maybe one of our goals in life is not necessarily to be happy but to find meaning and find joy. There are a lot of wonderful things we can find in life.

If we send a message that by legalising euthanasia you can decide exactly when you want to die and how you want to die, I think it is going to become so normalised that the mentally ill are going to say, 'Why can't I have euthanasia? Why can't I die? Why should I suffer? This guy has a cancer diagnosis and knows he is going to die in a few years—one year, two years, three years—but I have manic depression or schizophrenia and I have to suffer for a very long time. Why can't I have euthanasia?'

We need to reframe how we feel about suffering. You might think it is easy for me to say this, but I know about suffering. Like all of you who have lost family members, I have lost a father to old age, a mother to cancer, three brothers to cancer and a 24-year-old son to a dreadful disability due to a chromosomal abnormality from birth. His life was one of suffering. I would have to say that, although I would never wish that upon anybody, as a result of his suffering and what he brought to our family, the other three children, because of what they saw, what they were required to do and how they were required to help, they are amazing human beings who appreciate and love every second of life. They know how precious life is and they know how he suffered because he could not do what they were doing. In some sense they grew a tremendous amount from understanding his suffering.

In our society we have made the decision that we are not going to kill paedophiles, murderers, serial rapists and serial paedophiles. If we are so fond of killing people, why should the guy who killed Daniel Morcombe still be living? Why should he be living and breathing? You have decided that you have no right to kill him? What right do you have to kill anybody? Doctors are doctors and they want to be healers; they want to make people better. Even when people are incredibly sick and incredibly old they do not want me to suggest, 'Let's just move you on'; they want me to find an answer. I work very hard at finding an answer so I can relieve their suffering. There are many areas in medicine where we can improve. We can get better palliative care and have it out there more often.

In my family, one family member died at the Gold Coast Hospital, one died at QEII Hospital, one at St Vincent's and one at home. We did not even need palliative care. The general staff did a fabulous job of relieving their suffering in death. I know there are cases where there are people who need extra help and I think they should receive that.

CHAIR: Thank you Dr Neal, we might have to move to questions. I thank you for your statement. You have drawn on some commentary that we have heard today. There are particular views across the community on this issue. You spoke about increasing palliative care options.

Dr Neal: Yes, but I am also worried about my patients not trusting a doctor who has the ability to move them on or even suggest that they move on. I am a healer. I am a scientist and a healer. If my patients want to move on, then I suggest they go out of the medical profession and look for some way else to move on.

CHAIR: Would there be any protections for the most vulnerable, whether they have a mental condition or another condition, that you would consider important to put into any potential future legislation?

Dr Neal: Yes. I notice in Victoria that you do not even need to see a psychiatrist to treat untreated depression. We took the instance here of a man who is going to die in a few years—one year or five years or whatever—of prostate cancer. Why should he be able to access euthanasia without seeing a psychiatrist to treat his depression or other counsellors who could bring meaning to his life and help him? There are a lot of things that palliative care does to help people come to grips with the idea and make up with their families, for instance. It can be a wonderful experience. I would hate to see people making this kind of decision without seeing professionals such as a psychiatrist or a psychologist.

CHAIR: Thank you, Dr Neal. There being no further questions, I thank you for your contribution today.

CALLINAN, Mr Cliff, Private capacity

HYLAND, Ms Alicia, Private capacity

ROBERTSON, Mr Ian, Private capacity

STAFFORD, Mr Andrew, Private capacity

CHAIR: I welcome Cliff Callinan, Ian Robertson, Andrew Stafford and Alicia Hyland. Thank you each for making time to be available and for being patient with our timetable. You will hear a bell at the three-minute mark to wrap up your opening statement, and then we will move to any questions we might have. Alicia, would you like to start?

Ms Hyland: This is dedicated to a doctor, two nurses and a psychologist who deserve better. Ladies and gentlemen, how would you like to die? Currently I see it is not really your choice. Currently I see care based on politics, funding and your postcode. How have I reached this conclusion? I am a volunteer in a hospice and an aged-care facility. I attend all of the stakeholder conferences and I am an experienced midwife of 28 years. Why is a midwife interested in this? Well, midwives care for families and prepare for the birth. They work as advocates within a multidisciplinary team providing holistic care because when you are relaxed, empowered and health providers work together you have a good birth. Death could be the same, but it is not in Australia.

My agenda is to focus on solutions, to reduce fear and to make the most of the time that patients have left because we are all going to die one day—and I do not know about you, but I would like to have a good death. I propose that we have an independent board that reviews and consults with all stakeholders on the current situation and plans what it could look like with true multidisciplinary team collaboration; cost-effective use of public funds and transparent clinical governance; continuity, efficiency and evidence based care; public awareness and clarity on services available; and education and information for consumers and stakeholders.

In order to achieve this, I know from significant experience in project and change management that this board requires a terms of reference that achieves trust via robust transparency and significant consultation periods and a board that is made up of members of the public in good standing without their own agenda but with the best interests of patients, cost-effectiveness and efficiency of public funds in mind. Ladies and gentlemen, please let us take the profit and power and bureaucracy of dying away and give all Australians a good death.

