



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

Members present:

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

Staff present:

Mr R Hansen (Committee Secretary)

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

TRANSCRIPT OF PROCEEDINGS

TUESDAY, 10 SEPTEMBER 2019

Southport

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The committee met at 11.33 am.

CHAIR: Good morning. I now declare this public hearing of the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee open. I want to start by acknowledging the traditional owners of the land on which we are meeting today. I am Aaron Harper, chair of the committee and the member for Thuringowa. Other committee members present today are Mr Mark McArdle, the member for Caloundra and deputy chair; Mr Michael Berkman, the member for Maiwar; Mr Barry O'Rourke, the member for Rockhampton; Ms Joan Pease, the member for Lytton; and Mr Sam O'Connor, the member for Bonney, who is standing in for Marty Hunt, the member for Nicklin, who is unable to be here today. Before I go any further to introduce some of the local members who are here, Sam, as the local member, I invite you to say a few words.

Mr O'CONNOR: Thank you very much, Mr Chair. Welcome to everyone. I know I do have a few constituents from the electorate of Bonney, which is the best electorate on the Gold Coast. It is a great privilege to have a little bit of parliament come here to Sharkies, so thank you for coming along today. I really appreciate it. This means a lot. We do not normally get this many people come to our parliamentary committee hearings—certainly not the one that I am on; it is a little bit more dry—but it is a very important inquiry and we really appreciate you all being here.

CHAIR: Well said, Sam. Thanks very much. I also note that in the audience there is Ray Stevens, the member for Mermaid Beach. Welcome, Ray. Also joining us is John-Paul Langbroek, the member for Surfers Paradise. Welcome. I understand that joining us later will be Meaghan Scanlon, the member for Gaven.

The inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying was referred to our committee on 14 November 2018. The reporting date for this inquiry has been extended, with the committee now required to report by 31 March 2020. 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 witnesses are protected from legal action in respect of the evidence they may give the committee. If witnesses give evidence today which reflects adversely on an individual or organisation, it should not be taken as proof of the allegations being made. The committee may choose to receive but not publish that evidence.

The committee will not require evidence to be given under oath, but I do remind you that intentionally misleading the parliament or committee is a serious offence. Some of you may share experiences and insights today that are deeply personal and may also be very painful to talk about. I ask that everyone respect the rights of others to hold and express their views and I also ask that witnesses take care when referring to acts of suicide or euthanasia. For all those appearing today, you have been provided with a copy of instructions, so we will take those as read.

BROADBENT, Dr Andrew, Director of Palliative Care, Queensland Health

BUCKMASTER, Dr Nick, Medical Director General Medicine and Aged Care, Queensland Health

CHAIR: This hearing will start with a panel of local experts, and I welcome Dr Andrew Broadbent, the Director of Palliative Care, Queensland Health; and Dr Nick Buckmaster, Medical Director General Medicine and Aged Care, Queensland Health. Thank you both for being here, gentlemen. The two doctors in front of us will give us an update of what aged-care services and palliative care services in this part of beautiful Queensland look like. We will then hear from people who provided written submissions to our inquiry and others who have asked for the opportunity to speak. If you have not done so already, please see Rob Hansen, who will register you to speak later on this afternoon. This hearing is being recorded and transcribed by Hansard and witnesses will be provided with a copy of the transcript. You may be photographed, as it is a public hearing with media attending. I welcome our two doctors and I invite you to make an opening statement. Then we will move to questions.

Dr Broadbent: Thank you for allowing me to attend this committee. I am the medical director for supportive and specialist palliative care for Gold Coast Health. I have been the medical director here on the Gold Coast for the last 3½ years, since coming up from Sydney after 20 years there. I

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have extensive background in health management as well as service redesign for hospitals as well as managing palliative care services. Since arriving on the Gold Coast—obviously the best place to be—I have been involved in leading the redesign of the service here, which includes building multiple coalitions of the willing in both palliative care and end-of-life care, or care at the end of life, within the Gold Coast, and this includes inside and outside of Gold Coast Health. We have partnered very well with the primary health network here, the PHN, and also the Queensland Ambulance Service, but unfortunately, whilst we have plenty of willingness, there is perhaps not as much funding as we would like.

For a small service for its population, the Gold Coast palliative care service I believe hits well above its weight in innovation of service delivery, which it has really had to do because of the resources we have. We are, for example, Queensland leaders in the collecting of palliative care data on our service and the redesign effects of that. We are the state, if not world, leaders in providing palliative care telehealth. We certainly provide large amounts in Queensland. We also provide a large amount of education. This includes novel designs such as an app that works for both the Apple iPhone and the Android operating systems which contains a knowledge base for junior doctors, allied health staff as well as services outside the hospital system such as general practice and Queensland ambulance staff.

We are about to embark on a couple of very interesting journeys with our partners. This includes with the primary health network an education program into the nursing homes that we do not otherwise really service on the Gold Coast, of which there are about 80. This will be a pilot program for 12 months and we hope somewhere there will be some permanent funding found for that. For the Queensland Ambulance Service there will be direct video links to their frontline ambulance staff as well as an education package. We expect both of these to commence in the next four to eight weeks.

CHAIR: That is a new program?

Dr Broadbent: These are both new programs, yes. They have all come from temporary funding. I do have a number of documents I am happy to give to the chair. Once again, thank you for allowing me to talk.

CHAIR: Thank you very much. Just very quickly for the benefit of people here today, in the area of palliative care, how many beds do you have available in this region?

Dr Broadbent: We have 20 beds available, but this winter we have been going up to 24. The predictions we have are that we probably need more towards 40. With the rapidly growing population of the Gold Coast, we certainly expect to need more and more.

CHAIR: That is one of the things we keep hearing throughout Queensland—the ageing population. I think it was the Grattan Institute that said that by 2026 we will have around 800,000 people aged 65 and over in Queensland and it goes out by millions over the decades, so we certainly need to get this right. Thank you very much for that. I welcome Dr Nick Buckmaster.

Dr Buckmaster: Thank you. I am a pre-eminent staff specialist and a general physician. I am the director for general medicine and aged-care services in the Gold Coast health service district. I also have had now 25 years being a specialist within Queensland Health. God help me! During that time I have seen marked changes in our health system. We have seen increasing efficiency in our hospital services for acute medicine and we have seen, I believe, increasing inefficiency in our health services across-the-board for aged care and for palliative care and care of the dying.

Every day as director of general medicine in our acute services we see many patients sent in from the community for end-of-life care where we know that they would prefer to have died at home. Every day we see people sent in from nursing homes because nursing homes are unable to manage the care needs of those patients, whether it be because of behavioural problems, whether it be because of nursing care problems or occasionally because they need higher levels of medical care.

Unfortunately, despite the fact that we have a rapidly ageing population, when I started as a specialist the average age in my unit was in the 70s but now it is in the higher 80s. We need to have change in our health systems and we need to have it done urgently, because we are losing the battle and we are wasting money and we are being inhumane.

CHAIR: Thank you very much. That was well articulated. Thank you for your years of experience and being frank and honest about that. Right throughout Queensland we have heard of people waiting years for aged-care packages at home. I think there is some data that 70 per cent to 80 per cent of people would like to be at home at their end of life—surrounded by family—and not be in a tertiary institution. The reality is that we are hearing of thousands of people waiting. I will highlight the worst case that I shared yesterday in Ipswich of a lady in Hervey Bay who turned up to our public

hearing because that week she had received her aged-care package for her husband, who had died four years earlier. This is not acceptable in any way, shape or form. We need to make sure that we have those people accessing their packages early. From a committee point of view, we think this places, as you articulated, a burden on our already busy public health system. We have some data around how many acute beds are being taken up by people who need residential aged care.

This morning we visited the Redlands facility. We have 16 state-run facilities. As you may have heard, the government has introduced a bill to increase ratios in our public system and place private facilities on the map, if you like, to at least report what they have. We are hearing of disturbing instances of a lack of nursing over a 24-hour period. For 70, 80, 100 or 120 people, there may be one nurse on. Do you think that has an impact on your ability to care for people? Where do you see these things that we are hearing?