CHAIR: Thank you very much, Alicia, for your contribution today. In summarising, you are a supporter of voluntary assisted dying?

Ms Hyland: I believe that it is about patient choice and family choice. That is what it comes down to at the end of the day. It is not about politics, bureaucracy or anyone else's agenda but that.

CHAIR: Thank you very much, Alicia, for your contribution. Welcome, Mr Stafford.

Mr Stafford: I appear at the inquiry today in my own capacity and also on behalf of my mother, Sue. I would like to thank the committee for the opportunity to speak. Sue suffers from early onset Alzheimer's disease. She has been bedridden and unable to communicate for over 20 months. She is 72 years old. She was diagnosed with the illness in November 2011, was forced into retirement in 2005 and began suffering symptoms from at least 2002. This has been a 17-year journey. Previously Sue had a long career in public health, culminating in a decade-long stint in the aged and extended care unit for Queensland Health.

Unlike many sufferers, and perhaps as a result of her background, Sue also retained insight into her condition even after she was admitted into full-time care. She knew all too well what lay before her—that she would soon forget those she loved the most and the dehumanising loss of identity and dignity. In her words, she was dying by degrees. I lost count of the number of times she told me she wanted to cut her own throat. On more than one occasion she asked either me or my brother to kill her. I accept that she would not have put us in such a position had she been in full command of her faculties. I also know as her son that it is not a life she would ever have chosen. Her psychological suffering has been immense, and as her sons and carers we have suffered with her.

Dementia Australia has argued that psychological suffering ought to be recognised in VAD legislation while distinguishing between cognitive impairment and mental illness. It put forward that people with degenerative conditions should be able to make an enduring request to access future VAD legislation via an advance health directive.

Two weeks ago Sue contracted the flu and had fluid on her lungs. Under her advance health directive we ordered that she receive no medication or treatment other than pain relief. We were told to prepare but, while her mind is long gone, her body is still young and she beat back the virus. She cannot receive palliative care. At this stage, she is not dying. It will take another infection at some stage. If she stops eating, medical staff will not intubate her, but the line between spoonfeeding and force-feeding is sometimes hard to distinguish. This has been her reality for four years now. It could be many, many more years yet.

Limiting access to VAD legislation to those with not long to live effectively discriminates against those with degenerative illnesses who are no less sure of their end—only when it will arrive. It is, I acknowledge, of course true that people with dementia can lead fulfilling lives for many years, but it is my submission that quality of life and function should also be considered. I am acutely cognisant of the moral, legal, ethical, spiritual and indeed political issues surrounding assisted dying, and I recognise that cognitive capacity is essential.

Had Sue had a legal framework to work within when she still had that cognitive capacity, I am sure she would have made a different choice. It is estimated that by 2025 more than half a million Australians will suffer from dementia. This issue will not go away. Finally, I would like it placed on the public record that I wrote to the Leader of the Opposition about this matter on both 12 March and 18 July and I have not been given the courtesy of a reply.

CHAIR: Thank you, Mr Stafford. Thank you for sharing what is obviously a deeply personal and difficult story about your mum who is in this terrible condition. We have heard many times now about people wishing to have some kind of legal framework such as an advance health directive in which they can express when they have capacity that when they lose capacity they wish to be able to seek voluntary assisted dying. You are not the first, nor, I suspect, the last, to ask for that. We thank you for your contribution here today. It is important that we do consider that very matter going forward. Welcome, Mr Ian Robertson.

Mr Robertson: The first thing I would like to say is thank you to the committee for holding this hearing and for the opportunity for us to be here today to hear what is being said and even more so for giving me the opportunity to say a few words. I might be a little bit different to a lot of people who have talked to you and who have been talked about today. I do not think there is anything wrong with me—I am in perfect health—but I am 86 years old and I am starting to go on the downward slide. I say to myself and I say to this committee: what is ahead for me? There is not a hell of a lot ahead for me, because it is all behind me now. I know that at some time in the future—and it may not be that far ahead—my body is going to start to shut down, and when it does I might fall very quickly into a state where I do not know where I am. When I get to that stage I will have lost all control and all choice—and choice is what I want to talk to you about today.

I want you, please, to put something through parliament that stops it being illegal for a medical practitioner or somebody who is kind enough to give me, or somebody like me, something to end my life in a situation where I have no choice. That is what I am asking you to do—to make sure that at some time in the future you give me and people like me choice. All we want is to be able to make an individual choice about our life—in other words, my body, my choice. I do not believe it has anything to do with anybody else except me. If I make that choice—I do not know what you call it, but I have filled one in; you put it in with your will and say what you want to happen to you when you die—I think that should be binding. If you put it in writing when you are healthy that that is what you want to happen, it should happen. If you do that, I do not believe you should have any more trouble. It will even itself out.

I have one further point on this subject of dying. It is funny that nobody wants to talk about it. It is a pretty tough one, isn't it, because you only die once—you do not get any practise. Times are now changing so quickly. If you have a referendum now, you will get X to vote. If you have a referendum in, say, five years, I think it will surprise you how that figure will change because people are talking about it and it is no longer a taboo subject. It is the easiest way out for us anyway. It is certainly the easiest way to go.