Dr Buckmaster: There are many points of failure in this system. You have phrased one of those points of failure, which is the waiting time for access to aged-care packages in the community. There is no question that delays in access for people with higher care needs particularly leads to at times unnecessary admission to either nursing homes or hospitals. There are also, though, failings in the funding for nursing homes, the adequacy of the ability to attract and retain skilled nursing staff and also difficulties with attracting and retaining medical staff to those facilities.

CHAIR: One of the other issues we hear is that GPs are not incentivised to go to residential aged-care facilities to treat people because of the Medicare rebates they receive. Do you have any commentary on that?

Dr Buckmaster: There are business models for general practice. Again, they are fairly complicated, but there are real problems with the ability for general practitioners to effectively provide care to people in nursing homes. They have some similar barriers to access in terms of time and the ability to give resources to people who are wanting to die at home. I am sure Andrew can speak to that.

Dr Broadbent: Yes, I would agree with Nick. That was very well put. We have huge issues. There are multiple points of failure. Certainly a large one is the funding of care at home. From my point of view, there is a very big difference between New South Wales and Queensland. Having really no access to funding packages makes it very difficult to send people home, particularly on the Gold Coast, which is significantly demographically different from perhaps Brisbane and other metropolitan areas.

CHAIR: Thank you. I recognise the member for Gaven, who has just joined us. Welcome, Meaghan Scanlon.

Mr BERKMAN: Recently we have heard people describing issues with mental health patients and, effectively, once they reach the age of 65 not having facilities available for them and ultimately being shunted into aged-care facilities when, in fact, they need higher level mental health support or psychiatric support. Can you confirm that? Is that an issue here in Queensland that you have come across? How does the department deal with that?

Dr Buckmaster: I would not answer it directly with a great deal of expertise, but I can tell you that one of the major issues we face within the acute sector is issues with challenging behaviours in people who have potentially chronic mental conditions but, more commonly, chronic cognitive dysfunction—brain injury or people with dementia. This is a huge area of failure yet again. It is causing real difficulty with how we work with people with challenging behaviours in the acute setting.

The acute setting is set up to look after acute problems. The amount of nursing care and security requirements that we have for a number of our patients who have now been in for very many months is enormous. Of course, that is not covered by casemix in any remote way, yet it is a significant portion of our budget.

Dr Broadbent: It is certainly an issue recognised in Gold Coast Health. I am a member of the clinical council of Gold Coast Health, which is one of the lower divisions of the clinical senate. Within our group we recognise that and we have asked the hospital to have a forum next year, or later this year, to help the staff develop management plans with patient load, which is becoming more frequent. I think one of the particular issues, again, for Queensland but particularly for South-East Queensland and the Gold Coast is that there are very few community based services here. These unfortunate people by default end up in an acute hospital system, which is not geared up to manage them best because the skilled experts in the community just are not there to facilitate their care at home. That is true for geriatrics, aged care, palliative care and mental health and I am sure a number of other fields on the Gold Coast.

Dr Buckmaster: If I may add, I was very disappointed that the Commonwealth, in establishing what I might call forensic units for people with aged care and challenging behaviours, did not elect to proceed with giving any funding to the Gold Coast region. I think that is a craziness, given that we are the sixth largest city in Australia.

Mr BERKMAN: Dr Broadbent, in your earlier answer I think you referred to differences in the funding that is available for in-home care between Queensland and New South Wales. Can you give us a snapshot of that difference?

Dr Broadbent: Yes, significant differences. Obviously, the federal issues are consistent across the country and we have many of them. Somebody would be dead for a significant period before their level 1, 2, 3 or 4 package comes through. We particularly need the high-level care—level 4. In New South Wales, we have a number of packages that are available to not just palliative care services but all the medical services. One of those is called ComPacks, which is the community package for home care to get people from acute hospitals back into their place of residence. Essentially, you have a bucket of funding that will last between six and eight weeks that you can utilise for extra services on top of what you also do not get in Queensland: the free community nurses. There are co-charges here. We know that the Gold Coast is very different. It has probably very few financial resources in comparison to other areas. Even small charges are barriers to patients getting nursing care here.

Palliative care itself has a very small bucket of money for this area health service. There is a big variation, as I am sure you have found, across Queensland. Some have almost nothing and some will have significant. We have almost nothing in our bucket to help to keep people at home. That package would be great.

The other one is the HammondCare package that keeps people home in the last week or two or life. We know that that is where people want to be when they die—at home. They would rather not be in an emergency department or in the acute wards. This is another package that we developed in New South Wales. That really facilitates the extra perhaps six to eight hours of an AIN—an assistant in nursing—or a care worker at home to give the family extra support. It is often targeted at night-time because, as we all know, if we have to be up all night we really do not function the next day. These are just assistants.

Other things, for example, are that there is a lot of free equipment. We have an issue that we are trying to work with MASS at the moment, with palliative care being excluded from any MASS funding. For that—the ‘P’ word as we call it—we now have to be very careful with our involvement with people who need equipment, because as soon as we get involved they will defund that or they will not give them the equipment. That includes home oxygen and a number of other pieces of equipment. Yes, there are disincentives to be linked to palliative care and using the ‘P’ word.

Mr BERKMAN: It has become apparent that, certainly around the south-east corner, as I understand it, not-for-profit providers have carried a lot of the burden of in-home palliative care. Karuna is one that I am familiar with in Brisbane. Do you have those sorts of services operating on the Gold Coast? How close do they come to meeting that demand?

Dr Broadbent: There are a number of non-government organisations. The main nursing services we work with are Anglicare, Blue Care and Ozcare, with very good services. They are part of our coalition of the willing. They have in their DNA that they are caring. We also have Hopewell Hospice, which is now linked into the children’s hospice in Brisbane. Again, they are part of our coalition of the willing but the resourcing really does not allow them to do a great deal. A lot of their work, particularly in the hospice, is funded locally. They work closely with us. We meet with them every week—all of those NGOs—as an integrated service delivery. Their meeting was on this morning. That is so we can highlight cases that we particularly need to, but they are limited by their funding. Again, they are vital. In New South Wales, you do not have this issue so much on funding.

CHAIR: I think you articulated that when you came before us with the palliative care group.

Mr O’ROURKE: In regard to in-home support and the availability of funding, how often would you have a patient in the hospital who cannot be discharged for an extended period because of that limited funding for in-home support? How long would they be taking up a bed that should be freed up?

Dr Broadbent: The false economy is staggering. Every day—twice a day, three times a day—I am seeing patients who could go home if we had appropriate packages of care or funding but they cannot. We just cannot give them the resources. It is not just nursing care. To keep somebody at home you need a variety of staff. That includes particularly skilled allied health staff and other doctors

as specialists to assist the generalist doctors such as the GPs. I am happy to seek leave to table a document of our current staffing resources with the gap that we have. I have brought enough for each of you to have one.

CHAIR: We will have to procedurally get that tabled. Is leave granted? Leave is granted.

Dr Broadbent: Within that, if you need a physiotherapist to visit the house to assess their mobility and their safety, you cannot do that very quickly. We have half the physiotherapists for the community between the border and the Yatala Pie Shop and between Surfers Paradise over to Canungra. We cannot do that. We have limitations, and that is shown in some other data that I am very happy to give you. I have some data sheets to give out that show where we fall down as a service, because we cannot provide staff to do anything.

The default then comes into ED. We know the cost to ED—false economy—of \$2,000 to \$5,000 and to acute medicine and to Nick's team or my team of another \$1,000 a day, yet for small change this could be prevented. We know that. When you compare ourselves in this document with the Palliative Care Australia guideline, we fall well below the minimum data, the minimum staff numbers. That is a minimum, not a suggested maximum.

CHAIR: Thank you.

Mr O'CONNOR: You mentioned the community package from New South Wales. Is that a state funded package?

Dr Broadbent: Yes.

Mr O'CONNOR: Could you detail what they get in New South Wales compared to here?

Dr Broadbent: I use the analogy that they interleave. You have almost the direct opposite in each state. If I sat on the border or a boundary street and I jumped across from the left side to the right side of the street or lived in the middle, I could get what I need, which would be just about perfect. The package of care—I do not have the direct sums with me—is usually enough for that six to eight weeks of: 'Yes, we can put on a nurse for an extra three to four hours a day. We can supply the equipment. We can get community teams to go in and do these assessments.' Much like a level 4 package, you have the options of what the case manager and the family decide is needed the most. It is a flexible package of care. That is also true for the end-of-life care package that HammondCare develops for half of New South Wales and Silver Chain delivers for the other half.

Mr O'CONNOR: Does that lead to fewer people dying in hospital?

Dr Broadbent: Yes, that is what we believe. That is also true for fewer acute readmissions. The geriatric team is a large user of the ComPacks package in New South Wales. Nick is probably better to describe what he requires here. That is just one of those things. It is equipment as well. It is the allied staff as well. There is a large number of points of failure.

Mr O'CONNOR: Dr Buckmaster, you mentioned that every day you are getting patients in from nursing homes. Do you have any figures on that? What sorts of situations are they coming from?

Dr Buckmaster: I am speaking anecdotally on that. We happen to have the largest general medicine department in Australia, probably head and shoulders. General medicine gets in around 50 patients a day out of which, as a rough rule of thumb, there would be two or three at least who should have remained in their nursing home had there been adequate ability to support the patient there. We have locally put in place some effort to try to provide some better guidance to the nursing homes, but it tends to fall apart quite quickly after hours. It also falls apart regularly because there is often relatively inadequate advance care planning that is being done out in the community.

CHAIR: That is very important. For the benefit of the member of Bonney, who is joining us today, we did have data from the Queensland Ambulance Service in 2016-17 of 34,000 transports from residential aged-care facilities in Queensland, of which there are 469. We see the benefit of having more staff—eyes on patients—in those homes and perhaps a higher level of care to prevent those transports taking up acute beds.

Dr Broadbent: The end-of-life committee, which I am member of, did some data searching for Gold Coast Health for patients who come in from nursing homes and die in the hospital. There are about 30 admissions per month—so one a day—and the average length of stay was about four days. That would have been 30 times four bed days that could have potentially been prevented, but, again, you do need those points, being advance care planning, which is not being done very well, and discussions with the family. Then when something happens we need involvement with the Queensland Ambulance Service and the nursing home and the hospital-avoiding teams that you get in other states—they are really not in Gold Coast Health—that can suddenly go out and visit the

patient, whether it be at 7 am or 7 pm, to prevent that admission. There are certainly models used a lot in New South Wales. There is a little bit of investigation here I believe on that model, but you do need the resourcing.

Mr O'CONNOR: Are the 20 palliative care beds that you said are available on the Gold Coast all exclusively within the HHS or does that include some of the beds up the road at Hopewell Hospice?

Dr Broadbent: No, the hospice are hospice beds. They have eight or nine, of which one or two are funded—you would have to ask them directly—by Queensland Health directly and not through the health service. The rest are usually funded through charity or through private insurance. We have 20 funded specialist palliative care beds on the Gold Coast, of which four are currently based at the Gold Coast hospital. We have moved them up from Robina. We have 16 at Robina, but that gives us flex to go to 20. Pretty much all winter we have been at 24 beds, which was better than last year, when we could max at 20 and have no input on the Gold Coast. I am happy to show you our palliative care plans for the next few years, which are reliant on funding, where we plan to increase the number from 24 to 28 beds in total and carry on going up as our resourcing increases.

Mr McARDLE: I want to start by going to the royal commission. In the early days of the royal commission you would have received a request from the commission to produce certain data with regard to Queensland Health nursing homes operated by the HHS. Do you operate nursing homes in the HHS?

Dr Buckmaster: No. We have a small section of one of the local nursing homes that we rent out for people who are either awaiting placement or in no-man's-land with QCAT or who have basically unresolvable differences between their health attorney and what is possible—

Mr McARDLE: So the answer is that you do not operate a nursing home?

Dr Buckmaster: Yes.

Mr McARDLE: What is the population base of the HHS at the moment?

Dr Broadbent: It would be 600,000 as a minimum. Certainly in holiday season it is far more.

Mr McARDLE: Could you break that up into age—50 on to over 100? Could you take that on notice so that I get an idea of what we are talking about by way of breakdown?

Dr Broadbent: Yes.

Mr McARDLE: How many deaths per year occur in the HHS? There is a reason I ask that question. Do you have any idea?

Dr Broadbent: As inpatients?

Mr McARDLE: No, across the HHS. Your planning would require you to know that.

Dr Broadbent: It is the standard one per cent of the population, roughly. Say there are 600,000 people—

CHAIR: We have been given that data previously and we can share that with the deputy chair.

Mr McARDLE: So it is 60,000, roughly speaking, that we are talking about—one per cent?

Dr Broadbent: One per cent of 600,000 is 6,000, of which I can roughly tell you—

CHAIR: There were 30,000 deaths in the last year. That is the data we have been given. It is broken down by HHS.

Mr McARDLE: It is a bit more than one per cent.

Dr Broadbent: It might be one and a bit. We would all like to live to 100, but we do not.

CHAIR: That is across the state.

Mr McARDLE: How many patients die as acute inpatients within the HHS facilities in a year?

Dr Broadbent: In the hospital itself it is around—

Mr McARDLE: In the HHS as a whole?

Dr Broadbent: About 1,200, we believe.

Mr McARDLE: They are acute patients?

Dr Broadbent: They are subacute and acute. That is within the hospital system. About 200 to 300—it varies from year to year—will be in specialist palliative care. A similar but slightly larger number will be in acute medicine. Nick mentioned general medicine. Most people die in acute medicine and not in palliative care.

Mr McARDLE: So about 1,200?

Dr Broadbent: Roughly, yes. The third place would be in intensive care and the specialist ology units.

Mr McARDLE: You have a budget for 2019-20 of \$1.575 billion, according to the Queensland Health website. Dr Broadbent, what proportion of that is set aside for palliative care?

Dr Broadbent: That is a good question. I have not got my budget this year yet so I cannot really answer that. I did notice that somebody asked that in Rockhampton. My answer would be probably not very much. I think you would find that would be consistent—

Mr McARDLE: Let us try to pin down 'not very much'.

CHAIR: How about we take it on notice?

Mr McARDLE: Let me finish, Mr Chair. Let us go back to 2018-19. The budget would have been done by now?

Dr Broadbent: And finished.

Mr McARDLE: What was the proportion of that budget that went to palliative care?

Dr Broadbent: Of the \$1.3 billion you are probably looking at the one per cent type level as well. I do not have those figures. I am not the financial person. As doctors we do not deal with those figures all the time. This year we hope to have greater visibility.

Mr McARDLE: You are the director of palliative care, so it would be within your province to be aware of that. Can you take on board what would be the percentage of the 2018-19 budget for palliative care and can you find out, at some point in time when you get your allocation, the 2019-20 proportion for palliative care?

Dr Broadbent: I am very happy to.

Mr McARDLE: Can you explain to me why you may not be aware or have not got the budget? It is now September.

Dr Broadbent: That is a question for higher up. There have obviously been discussions, from what we understand. I had a conversation last week about where the budget is. We believe the budget has been loaded, which means going into the computer systems. It has passed the agreements with Queensland Health. It has gone down the various levels. We are about to be shown the budget as medical directors—I am not sure if Nick is going to be shown the same thing—next week. It is the middle of September. In my 20-odd years as a medical director that is actually pretty early. I have had November and December experiences in previous roles.

Mr McARDLE: Are you operating now on a deficit basis?

Dr Broadbent: We are operating in the unknown, which is true for most services. There are a number of ways they operate. This is historical, and what they are saying from last year is that we continue what we did last year. We know there are EEPs or SIPs coming through—enhanced efficient programs—for which we then have to find one to two per cent. Within our budget nobody has ever said we are getting any more. It is the same staff carrying on doing the same thing. What we are doing as a service is looking at outside Gold Coast Health for additional funding. We are being told pretty clearly that there is no funding.

Mr McARDLE: It might be a good idea to do it.

Dr Broadbent: We wish we did not have to do it.

Mr McARDLE: It might be a very good idea to do that.