The other thing is that I hope I will have a choice because at the moment I do not have a choice: I would have to go into a nursing home. If I lose my mind, I have had it. I have no more control. I have four kids. They say to me now that they do not want to lose their dad. I simply say to them, 'Yes, but look at the other side of it. I don't want to inflict upon you looking after me in that bed for maybe four, five or six years.' That is the other side of it. That is why I say to you that we want that choice to be able to end our lives in a gentle way, if we want to. It is our decision and nobody else's.

CHAIR: Thank you very much, Mr Robertson. I think you and Everal Compton would make good companions.

Mr Robertson: He said it better. I know him and I have known him for a while. I did not realise he would be in a place like this. I thought he was still building the railway.

CHAIR: I think it must be the era. That was very well spoken. Thank you very much for your contribution here today, Mr Robertson. Welcome, Cliff Callinan.

Mr Callinan: Thank you for letting me speak here today and thank you to the committee for your efforts in this matter. Many of us baby boomers have experienced the death of our parents and realised the atrocity of what is happening. Having read many of the submissions made to you, I see this as an epidemic of horror.

My strong and proud mother was an 18-year-old in the Air Ministry in England during World War II. One of her jobs was to return the highly secretive UHF radios from a North African assignment back to England for the famous dam buster raids. She was in the war room when they called the raid. She trudged the jungles of Africa and lived a full and exciting life of adventure, dignity and pride. To have seen her reduced to a commodity in a nursing home in her final stages, followed by dying of thirst in the whole hospital system under the doctrine of double effect—words fail me. It was a barbaric system of inflicted cruelty, a betrayal of her worth as a human being and a failure to her dignity. My mum was completely ready to go. Most body functions were gone, her hip was broken, she had had a massive stroke after the Warfarin was stopped and she had nowhere to come back to. The doctor said that she was too fragile to operate on and that she had 10 days to go. I wondered how he knew that.

Here is the crux of my presentation today, which is something I have not seen raised before. Because of time limitations, I will go straight to her last four days of end-of-life care in a major hospital. I do not suppose many people would sit with a dying relation for the whole of those four days. I assume that most would visit for a few hours. Doctors would be there for maybe 10 minutes. Most people would observe the patient lying in what appeared to be a peaceful state and then go home. I sat with my mum for the last four days. She mostly appeared peaceful. Paralysed in her drug stupor, she was unable to drink and was now dying of thirst. During those four days, she was able to communicate with me. I squeezed her hand and she would squeeze my hand back. Do you see what that means? Her mind was working and she was trapped in a paralysed body. With two days to go and now dying of thirst, she sat up and shook violently in horror for two full minutes and then fell back into the stupor. Do you want me to demonstrate?

CHAIR: I think we can take on board what you are saying.

Mr Callinan: Hand shaking, body vibrating, for two full minutes while I cuddled her. Every muscle in her body was rippling. This is what the system calls a peaceful end; end-of-life care. I put it to you that it is an atrocity. Who knows what torment and horror was going through her mind during those last four days? I knew my mum well and she would not have wanted to end like that. Somebody mentioned before about executing criminals in America. They put them to sleep quickly. They give them an injection and then they stop their heart. Could you imagine if they strapped them into the gurney or restricted their movement with drugs and left them there to die of thirst for four days? There would be a worldwide outcry. How come it is okay to do it to our elderly?

This is my life and I agree with you: nobody has the right to tell you or me that I have to suffer. I am concerned the laws that will be introduced will be tokenistic and way too restrictive. Poor laws will force us to make an early decision when approaching death, in case the system gets in the way. On the slippery slope argument, it did not work for the LGBT debate and it will not work here. Do you know how many laws are on our books so that you can get busted for riding a pushbike? I stopped counting at 150. I think we can control a slippery slope. Thank you.

CHAIR: Thank you very much, Cliff. Your mum sounds like a remarkable lady.

Mr Callinan: She was good.

CHAIR: I agree it was a terrible end to her life, having listened to that personal story you have shared with us today. I have no direct questions to any of you. You have each articulated your points very well. Are there any questions?

Mr BERKMAN: Thank you all for being here. Andrew, you are a constituent of mine. We have met and spoken about this previously. You have showed me footage of your mum, as you have described in your submission, with the kind of convulsions that she is constantly wracked with.

Mr Stafford: Yes.

Mr BERKMAN: We have also spoken about the complexities of dealing with dementia in this debate. We have heard plenty of evidence about schemes overseas and how in the Netherlands, while there is provision for people without capacity to access VAD, in practice that does not happen
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because there are so few practitioners who are prepared to go there. In Canada, similarly, it is not a set time frame. There is provision that the eligibility criteria relate to the reasonable foreseeability of death, which does catch dementia sufferers like your mum.

Mr Stafford: It is a certain death. It is a terminal illness.

Mr BERKMAN: Yes. What we heard from experts who are working in Canada, though, was that that tends to be accessed only by people in circumstances where they have to choose to end their life early. They might have more years left, but before they lose capacity that is the way they have to choose to end their lives if they want to access VAD. In all the circumstances, do you think your mum would have chosen to do that?