Dr Broadbent: Absolutely. I have a masters in health management and, as I said, I would love to get those figures early and go through. Nick would like that. We do not get to pick what is spent on what. That is all done by other people. Nor do we get to pick what activity is chosen. That is also done by others. The medical directors end up running the system as best we can within the limitations of the—

Mr McARDLE: Let me get this straight. The medical directors, who are really providing the frontline services, will not be advised as to what their budget will be nor what they can spend it on until November or December this year? Is that what you are saying as a general statement?

Dr Broadbent: That is right, because it is historical. What happened last year continues. If I want to put in place change—and I do try that because there is a law of one per cent; I make a small adjustment to everything, whether that is a slight increase in staffing or a slight decrease—all of that requires about a two-year program to change.

Dr Buckmaster: I would like to endorse what Dr Broadbent has said. Although we are expected to provide medical leadership, and we do, at least in our health service the budget setting occurs away from us. The prioritisation of where funding is allocated tends to be tied to activity targets which do not reflect the needs of aged individuals nor palliative care. I welcome this inquiry because my hope is that it shines a light on the need for the ability to measure outcomes in aged care and in palliative care which are meaningful to the community and which then can have appropriate funding.

Mr McARDLE: I agree entirely. After-hours palliative care is an issue I want to talk about as well. I know you have 20 beds—16 at Robina and four on the Gold Coast. Can you define the after-hours palliative care service for me?

Dr Broadbent: After-hours specialist palliative care is just a doctor on call, which would be a registrar, and then a consultant as second on call. There is no on-call service for nursing that is specialist. There is some generalist nursing done by one or two of the NGOs for their patients in the community but there is a very little. We know that Queensland Health works between 8 am and 4.06 pm. At 4.07 pm there is really very little access to advice locally. I am very happy to seek leave to present what we have a plan for. Again, the coalition of the willing has developed plans, but there is no funding for these plans which includes—

Mr McARDLE: I would encourage you do so.

Dr Broadbent: We seek funding all the time. I have about three grants we are trying to write which you are probably aware Queensland Health is releasing.

Mr McARDLE: Are you saying to me that after hours or on a weekend there is a doctor on call on a telephone but there is no home visit or no ongoing support outside of the normal work hours of the hospital?

Dr Broadbent: That is right. We will have registrars who will come and a consultant who will come and see acute patients who are unwell and ones who need transferring into our unit or acute consults that come through emergency because we can stop them. We do not have any system to do that. That is right, there is very little on the weekends.

We have in our plan, which I am happy to present to you, a seven-day-a-week nursing service, but it requires resourcing to do that. It would be pretty consistent that you would get that in many metro services. Unfortunately, we do not. We are in between that regional service with not very much and a metro service that would have more. We are in between.

Mr McARDLE: Are you seeking leave to table that document?

Dr Broadbent: Yes, I am. I have one for all of you. I have a number of documents. This is a three- or four-page brief on the enhancements we have seeking—some of them that will kindly get us up to minimum level. For example, in that is that very point you have raised, which is an on-call palliative care nursing service—one that would, for example, go from 7 am to 7 pm Monday to Friday, which is our first step, and then a weekend service. It also talks about providing a service into nursing homes. We are the only metropolitan service or regional service of any size, that I am aware of, that does not go into nursing homes. That is historical. There is no funding for that at the moment. I have put plans forward and we may get funding one day, potentially out of this parliamentary committee.

Dr Buckmaster: I was going to offer an observation. My wife is a domiciliary nurse working with one of the three major nursing services. A significant proportion of her work is palliative care. I witness regularly conversations about the difficulties in achieving good pain relief for people out in the community after hours. When she is on call I hear the conversations. Unfortunately, it is not fair or reasonable for the after-hours medical locum services to be looking at prescribing large quantities of opioids. Nor is it reasonable, as occasionally happens, for Clare to have to tell the patient to come into the emergency department.

Dr Broadbent: We have clear data on those issues. I ask for leave to present our data documents, which show exactly that.

CHAIR: For the two documents presented, is leave granted? Leave is granted. Thank you very much. The announcement midyear of \$17 million from the government to improve palliative care services in regional Queensland is something that you may have heard about. I think that is a good start. We are yet to make our recommendations. Clearly, as directors, having input into the needs basis in your area is vital going forward.

Dr Broadbent: I make the comment that South-East Queensland is excluded from that grant, so the Gold Coast is not able to apply. I have had that direct conversation. However, through our telehealth expertise I am creating a coalition of the willing through regional areas. I have discussed Southport

with the directors of medical services at Rockhampton, Bundaberg, Toowoomba and further west, which is the south-west health service, creating and having the Gold Coast as a hub. However, we cannot ask for service enhancements for our Gold Coast area on the current funding.

CHAIR: Of course, we are making recommendations in our report going forward, so thank you for that. I have a point on the PHN paper you presented. We have not had too many PHNs come forward. What is the working relationship like? It is hearsay that millions of dollars are being sent back if not used. We need to make sure that we are accessing those dollars, both federally and at a state level. What is your relationship like with the PHN?

Dr Buckmaster: It is good. As it happens, I am actually on a committee with the PHN at present, looking at working on a pathway for care of the dying and palliative care, to try to integrate our systems. One of the things that is a problem throughout Australia, but particularly across any palliative care or aged-care or chronic disease sector, is integration. We have done quite a bit of work, although I am a little discouraged at the moment, not from the PHN's perspective but because of other constraints, as we appear to be losing ground in developing effective integrated care processes.

Dr Broadbent: Not all PHNs are created equal. The Gold Coast one is very good in comparison to others I work with. We have very good relationships. I sit on a committee, as I think Nick does. About every two months we meet with the PHN. The PHN is part funding our nursing education home program, which will be almost the only thing we have into nursing homes. With us they work in a cooperative manner on a number of other projects that I have not mentioned. One is the advance care planning project, which is a national project that we have applied for, as well as Greater Choice. We have worked together with them on two big grants.

Like all, their issue is having the funding to carry on a project. I do not think they send any back here, to my knowledge. If they do, I am very good at asking, 'Have you got any money left?' I have option after option, as you will see in the one that I have given you for our health service plan, which does include the PHN. As part of developing that, I have multiple things that I can ask for. Basically, I have it all ready to go and I ask, 'Can you do this?', 'Can you do that?' and I push for a yes. People have sympathy and empathy. What they cannot do is the compassion bit, which is use their hands or their budgets to give us the money for us to expand our services, but they certainly have the first two: sympathy and empathy.

Mr McARDLE: With the palliative care beds, at the moment there are 20, combining Robina and the Gold Coast, going to 24 to 28 and then to 40 at some point in time. Do you have a time line to get to the 40 at this juncture?

Dr Broadbent: No, we do not. It depends on funding. We are trying to put together and gather data that shows clinical need and then we do the usual budgetary discussions every year. Again, it is not up to us to decide. We know there is historical funding and there is ABF funding. Neither of those benefit palliative care, because in our ABF activity you do not get recognised for avoiding hospital admissions. You are recognised for providing high-cost, expensive services, but they will not hospital-avoid. Then there is hysterical funding, which I am sure you all know about. None of those come down to palliative care being funded. Again, people have a lot of sympathy and empathy. We get on the list of 'we'd like to fund you and you are No. 3' but we never get to No. 1. We have had a few enhancements but very little.

Dr Buckmaster: Mr McArdle, there is a secondary barrier that may cause problems in achieving those sorts of bed numbers. That is, the Gold Coast Hospital and Health Service is basically out of space. Unfortunately, we have had to have a ward closed over winter because of essential refurbishment work. When that is reopened, which it is in the process of right now, that is the last of our beds. There is a need for building more beds in this health service.

Mr McARDLE: How many beds are in that ward and what type of ward is it? From that closure is there a flow-on impact, for example, to theatre et cetera?

Dr Buckmaster: Absolutely. It was a 28-bed ward at Robina Hospital. We did open beds at the Gold Coast University Hospital. The intent is that they will remain open as we have reopened the ward this week. The flow-on has been that we have had a large number of general medical patients boarded out into the aged-care ward, the surgical wards or the palliative care ward at Robina.

Mr McARDLE: That was going to be my next question. We talk about palliative care beds, but wherever we have gone we have found that those beds are used across the hospital for acute, surgical, medical and palliative care. Is that the same situation here or are they designated purely for palliative care patients and can be used only for that purpose?

Dr Broadbent: They are not designated purely. As good corporate citizens, if medical needs the beds and we do not, we are very happy to be part of their greater team. As we have said, we need 24 sometimes, in which case we may take a few from medicine. The ebbs and flows are there; it is just that the sheer number is not enough. As you have mentioned, we will have another population of Townsville, essentially, coming to the Gold Coast in the next few years. The beds are running out and it is going to be challenging. Obviously, that is an issue for those higher up than us. We will develop models that may help and ask for appropriate funding that will help that. Hospital avoidance, for example, is something they could do a huge amount with here. Do we need all the beds? If you look at what has happened in New Zealand, there has been a significant restructuring of how they provide services, and hospital avoidance is really very high in the KPIs of chief executives. That is an issue for Queensland Health, to put the right KPIs into the right agreements.

Mr McARDLE: Am I right in saying that ABF funding is supreme and that calculation dictates palliative care outcomes?

Dr Broadbent: Historical funding and then ABF at the moment. It is very hard for us to get more funding through ABF because of hospital avoidance.

Mr McARDLE: Is it also the case that the palliative care funding may be cherrypicked throughout the year and placed in other areas? You do not get a set figure, but if it stays stagnant and you draw down, that figure can be cherrypicked and moved into other areas of the hospital and that then impacts the total funding pool?

Dr Broadbent: I have certainly seen that happen in other health services. Gold Coast Health does not really work like that. Whilst I do not have control of a budget, they do not suddenly say, 'Right, your staff have to leave there and go into acute medicine.' I have not had that experience. I have elsewhere, where I have lost significant funding, but not on the Gold Coast.

Mr McARDLE: That raises the question that, if palliative care is going to become more critical, there needs to be some rigidity around funding, the use of funding and being accountable back.

Dr Broadbent: Absolutely, I agree. We are probably the only service in Gold Coast Health that collects outcomes data. I know the segue is to the sheets that I have given you, which is PCOC, Palliative Care Outcomes Collaboration. We know what outcomes we create, not just outputs. Outputs are really meaningless in today's environment. We have done the next step: to say that these are our outcomes and they tell the story of what we do with the money. We know that outcomes of the PCU are very good; the outcomes of our community team, which is small, cannot be good because every time there is a problem they have to come to a hospital. To a degree, our inpatient unit can fix those problems—nausea, vomiting, pain, anxiety, fatigue, family issues—but we could have prevented that admission. If you ask me what is a better model, I would like to have more flexibility about what I can have as a whole, but I need to flex it between inpatients and community. I have had those models elsewhere. That is a model that I would like to have more on, which is that today you actually need it in the community to prevent an admission rather than it going to general medicine.

Mr McARDLE: Going back to the document that you tabled, you have 25.1 FTEs in the palliative care profile for the 2018 funded year. What year would that number have covered the needs of the unit for?

Dr Broadbent: That FTE probably reflects, again, historical funding. That is probably about 1992 figures.

Mr McARDLE: From 1992 that would have been the figure that you needed and in 2019 it is 30—

Dr Broadbent: That is right, because you have gone up by a figure of nearly 50 per cent of what we need to achieve bare minimum. That is not to be world class—there is a big difference between the two—but bare minimum. Absolutely, we are stuck with a Gold Coast population of about 300,000, but we now have 600,000.

Mr McARDLE: Dr Buckmaster or Dr Broadbent, you made a comment about the reasons older long-stay patients stay in hospital. There are four or five categories: waiting for a care bed but are hard to place because of behaviour or dementia, waiting for a guardian decision, waiting for an asset test or financial assessment, waiting for a home care package or not covered by the above. Data on that is tabulated on an irregular basis, as I understand it. Can you take on notice, as of today's date, the number of patients who fit into one of those categories? Is that too difficult to do?

Dr Broadbent: It is easy to do a prospective data collection. From a palliative care service, most of them waiting for a nursing home would be not due to decisions, not due to QCAT. That would be about symptom control and that they are on the borderline for symptoms. Whilst they may need

the palliative care unit for one day a week and seek a nursing home as the right level, because the nursing homes cannot be upskilled or supported with the care needs on that one day we know they are going to come back to us. Our issue is that we can send you, but we know that you are coming back on Tuesday, in which case it is difficult and we have to spend another week or two asking, 'Can we get them even better?' If we had a better community program, that hospital avoidance and early discharge planning could be done better. In geriatrics in New South Wales they have a rapid response team and we would need one as well. We have proposed that. It is in the plans. To do that you need a community team of a certain size. Absolutely, we would agree.

Dr Buckmaster: Across the health service, my recollection—and I apologise if it is slightly inaccurate—was that we were dealing with somewhere around 50 patients at any one time who were effectively in limbo. Within the non-mental health side of the health service, that is fifty out of about 650 beds, from memory.

Mr McARDLE: Across those five areas?

Dr Buckmaster: Yes. There is probably a smattering of NDIS people, and that is growing at present.

Mr McARDLE: Doctors, thank you very much. I appreciate your candour here today.

CHAIR: There is no doubt that increased funding to residential aged-care facilities—or level of care is perhaps a better way of putting it—would take the burden off the public health system; is that correct?

Dr Buckmaster: I think it would be part of the problem. It is also about how care is organised.

Dr Broadbent: It is part of the solution, absolutely.

CHAIR: If we gave you a wand and you were able to get rid of the bureaucracy that we see in getting home care packages—or whatever the blocker is—to me it seems you need accessible funding, make it fair funding and make it now, because at the end of this there are people who deserve good quality care in aged-care facilities.

Dr Broadbent: Absolutely.

CHAIR: That wraps up this session. We thank Dr Buckmaster and Dr Broadbent.

CARTWRIGHT, Emeritus Professor Colleen, Southern Cross University

CHAIR: I welcome Professor Colleen Cartwright from Southern Cross University in Lismore. Your submission is significant.

Prof. Cartwright: Thank you.

CHAIR: You are perhaps marinated in aged care. This is something that you have done many papers on and I think your work will certainly help our committee going forward. We welcome you here today and ask that you make an opening statement.

Prof. Cartwright: Thank you very much for that. I appreciate being here. Yes, I have been working in aged care, palliative care and end-of-life decisions for over 25 years. While I am with Southern Cross University and the main campus is in Lismore, I am based at the Gold Coast campus, which is why I am here. My comments today will be mine and not the university's; I need to make that clear. Some of you might groan when I tell you that as part of a big statewide research project I developed the advance directive and enduring power of attorney documents that are part of the Queensland legislation and was seconded into the department of justice to assist with that legislation.

I have also done research in the Netherlands looking at their end-of-life work and throughout Queensland, New South Wales and in the Northern Territory, and in the Territory while the Rights of the Terminally Ill Act was in place. I am not sure that most people know that Australia was the first place in the world to have legislation that allowed both euthanasia and physician assisted suicide. With regard to the legislation in the Netherlands, while they were performing the actions under the Criminal Code they had a defence called force majeure—'there is no other way I can relieve my patient's suffering'—but they had not actually passed the legislation by the time the Northern Territory did, and then the Commonwealth government overturned the Northern Territory legislation. Just as a little aside, there were 12,000 submissions made to the inquiry that overturned that. I actually have them all in my garage and I can tell you—

CHAIR: I have a few thousand I can share with you as well.

Prof. Cartwright: Yes, and I can tell you that, while the prime minister did not tell any fibs at the time, I have done a forensic examination of 6,000 of those 12,000 so far and they did not actually tell the truth either. To conclude my opening statement, I am currently emeritus professor at the university and Chair of the Human Research Ethics Committee. I was delighted to hear our previous palliative care specialists talking about telehealth, because we have to operate smarter as well as harder. I have been doing a lot of work in the telehealth area, including with older Aboriginal people, who were able to use it very effectively, too. I do not know if you want me to say more or leave it up to you to ask questions.