Mr Stafford: If there had been legal provision via, say, an advance health directive, she might have chosen—she would have chosen, let me clarify that, as I know her very well. She would have chosen to take advantage of that law, not at the time but at a predetermined point when she felt that her quality of life was not worth continuing with. As I said before, she has been bedridden and unable to communicate and really does not know who she is let alone anybody else anymore. I do not think that is a life she would have chosen, no.

Mr BERKMAN: How do you personally feel when you reflect upon the idea of someone in your mum's condition with terminal dementia having to choose to access VAD while they still have capacity, as opposed to a scheme that allows for the use of an advance health directive?

Mr Stafford: I am not sure of your question, Michael. Can you clarify, please?

Mr BERKMAN: In terms of the Canadian provisions, we heard evidence that people were choosing to access VAD while they still had capacity, because they were not able to give that final tick off once they had lost their capacity.

Mr Stafford: I certainly understand that capacity is vital. I cannot see how any parliament could legislate to allow people to make a choice when they have lost legal capacity to make legal decisions about their lives, let alone the manner of their deaths. I guess what we are talking about is creating a provision within an advance health directive while people are healthy, before they might actually be ill at all.

Mr McARDLE: I congratulate all of you and thank you sincerely for being here today.

CHAIR: Thank you all for your contributions.

CRAGG, Ms Carol, Private capacity

JANSEN, Dr Evelyn, Private capacity

MARSHALL, Mr Stephen, Private capacity

THORPE, Ms Gail, Private capacity

CHAIR: Welcome to each of you. I will ask Dr Evelyn Jansen to begin proceedings with an opening statement.

Dr Jansen: On 22 May last year in the Holy Spirit Hospital, my husband John, 53 years married, completed his statement of choices, his advance health directive. He had a tumour on the spine that had begun to compress the spinal cord. The prognosis was agonising pain, advancing paralysis and then death. He had gone through all the treatment he could manage. [REDACTED] witnessed the signature of the statement of choices and that statement was circulated to health authorities. John had written—

I would not want to be forced to linger as a prisoner in a hospice or hospital bed needlessly suffering until the inevitable end. I have seen family members in this situation and would not want this for me. What would give me comfort when nearing death? Knowing in advance that the end of my life will be pain-free, peaceful and quick.

Two days later, a St Vincent's nurse made an unexpected home visit. She took a copy of John's statement and managed to convince him that palliative care would afford him that end-of-life comfort. John was admitted to St Vincent's on 30 May when his pain could no longer be managed at home. He was relatively comfortable for the first couple of weeks, but on 14 June he lost control of his legs, bladder and bowel and from then on he was a needlessly suffering prisoner. He was dead from the chest down, mortified at what he was putting his kind and caring nurses through in their efforts to clean him up, in constant and increasing pain and wishing to die. He suffered in this state for three full weeks until 5 July, sedated but distressed and agitated until the end.

Four things have led me to believe that John's treatment was driven by a shrewd business model rather than a compassionate care model. First, there was the eagerness of the home visit which I have come to see as a sales pitch. John was actively recruited and sold an unfulfilled promise.

Second, there was the answer I received to the question of how long John could stay in palliative care. His doctor told me, 'Thirty-five days, no questions asked', after which he would have to go home or to a nursing home. John died 36 days after admission. No time limit was set by his private health insurer. Was it a hospital business decision to ensure a regular turnover of beds?

Third, there was rationing of pain medication. Although John was paralysed, he was in almost constant pain. Doctors told the family they were trying to strike a balance between keeping John as pain free as possible and as alert as possible. Alert for what? So that he could be fully aware that he was lying, as he put it, 'stinking in my own shit' with pressure sores breaking out while the cancer continued its agonising destruction?

Fourth, there was the 'how did we do?' survey. A month after John died, St Vincent's sent me a 17-question survey, each item to be rated from 'very satisfied' to 'very dissatisfied'. Was that a follow-up in accordance with good business practice? John's statement of choices was not worth the paper it was written on. He died in exactly the way that he had most feared. He was sold palliative care and it sold him short.

CHAIR: Thank you, Evelyn. That was a difficult story to relay.

Dr Jansen: It has been difficult to live with since. I have been so angry.

CHAIR: I bet. Did you fill out the survey?

Dr Jansen: I filled it out. I have actually got a copy of my diary entries from the time that John was in hospital. I filled out the survey only by completing my own comments on the back. I could read you what I wrote to Dr Good who sent the survey. There were 17 questions. I have actually got his statement of choices here, too, in full. I did not fill it out on the front, but I wrote—

CHAIR: Would you like to table that?

Dr Jansen: I will table all of my papers, if that is convenient for you?

CHAIR: Thank you. Is leave granted? Leave is granted.

Mr McARDLE: Have you retained copies for yourself, as well?

Dr Jansen: I do have copies.

CHAIR: Leave has been granted. We will appreciate reading that and thank you again for sharing that with us. What are you a doctor of?

Dr Jansen: I have a PhD in Education Administration.

CHAIR: Thank you very much. Welcome, Ms Thorpe.