CHAIR: No, I think we will get straight into some questions, but we did have the pleasure of Marshall Perron, the former chief minister, before us just a few weeks ago in Brisbane and he talked about his experience in bringing that legislation forward. That was quite interesting. We also have had the opportunity in our travels—and I think you are correct in suggesting this—to go to places like Palm Island, Longreach or Mount Isa. We have been up and down Queensland. We think this is quite a significant inquiry and it covers a few areas, but we have seen the benefits of telehealth in rural and regional Queensland already, and people literally want to stay in their communities. Out in Winton they can use a tablet to talk to palliative care specials, so there are advances in technology.

Prof. Cartwright: Yes. In fact, when I did a big project for Kyogle Council not so long back, there was one man with severe dementia who would not sit and talk to a doctor in his office, but put in front of telehealth he would talk to the television and was very happy to do that.

CHAIR: There you go.

Prof. Cartwright: I think we have some extra side bits coming in through telehealth as well.

CHAIR: Yes, absolutely. Professor, I will start with a question, and it is on page 2. I wanted to get straight into it in relation to consent of medical treatment and health care in adults who lack capacity. This has been brought up time and time again in our hearings, particularly around people wanting to see a clause in the bill, if you like, possibly, of having their wishes in an advance healthcare directive space honoured with perhaps something around voluntary assisted dying. The bill that we have seen pass in Victoria talks about having capacity. Can we explore that a little bit? You have done a lot of work in this space.

Prof. Cartwright: Sure. Yes, it is an interesting one because, for example, in the Netherlands you can request assisted dying in your advance directive, but unfortunately it is not very often honoured. The reason for that is that when the doctors in the Netherlands first started assisting people

they were hammered—absolutely hammered—by everyone all over the world and accused of doing all sorts of nefarious things, which in most cases they were not. Because the legislation there requires a current repeated request, they are afraid that they will be accused of not following due process if they follow a request in an advance directive because it is not necessarily current because the person made it before they lost capacity. The problem now, according to my colleagues in the Netherlands, is that because people over there are learning that their requests in their advance directive will not be honoured they are asking for assistance to die before they really are ready to die, which is sad.

The other issue is that we are discriminating against people with dementia. In terms of the legislation in Victoria—while it is six months for diseases other than neurological diseases and expected time to death is 12 months for all others—with someone with dementia, even 12 months out on, let us say, a 10-year trajectory of the disease is not going to have the capacity to request assistance, so they are going to miss out in every way. I think that there should be some provision made, with very strict conditions, for a request in an advance directive to be able to be honoured.

CHAIR: We are hearing the impacts now of dementia in our ageing population. I do not know if you can talk to that particular point.

Prof. Cartwright: Again, there are two sides to this one that I would ask everybody to keep in mind—that is, the majority of people over 80 do not have dementia. Often a person over 80 will be treated as if they do. They will go to the doctor with their daughter, son or whoever and the doctor will talk to the daughter or the son instead of to them. Approximately 18 per cent of people over 80 have dementia. That means that 82 per cent of people over 80 do not have dementia. Over 90 years of age it goes up to 35 per cent. That still means that 65 per cent do not. The point though is that as we all get older—every one of you there, including me too—the speed at which information crosses our synapses slows down. The older we are, the slower we might be in making decisions and people often get impatient and do not let older people speak for themselves. That is unethical; that is just not okay.

In terms of the tool that they use to assess capacity—I do not know if I even said this in my submission—they use a tool called the mini-mental state exam. The mini-mental state exam is not a capacity assessment instrument; it is a screener. It is not bad for measuring change across time. I once asked one of my research assistants if I could administer it to her and she came in borderline competent. She was not. She was a woman with low education who used to come in and help with mail-outs and so forth. I would have left my centre in her charge any time. There is really good evidence to say the MMSE should not be used for older people and people with low education, so who does it get used for? Older people and people with low education. I did ask a medical student to take seven from 100 and keep taking seven from the result until I told him to stop and he said, 'Not without my calculator.' I asked someone else to spell 'world' backwards. She said, 'I'm a rotten speller. I probably couldn't even spell it forwards.' On the basis of such stupid questions, people are deprived of their rights to make their own decisions. In addition to that, one of the questions is—and I remember in the Rudd-Gillard era asking an old man this—'Who's the prime minister?'

CHAIR: Nobody knows!

Prof. Cartwright: One said, 'Who cares?' and another one said, 'What day is it?'

Mr McARDLE: They flow past that time line, too, by the way.

Prof. Cartwright: In terms of knowing who has the right to consent, I do not know if we have time, but can I put up a little scenario?

CHAIR: Yes, certainly.

Prof. Cartwright: Good. Here is a woman who was diagnosed with motor neurone disease six months ago. She has been in a car accident. She is unconscious. She is in hospital. The hospital records say that her husband, Peter, is her next of kin, but they have been separated for quite a few years. For the last five years she has lived with her same-sex partner. They had a son, who has enduring power of attorney for finances, and her daughter has just taken leave of absence to care for her mum. All four are in the hospital room. You could ask for a show of hands who has the right to make her decision. Can I ask you for a show of hands?

CHAIR: I read your case study in here, so that was interesting.

Prof. Cartwright: Can I ask the audience?

CHAIR: Yes.

Prof. Cartwright: By way of a show of hands, who thinks it is the husband? Who thinks it is the partner? Who thinks it is the son, who is the enduring power of attorney for finances? Who thinks it is the daughter? In the legislation in most states and territories, if you have not written an advance

directive and you have not appointed your own substitute decision-maker, the order of authority is spouse, including de facto or same-sex partner, provided the relationship is close and continuing. It is not her husband and it is her partner. If she did not have a partner—if you do not have a partner or spouse—it comes to non-professional carer, so it would have been her daughter. I have seen some horrendous outcomes because the right person has not been allowed to make the decision—the person who knows the person best.

CHAIR: We only have a few minutes with you, so I am going to open up to questions.

Mr BERKMAN: Thank you so much for being here. I am interested to interrogate you in terms of the material you have put in your submission on polling and public support for VAD legislation. We have seen various polls come out on this over the years and I have heard the observation made that no credible poll shows any less than 70 per cent support for VAD, or something along those lines. You have referred specifically to one poll that showed about 80 per cent support, which does itself come from a fairly well recognised interest group in this space. Can you just flesh out what it is about that poll that makes it particularly credible and others that undermine their credibility?

Prof. Cartwright: Sure. Part of the problem with opinion polls is that they often use terminology like, 'If someone is in unrelieved pain with uncontrolled suffering, should the doctor be allowed to help them to die?' No, they should not; they should sue their doctor. There is no excuse for a terminally ill patient to be left in pain. It is a human rights abuse. Even the Catholic Church accepts what is called the doctrine of double effect where your primary intention is to ease pain. A foreseen but unintended secondary consequence may be, but usually is not, hastening death by a few hours or days. The reason the Catholic Church accepts it is that the first person to use the term was St Thomas Aquinas.

However, back to your question on opinion polls. That particular opinion poll from the Clem Jones Group did not use any of those emotive terms. In the research that my colleagues and I have done over these 25 years we set up a committee of people across the spectrum: those strongly in favour of assisted dying, those strongly against it and people in-between—doctors, lawyers, nurses, all sorts of people. Every question that went out in our questionnaires had to pass that whole committee so we would know we were not asking leading questions. That Clem Jones opinion poll did something similar. They did not talk about unrelieved pain and uncontrolled suffering. What we are looking at here is if someone has a terminal illness their death is foreseen and they decide that their quality of life is so poor that they do not want to be here anymore. That is what we should be talking about, not whether they meet this criteria of level of suffering.

Mr BERKMAN: I do not mean to labour too much on polls because obviously we will not necessarily be guided by polls in any case. The parliament will make this decision by its own mechanisms. From all your research, what is your reflection on that general observation that no credible poll has shown less than 70 per cent?

Prof. Cartwright: It is getting higher. In the research that I did from 1995 to 2000 across big population based studies in Queensland and the Northern Territory and some in New South Wales, what we found was an age related slope of support. In the 18- to 29-year-olds it was about 80 per cent even back then in favour of changing the law. For the 75-plus it was about 65 per cent and it was a direct age related slope. Every age group was still above 50 per cent. Now, if that 18- to 29-year-old response is a cohort effect and if that group are now currently moving through society—and that group are also far less religious than a lot of their forebears—I would be amazed if it was not going up over the 80 per cent.

Mr O'CONNOR: Thank you very much for your submission and your very detailed answers to some of those questions. I just wanted to ask you a broad question because you covered most of it in your submission. What would voluntary assisted dying look like if it were to be allowed in Queensland? What do you think it should look like?

Prof. Cartwright: I think it should look very much like the Victorian legislation insofar as the process that was followed in Victoria was impeccable in terms of the two committees that were set up. I do not think you need to go all round the world again like the first one did because they found, as I did in my PhD research, that most of the claims against assisted dying do not hold up. In fact, looking at the older people in the Netherlands, for example—because one of the claims that is made is that all the old people will be bumped off, which is just a load of rubbish—the records over there will show you that the very oldest do not receive assisted dying in the Netherlands. When I asked my colleagues over there why, they said because it has not been part of their culture as they have grown up. They have not thought to ask for it. If you took the Victorian legislation and you looked at the Canadian legislation and you combined the two, you would have a very good system.

In terms of the difference between the two, firstly, Canada does not have a time to death. Canada says that death is reasonably foreseeable. With the six months, given my discussions with the people in Victoria, the only way they managed to get the legislation through their parliament was to say death is expected in six months because when they had it at 12 months they were still getting too much opposition. They were able to put in 12 months if it was a neurological disease, but that is so arbitrary and one of the hardest things for a medical practitioner to learn is prognosis. They will tell someone that they are going to die in three months and they are still here in two years and they will tell them they have probably got a few years left and they are gone next month. It is so arbitrary that it becomes meaningless. There are 68 safeguards in the Victorian legislation. I was involved when we were looking at developing the documents for Victoria, the reporting documents and the training documents. They have done a splendid job.

Mr O'CONNOR: You did just allude to some of the issues that you have with the Victorian legislation. You mentioned a few others in your submission. Do you want to expand on some of the shortcomings that you thought it had?

Prof. Cartwright: I think it is okay that they ask people to be there for 12 months, that they have to be resident in Victoria for 12 months, that they are suffering from a terminal incurable illness, that the level of suffering—and this is important—is something that they find intolerable no matter how good the palliative care or other support services. What might be okay—I might find it acceptable, but also in all of my research—is that it is not pain that causes people to request assistance to die; it is loss of control, loss of independence, being a burden on families, loss of dignity. One woman said to me, 'All my life I've been independent. If at the end of my life you force me to be dependent, you have negated my whole life.' It should not be up to us to decide when someone's life has become unbearable to them.

CHAIR: In your response to question 25—'Should voluntary assisted dying be allowed in Queensland? Why/why not?'—you responded yes. The first point is benefits include regulate currently covert actions. Can you unpack that for me?

Prof. Cartwright: Mr Harper, if I wanted assisted dying, I would know who to ask and how to ask. Why should I have access to something the rest of the community does not? For me that is a social justice issue. If you have an opportunity to read an excellent book *Angels of Death—Exploring the Euthanasia Underground*, which was written by Roger Magnusson from Sydney uni, he documented in Brisbane and San Francisco an underground network in the LGBTI community which supported people to end their lives. It is very, very specific. I talk to doctors and nurses all the time and they say, 'Oh, yeah, you know, I could see how much suffering this person was going through. Maybe I leant on the syringe a bit heavier than I might otherwise have.' They should not have to and they should not have to be in fear of somebody reporting that. There should be very clear guidelines.

The other thing is in the Netherlands, once the legislation was passed, doctors and pharmacists were able to work together to work out the best drug regime with the least side effects. Before their legislation was passed families knew they were assisted but had to pretend that they did not, so families can grieve openly. There are other reasons, yes.

CHAIR: You talked about some evidence based research in Brisbane. Can we get that? Can I ask for that on notice, if you can provide that to the committee?

Prof. Cartwright: Sure, yes. I can probably send you the book.

CHAIR: I think I could have you here all day, but I will move to the deputy chair. We have a big day ahead of us.

Mr McARDLE: I join my colleagues in saying that I thoroughly enjoyed your paper and I thoroughly enjoy listening to you and your experiences as well. It is worldwide and I think very well reasoned. I want to take you to page 50 and question 32: under what circumstances should VAD be accessed? You say, 'If a person is suffering from an irremediable condition which in their opinion makes death a preferable option, access to VAD should be possible.' You also said in answer to a question from the chair, I believe, that you could qualify if your life is at an end.

Prof. Cartwright: Yes.

Mr McARDLE: You would remove all barriers in relation to having a terminal condition and if a person of, say, 18 years of age believed that their life was at an end—because it is not aged related—you can feel that way—

Prof. Cartwright: It does not have to be age related, but it does need to be—

Mr McARDLE: Please let me ask the question.

Prof. Cartwright: I beg your pardon.

Mr McARDLE: If it is simply that you feel that your life is at an end, it might be an 18-year-old or a 19-year-old or a 25-year-old who feels, for whatever reason it might well be, their life was at an end. Do you mean to include somebody of that age group, if they feel their life is at an end, should access VAD or are you more concerned about an older person who is going through something in their life who feels what they are going through means to them that their life is at an end?

Prof. Cartwright: I do not think an 18-year-old or any other age, even an 80-year-old, who also does not have some comorbidities such as a terminal or chronic illness or something. There has to be an obvious reason why someone would say that their life has no more worth or their life is at an end. I realise there are some people in their very late ages—and the 106-year-old man who went from Australia to Switzerland recently is an example of that—if their quality of life is very poor as judged by them but also judged by any reasonable person.

Mr McARDLE: That is a different question, because what you say here is in their opinion. That is a subjective test. If I can say this: what you would say is their life is at an end, but you would also require a subset of circumstances, for example, a medical condition, to justify that conclusion being reached?

Prof. Cartwright: As I say there, if a person is suffering from an irremediable condition—that is, they are going to die.

Mr McARDLE: That is a very wide term though, is it not?

Prof. Cartwright: Yes, and I suppose you could put dementia under that.

Mr McARDLE: Yes, you can. We will talk about that in a moment.

Prof. Cartwright: My brother has eight chronic illnesses and managing his care is a big challenge, let me tell you.

Mr McARDLE: I think the issue is wider than simply saying your life is at an end. It has to be surrounded by a cohort of factors.

Prof. Cartwright: Yes, indeed.

Mr McARDLE: I found your section on surveys absolutely spot-on in relation to general polling. You then applaud the Clem Jones Group and Dying With Dignity Queensland as having questions that are, in your opinion, suitable and give a fairly accurate answer as to the sense of how people feel. I note the percentages there. Is there a survey that looks at the answers relating to the following categories of people: 1, those who do not have a terminal illness; 2, those who are family members of those who do have a terminal illness; and, 3, those who have a terminal illness? I want to try to get an idea of where the age groups sit in that cohort based upon their own lived experience. My concern is that when you face a situation your idea or concepts can change dramatically because suddenly you are confronted with something. Is there a study that breaks it down into that sort of level?

Prof. Cartwright: Certainly there was a study done in the United States some years back which I will try to find for you if I can where people completed advance directives and they were people who had terminal illnesses. They were surveyed every two years as the disease progressed to see whether their wishes had changed. The only change was that they changed from wanting more treatment to wanting less. If you had followed the advance directive when they had lost capacity you would not be giving them less treatment than they wanted. There was very little change—very little indeed—over that time period. Sometimes people say if you look ahead you will think that if you had that illness you would not want to live. It is the same for people in wheelchairs, for example, but when you get there you find you can. The point is that while someone has capacity then it is up to them to decide at that time, wherever they are on their trajectory. The only issue would be if someone asked for something in an advance directive and, as I said, that is not being honoured anywhere anyway.

Mr McARDLE: If you could make your best endeavours to find that study, I would be keen to look at that breakdown as to those categories.

Prof. Cartwright: I think I referenced it in my PhD.

Mr McARDLE: On page 48 one of the questions is, 'Would you like the option of voluntary assisted dying to be available to you if you were terminally ill and you considered your suffering was intolerable?' Eighty per cent said yes. The question, however, does not refer to palliative care. Does that skew the figures?