Ms Thorpe: I am a registered nurse, recently retired after 40 years in practice. In the short time I have, I want to talk about the three topics, even though I sent in a submission on voluntary assisted dying. First, there is aged care. I have had a couple of good friends recently in aged care. There are a few points that I want to bring forward. Staff ratios are long overdue. Having two so-called nurses or carers with minimal training for 25 elderly, vulnerable patients is disgusting. The care is not care. It is a do-not-care place. That is one thing.

Not having an RN on at night is absolutely terrible. My colleague goes home at night expecting to be called by, again, so-called nurses. There is some training. There are AINs and ENs, but that is it. She expects to be phoned up about things or to be called out. The whole nursing home has nobody at registered nurse level. That is a very poor thing. I think that if the relatives were aware of that, they would be as disgusted as I was when I heard it. Unfortunately, frequent errors are made in aged-care residences because, again, of the low standard of staff. Having worked in hospitals for years, we expect a standard for patients in care and residents should be afforded the same level of care.

Wrong patients are seen. For example, my friend was woken up in the middle of the night. There was a man standing next to her bed. My friend was 90 but as sharp as a tack. The nurse came with him. He did not introduce himself. She did not know who he was. He said, 'How are you?' She said, 'I'm fine.' 'Good,' he said, and wrote something down and they both went. The next day she had an extra tablet in her little tablets that she was given. She said, 'What's this?' They said, 'It's your antibiotic for your chest infection.' She said, 'I don't have a chest infection.' Through investigation she found out that it was for the patient next door and the doctor should have been visiting the person next door. The nurse had not taken the time to even identify the patient, let alone the doctor, who had not introduced himself, or Rita would have said, 'I'm not her.' This sort of thing happens over and over again. I have witnessed a tablet being so-called dissolved in water, when it was enteric coated and was not dissolvable, by a nurse who did not know what he was doing. The blister packs are set up by an RN and given to people with very little training, or no training. They just dish them out as they go along the ward. It is in great need of an overview.

There is a massive gap between the aspiration, the ideals of palliative care and its reality. We only have to have relatives like I have had recently—in the last 20 years—going through palliative care to see that. Many patients in palliative care are still suffering day by day, even though I have been told time and time again, 'This is 2019. They should not be suffering. They should not have pain. We should be able to do something for them.' It is very distressing to sit next to someone for four days and see them dying. Many people here have had that experience and I have recently. My friend went into intermittent agitation. I was told, 'As soon as she becomes agitated, come and get the nurses and they will come.' Half an hour later they came. In the meantime the agitation had become really high and I was told, 'Sorry, we got held up with somebody else.' There is a lot more that I could say.

Voluntary assisted dying has to be at the patient's choice. As somebody just said, it is nobody else's decision; it is my decision. My father wanted a plastic bag to go over his head when he knew he was dying. He asked my brother to help him, just to practise. He ended up laughing, which was something, so he never ended up doing that. Fortunately, he died suddenly. It is a slippery slope to say that we are having euthanasia. Rubbish. This is voluntary. This is voluntary assisted dying. Somebody just said, 'We have to put up with every little suffering.' You put up with the suffering. I do not want to. This is my choice. Thank you.

CHAIR: Thank you, Ms Thorpe and thank you for your 40 years of nursing and sharing with us the recurrent themes I keep hearing of choice and voluntary. They have been recurrent throughout our travels. Thank you very much. Welcome Ms Carol Cragg.

Ms Cragg: I hardly know what to say after all of that. It is just appalling what is happening to people. I really appreciate the fact that this hearing has been set up. I think it is fabulous that we are able to talk and that you are putting in the time and listening. I have only heard a short period, but you have been hearing it for weeks and months. I do not know what your brain is like by now. It must be terrible. I keep hearing about advance health directives. The first time I have heard about a statement of choices was from you. This is something that I think—I do not know if you have read it—

CHAIR: Yes.

Ms Cragg: You surely would, but it even asks you where you want to die, which I think is fabulous, and what you want to have happen to you after and what your philosophy is. I think it is excellent. Everyone should get one. That is what I think.

I really want to emphasise that more than 60 per cent of us from various surveys want voluntary assisted dying. It is going up and up all the time. If I knew I was sinking into dementia at the time I was aware of it, because I have certainly lived a curious, active life, I really would not want to hang around for too much longer until I knew I was right into that demented stage, so I have my statement of choices. Why keep us alive in misery when we want out? Think of the money that would be saved if we were not all kept in nursing homes against our will and at huge expense. The government could spend that on rural and remote and Aboriginal health, which really is in need. That is something else that we could think about.

As far as the AMA goes, they are a conservative group, but there are still about 30-plus per cent, nearly 40 per cent, of them who agree with voluntary assisted dying. I do not think that is usually emphasised. I would suggest they do a survey of all doctors and ask them what their opinion is, not just the AMA lot. That is something else that I would really like to see, because they will be involved in the assisted dying.

I have put all of my things in my statement and you have that. To sum up, mental suffering can be just as intolerable as physical. I think we need to have a balance. It is not just physical. It is not given equal weight in most of the VAD discussions. If I know that I am going to die and I choose not to linger on and on and on, why keep me here? It is torture. Thank you.

CHAIR: Thank you very much, Ms Cragg. Mr Marshall, welcome.

Mr Marshall: Thank you, Mr Harper. I am a semiretired dentist. I come from Caloundra and I volunteer helping people—

CHAIR: Caloundra, a good part of the world, according to the local member.

Mr Marshall: I am from Mark McArdle's area. I have been shaken up by some of the testimony today, but I still carry some concerns. Initially, what got me here were two stories that I retained from my youth. One was from my 30s with a lifelong friend of mine, who was usually very laconic and as casual as anything. We got on to the subject of suicide and the outpouring of sorrow and anger at the situation that his grandmother went through when his grandfather had dementia and the abuse that went on from that has always stayed with me.

At the same time there is another story from my 40s when a family friend of mine—a long-term family friend of mine—rang me to tell me about the death of his father who was a lovely man, full of principle, but he was very difficult to follow in his principles and even more difficult to follow him in his application of them. For instance, he was a good Labor man until Bob Hawke broke the pilots' strike and he never voted for Labor again.

He came down with a melanoma and his surgical operations were disasters. Finally, he said, 'At 72, I've had my Waterloo. It's time now.' He refused further treatment. He refused radiography—radiation therapy. He was supported by morphine treatment. Most of the time he was unconscious towards the end, but then at other times when he had an audience—and it was not a dignified audience; it was an audience where he was racked with waves of pain but, through that—he was joking and laughing and taking great interest in even trivial things like telling someone how to get around London a bit quicker.

My concern is that—and it may come as good news to many of the witnesses today—the slippery slope is alive and well. You will probably get what you are asking for because of the slippery slope. People will say, 'There's no slippery slope in Australia. We have all of these safeguards,' but when you look at the situation in Belgium, they had safeguards, too, but doctors kept extending the scope of the voluntary assisted dying. It must not have been well enough regulated. It is not sufficiently regulated and we know—it is common knowledge, it is published knowledge—that one in 60 deaths in Belgium are involuntary assisted dying. That is mercy killing. They are done by doctors who are saying that they do not even inform the family, because they feel that it is a medical decision and for themselves alone to make.

CHAIR: Mr Marshall, we have been given that data as well through various sources. I think it is clear your position is that you are not in support of introducing a scheme of voluntary assisted dying.

Mr Marshall: I already see a pattern of this slippery slope in Australia. Would you like to give me an opportunity to present that?

CHAIR: In fairness to everyone who is here, we have more people to come up. I am happy for you to table any other information that you have. We have given everyone equal time here today. It has been a very long day. We appreciate you coming and sharing your views as well as everyone else who has been here. Are there any questions from any committee members?

Mr McARDLE: No.

CHAIR: If not, I thank you very much for your own stories and views and for sharing those with us today. We will call our final panel of witnesses for the day.

BARRY, Ms Katina, Private capacity

CROME, Dr Mark, Private capacity

GOMEZ GANE, Ms Daria, Private capacity

KAHLER, Ms Jo, Private capacity

CHAIR: We did not want to miss the opportunity for anyone to get to speak. At five o'clock on Friday afternoon, you are our final panel. We appreciate that it has been a big week and a long day. Thank you all for being here. Katina, I ask you to make an opening statement.

Ms Barry: Thank you. I really appreciate the opportunity to speak today. I am here representing myself, an ordinary citizen of Queensland. I come with a background of 62 years in this world and I would like to go out of this world through my choice. I am with Mr Everal Compton. I am also going to speak of my history and family experiences with death and with voluntary assisted dying implications for my grandmother, my great-aunt, my husband's mother and my father. My comments will mostly be around the suffering that people experience in dying in this country from the lack of care and understanding in our hospitals.

My father in the last five months of his life spent time in five different hospitals throughout Queensland, coming from a small country town, Yeppoon, outside of Rockhampton. He was at the Rockhampton Hospital, the Mater, the public hospital in Rockhampton, the Yeppoon Hospital, the Wesley Hospital here in Brisbane, the Royal Brisbane and the Mater Hospital. Of all of those hospitals, only one person understood what he was going through—that was the most junior member of staff in geriatric care in the Royal Brisbane hospital.

By that stage, he was suffering dementia. He was also suffering Alzheimer's. He was profoundly deaf. From the age of 21, he had only 10 per cent hearing in one ear. He had gone blind. He had no sense of smell or taste. The only thing left for him was touch. In that state, he was very little able to communicate with doctors, his family, his wife of 62 years and he was extremely dissatisfied with us all because we were not servicing his needs to the extent, as probably people here are aware, there was violence in the reactions of those people who are in that state. His beloved wife of 62 years, who was four years older than him and is now 91 years old and going strong, was heartbroken and could not make the last two trips to Brisbane to accompany him to hospital. I took six months off work in the last six months of my father's life in those hospitals here in Brisbane to assist him on a daily basis because the hospital care could not meet his needs.

He wanted to die, he begged to die in those moments that he had left to him when he was able to express his thoughts. To have to see your father or any other person in that state, we treat animals more kindly. You cannot tell me that he had quality of life. He had pain, he had suffering, both mental and physical. I think we definitely need to do better. If that requires us to be more compassionate, that is what we must do. If we need to make new laws and regulations, that is what we must do. As I hear across-the-board here this afternoon, choice is the word that is the common theme and it is something that the baby boomers and the generation older than me demand, insist upon. I think we need to meet that demand.

With regard to what happened in 1964 when my grandmother died and in 1977 when my great-aunt passed, they fortunately had doctors who had some understanding. I will not name those doctors, but they were able to pass through pain medication and move on. My partner's mother, who died in Singapore in 1969 from throat cancer, had an extremely understanding doctor who asked the 19-year-old son, 'Do you want your mother to suffer anymore?' to which the 19-year-old son said, 'No, I don't,' and they obliged. If they can do it in 1969, why can we not do it now?

CHAIR: I think that is well articulated, Ms Barry. Thank you very much for your contribution here today. Daria Gomez Gane, I invite you to make some comments

Ms Gomez Gane: What happened was that I was thrown into the so-called system and what I would like to do today is grab this opportunity to remind people that there still is a need to update the Mental Health Act in Queensland as it is, because I was thrown through it. Incidentally, it was a one-off in my life. I was not prepared; nobody was, as it turns out. Basically, social workers of the child safety department were threatening me with a Mental Health Act evaluation during criminal proceedings. I was a victim of crime, but I was treated as guilty. I was nearly put on lithium at the PA which would have made me really suicidal. After another medication for anxiety, it made me so anxious that I finally understood suicide, because I was in that nervous tension state, as Everal put it. It is so intolerable. It is not that you want to kill yourself; you have to. That is the point that I wanted to put forward.

There are risks for the aged-care Queensland assessment system for the nervous breakdown element. There are not enough controls in place. Laurel Beale told us that her husband was withdrawing from medication—the same anxiety one. It was so strong that I had to be weaned off it. The second one was all right. Doctor Hambleton mentioned the physical and intractable suffering. Has he had to wean himself off any medication? He is discarding the fact that Mrs Beale's husband had to without knowing. The prescribing doctor said, 'Yes, it is like a vitamin.' No, it is not.

I see an analogy. They say, 'The family won't see it,' but when they mentioned Einstein today that reminded me of his saying: in life it is not so much that people do bad things but others watch without intervention. My view is we need only strong interventions and the key word seems to be 'choice' instead of 'voluntary'—death by risk in everyone's case, or by degree when you have your degree, and I have one. Basically, that is it. I am really against the risks that the frail be mistreated in the way that they are not given a choice. If people are in enough pain, tick a box like they do in Switzerland and do 100 tests and fill out 100 forms but, if they make it through to the finishing line, it is their right. They have conquered the right to freedom which, to this day, I have not seen in place so far. Thank you.

CHAIR: Thank you very much, Daria. Thank you for your commentary. I welcome Dr Mark Crome. Before we begin, the committee has resolved to publish your submission and make the necessary amendments, as you pointed out.

Dr Crome: Thank you, Mr Harper. I will speak to three levels: the dying person, the assisting relationships and the many communities of interest. Firstly, the dying person: I acknowledge the fear that drives this debate about a need for voluntary assisted dying—VAD. I will call this the Third Way. Like my colleagues, I have been in attendance at quite a number of deaths, especially when I worked in hospital and in general practice. Death is never easy, always unique. But why the fear and the calls for the principle of autonomy to override the value of sanctity of life? I worked in medical research for over 20 years and I worked with the death statistics for Queensland Health. This debate is not driven by the way people die naturally. Most of us will either die suddenly or with a relatively uncomplicated death attended by our doctors, nurses and loved ones.

Secondly, assistance is required for dying and for large parts of modern history the doctor-patient relationship has underpinned a good death. I have tried to argue that a vast number of deaths still occur within the context of usual medical care. It is true that many people would like to die at home, or in other care environments, and palliative care can assist the community care system to do that. I acknowledge the small number of slow deaths complicated by difficult to manage pain or other symptoms, but we have the resources to manage these problems—better access and training are two areas in health service delivery, at the level of assisted dying, where palliative methods are added to usual care. The advocates for a Third Way are not sufficiently pointing to the new complexity being added to the system. I strongly endorse my colleges' submission 1203, the Royal Australasian College of Physicians, for all of its support of palliative care, but mostly because it points out that some doctors and other staff will face emotional harm in the VAD process and will need support.

Finally, as persons I believe that we are born into and die from many communities that we have worked and related to in our life course. I have heard Professor Ben White's talk on radio and I have heard Dr Kym Boon, liaison psychiatrist at the Royal Brisbane hospital, challenge Ben on the massive problem of dealing with capacity testing and consenting in the diverse settings where VAD will arise. My wife was a hospital social worker for 30 years, often working in cancer fields, and witness to the best and worst of dying. She agrees with Dr Boon's expressed concerns that there are many vulnerable people and that issues of coercion and undue family pressure are not easily addressed by simply reforming legislation and implementing protocols at the grassroots.

I have expressed my concerns about the way evidence and statistics are used in this debate. As a former medical researcher, I am aware of the many biases in studies like those used to show the experience in international jurisdictions to justify a move towards VAD. I submit that the vast amount of evidence talked about has a significant fear bias in it and I would welcome the media playing a more positive role in the stories it tells.

I am arguing that a good death can be reached in the vast majority of cases. Palliative care augmenting usual multidisciplinary health care can address the many problems being presented to this inquiry. We could learn much from people of other cultures, our Indigenous brethren and faith communities of religious or other type. I am heartened that even Paul Keating states that VAD 'is a threshold moment for Australia, and one we should not cross'. Thank you.

CHAIR: Thank you very much, Dr Crome, for your contribution. We will move to our last speaker for the day, but certainly not the least. Welcome, Jo Kahler.

Ms Kahler: Thank you. I was not expecting to speak today, so this is not very well planned. I have certainly thought about it quite a lot. My background is I was an emergency nurse for quite some time. I was also an intensive care nurse. When I was in Perth in 1995, I was tasked with rewriting the emergency manual for the hospital. Part of that brief was to introduce the concept of an advance health directive. That is basically my background.

With all due respect to palliative care specialists, at the end of the day the people who are sitting next to the patients are the nurses and the family members. That is just how it is. That has been my experience. I know there have been a lot of nurses in the room today. If you ask any of them, it will be the same experience. I would also like to say—I am not sure if you have heard it before—that, anecdotally, it happens in hospitals, the dual effect, whatever you want to call it. Sometimes it depends on the assertiveness of the family, the connections, the medical knowledge that that family might have. That is unfortunate, but it is quite a valid point. My husband is a neurosurgeon. We certainly have discussions about these sorts of issues all the time. I think it simply comes down to the fact that we need VAD laws to provide choice and protection.

I have also been intimately involved with the deaths of two members of my family—one quite recently and also an uncle who was diagnosed with motor neurone disease. That is a very unkind illness. I noted with interest that, when the Victorian laws came out, he would not have been covered. Essentially, his lungs became paralysed. It was through my intervention at the hospital that I was able to encourage the staff to administer a certain regime of drugs. I know that people have really strong opinions on both sides, but it is just simply the way it is. That is pretty much all I have to say. I have a question, though, for you, Mr Harper. You quoted a statistic about the seven deaths a year of teenagers with a terminal diagnosis committing suicide.

CHAIR: Sorry, it was not teenagers. We have written to the relevant authority, the Coroner, and it was seven deaths a month from suicide, so over 1.5 a week.

Ms Kahler: I beg your pardon. Sorry, I misheard you.

CHAIR: The question we asked was if they had been diagnosed with a terminal illness, which they had. They have been able to do a coronial investigation and provide us with the detail. Those details are for the committee at this stage.

Ms Kahler: Okay.

CHAIR: Some of the stories are horrific.

Ms Kahler: Will that be broken down? What is particularly relevant in Queensland is the postcode so that we get a true sense of what is happening in the bush.

CHAIR: We got a breakdown of regions. It is for the committee to resolve where to from here in relation to that information. It just gave us a snapshot of what is happening out there.

Ms Kahler: Okay.

CHAIR: Firstly, thank you for your work in nursing. We have had many palliative care nurses write to us in our thousands of submissions and express exactly what you have said—that they have witnessed horrific things. They are the people who are there with family. Notwithstanding the palliative care specialists who write the orders, it is the nurses who are there doing the turning, who are doing the nursing duties, and who have expressed to us some of the awful things that they have witnessed. Again, it revolves around choice. You said that you have seen it happen now. I just wanted to explore that a little bit.

Ms Kahler: Yes.

CHAIR: Have you seen it yourself?

Ms Kahler: Yes, I have, with the death of my uncle and also with the death of another family member just in the last months. I am not going to get arrested, am I?

CHAIR: No. We are just simply asking.

Ms Kahler: Yes.

CHAIR: Some palliative care nurses say that it is euthanasia lite. We have had ethicists and we have had people of religious backgrounds come in and say, 'The end result is death when you are giving a certain medication.'

Ms Kahler: Yes.

CHAIR: One particular fellow in Bundaberg, a palliative care nurse, termed it euthanasia lite.

Ms Kahler: Okay. I have not heard that term before.

CHAIR: That was interesting.

Ms Kahler: I heard people around the room as I said the words. It is just the way it is.

CHAIR: Thank you very much for your contribution here today. I thank each of you for your time and views. As there are no further questions, I will make a few closing remarks. It has been an extremely busy week for the committee. Firstly, to all the people who attended, whether they were in Ipswich, the Gold Coast, here today in Brisbane or those who attended our Earle Haven hearings, this is a significant body of work in aged care, palliative care, end of life and the issue of voluntary assisted dying. I thank each of you, many who have stayed with us throughout the day listening to other stories—sometimes difficult. Without the input of the people of Queensland, we cannot make recommendations going forward. We value your time and views that were expressed today. I also put on record my thanks to the committee—or those members of the committee who are still with me here today—for their work this week and our secretariat, Rob Hansen, who is beside me, the secretariat staff and Hansard for their work. I now declare—

Mr McARDLE: No, you do not. I want to thank the chair. The chair has certainly had an enormous role to play not just in keeping the unruly mob up here in train but also the staff. Chair, this will not be the end per se, but I think this committee has been chaired well, it has been chaired with respect and it has been chaired with equality to all. Thank you.

CHAIR: I thank the deputy chair. He is a good mentor. I now declare this public hearing closed.

The committee adjourned at 5.19 pm.