Prof. Cartwright: Palliative care cannot relieve all suffering. The best palliative care cannot relieve all suffering, not even all physical suffering, let alone existential suffering. As you just heard before, we are woefully under-resourced in terms of palliative care anyway and that is not a reason. Having inadequate palliative care should not be a reason to say we will let people end their lives. I

have had many people in throughout my studies say, 'I don't care if there's the best palliative care in the world. I don't want it. I have been dealing with this illness for years and years and years and I'm ready to go. Why can't I just go?'

Mr McARDLE: We could get into a debate about that all day, but we will not. I want to go to the Oregon stats that are published every 12 months and that you referred to, at least in a de facto sense. When you look at the stats as to why people access voluntary assisted dying, pain and suffering or pain are right down.

Prof. Cartwright: Right down.

Mr McARDLE: The top ones are such things as you are no longer enjoying life, you feel you cannot join in with your family, you are a burden and those sorts of matters. Those personal socio-issues become quite important. We have heard on many occasions that it is the pain and suffering that triggers it, but the research from Oregon says to me that that is not the case. There is a sense of burden, and I use the word 'burden' in a very broad sense. Is that part of the reason to access based upon the Oregon studies?

Prof. Cartwright: Based upon the three big population based studies that I have done in Queensland, New South Wales and the Northern Territory, we gave people a list and said, 'If you were terminally ill, which of the following do you think would cause you most distress?' They were not terminally ill at the time, but we asked them to choose which of the following. In every study we did loss of mental faculties came in first. Some people say to me, 'If I've already lost my mental faculties, it's probably bothering everybody around me more than it's bothering me,' but that is what people fear most. In every study we did, loss of control came in second. In my PhD loss of control was more the reason people asked for assistance to die than pain or suffering. In the first study we had 'extreme pain' and it came in at No. 3 and then the research team said, 'Why have we got extreme pain on this list? If the person's in extreme pain, they should sue their doctor.' We changed it simply to 'physical pain' and in the second study it came in at No. 6 and in the third study it came in at No. 8. In every study we did death itself came in last. People are not afraid of dying. They are afraid of loss of mental faculties, control, independence, dignity, being a burden on families, but 'burden' came in at No. 5 all the way through, not up the top.

Mr McARDLE: My final question is this: I understand that there are studies in both Holland and Belgium that look at people who have not given their consent to be euthanased. Are you aware of those studies? I assume you are.

Prof. Cartwright: Firstly, if someone has not consented and they have the capacity to consent, that is not euthanasia; that is murder.

Mr McARDLE: True.

Prof. Cartwright: If someone is no longer capable of consenting and their suffering is obvious and the medical practitioner in consultation with their family offers this as an option, I do not think that is a problem, particularly if the people have been smart—and I hope everybody in this room has done their advance care planning and appointed their substitute.

CHAIR: I ask at every single hearing, so put your hands up.

Prof. Cartwright: Okay. Who in the audience has written an advanced directive?

CHAIR: All right. Excellent. Well done!

Prof. Cartwright: And the rest of you are just going to leave it to chance, are you? Who among you has appointed a substitute decision-maker?

CHAIR: All right, Colleen.

Prof. Cartwright: One more. Do you think that person is tough enough to stand up and fight for your rights, because if they are not appoint somebody else?

CHAIR: I think that is an excellent way to end this session. Thank you very much, Professor Colleen Cartwright.

Mr McARDLE: 'Chairman' Cartwright, well done!

CHAIR: We do appreciate that.

FOUNTAIN, Mr James, Vice-President, Gold Coast Retirees Inc.

CHAIR: I welcome Mr James Fountain, Vice-President of Gold Coast Retirees. Thank you very much for your submission. I understand you have around 260 members with an average age of about 73. You have made some points in your submission that you would like to raise, so I invite you to make an opening statement please, Mr Fountain.

Mr Fountain: First, thank you very much to the committee for giving us the opportunity to put forward our comments, both from the perspective of the group membership and also from individual members. What I have here is a comment from the organisation as such—Gold Coast Retirees—and then I have a number of individual submissions I would like to make. You are right: we were established in 2017. Our membership is about 260 with an average age of 73. The interest in euthanasia has been very strong. At a recent meeting it was a very strong subject. We debated it and, as an outcome of that, we decided to participate in the inquiry and get personal member submissions into us. It was an encouraging response from 11 members and I am going to try to cover some of these today. I will read from the pages. I will read them out as such because, as an ageing retiree, I do not think I could handle 10 minutes of spontaneous comment.

CHAIR: We do have each and every single one of those in front of us. I think perhaps we should start moving into questions as to why you support it and what you say to those who oppose it, because we have heard those comments throughout our travels.

Mr Fountain: With regard to our summary from the organisation point of view, I am very heartened to say that it backs up Professor Cartwright's comments. In terms of member comments we made, I was very happy to hear the professor say the same thing from a professional's point of view and not from a layperson's view, such as us. I would like to be able to read out some of these personal comments. One is that we realise that consideration of VAD has to take into account things like freedom of conscience, protection and reduction and personal suffering. I think that lines up with that freedom to make the decision. We think there is a very strong argument why competent adults who are terminally ill or suffering from pain or unendurable afflictions be allowed to have the right to ask a doctor for help in dying peacefully and to control the time and manner of their death. Importantly, death should be a private matter and there is no harm to others. The state and other people have no right to interfere. Euthanasia is happening in the community where a significant number of doctors assist in protecting their patients against suffering.

We feel there are some anomalies in the current legislation. It is illegal currently for doctors to help intolerably in pain or afflicted or terminally ill people to die at their own request, but it is legal for people to commit suicide. Many take this horrible option to escape pain and the indignity of slowly dying. It is legal for anyone to die slowly of starvation and dehydration by refusing medical treatment, food and water. Third, it is illegal for a doctor to prescribe drugs for a person to induce a coma while their family waits for days, weeks and months for their loved ones to die.

As a comment only on the Victorian and Canadian legislation, which appears most relevant to Queensland, the Canadian model has as its objective to ensure that end-of-life patients are provided care that is respectful of their dignity. It allows a physician assisted death for an adult who clearly consents to the termination of life and who suffers from grievous and an irremediable medical condition. The act provides medically assisted dying and medically assisted suicide. It does not cover mental illness, long-term disability or any curable disease and the advanced directive is not possible.

As a comment on the Victorian legislation—and I think everyone understands the legislation—I think we get back to the six-month period of suffering. It gives those who are in intolerable suffering six months to live. They can be granted access to lethal medicine to end their life. In some cases dosage can be self-administered. Eligibility is extended to 12 months for neurodegenerative conditions. One criticism is that there is a possible weakness in the Victorian act given that there is no reference to dementia, and I think Professor Cartwright brought that out clearly. In many cases people are forced to personally cope with totally meaningless lives for many years, putting great strain and unhappiness on their relatives. Nor does the Victorian act include medically assisted suicide.

In terms of the attitude of the public—there was a comment before about research—there was strong support from the public at large when polled after the Victorian legislation was passed. A national poll in June 2018 showed VAD was supported by 73 per cent of the public. This was increased to 81 per cent with people 55 years and over. Our conclusion is that on the basis of the strong membership support for voluntary assisted dying Gold Coast Retirees fully support the objectives of the inquiry and strongly support the future Queensland government implementation of appropriate legislation. We believe the Victorian legislation is too conservative but appreciate the

hurdles the legislators had in passing the act. We are attracted to the clause in the Canadian act which allows medically assisted suicide. I think all of those comments backup what the professor came through with, so I am glad that the laypersons came through.

CHAIR: Thank you, Mr Fountain, and thank you for the work that you have done in bringing together Gold Coast Retirees. I think you have articulated your points quite well.

Ms PEASE: Thank you very much for coming in, Mr Fountain. I really appreciate the time and the effort that your association put in. I want to know a bit about your association. You formed in 2017?

Mr Fountain: Yes.

Ms PEASE: What was the purpose of it? Was it around the euthanasia debate or was it for another purpose?

Mr Fountain: It was based on a previous organisation, but there are basically some goals of the organisation. The membership is made up of fully funded and part pensioner retirees to gain a benefit from the provision of financial, investment and other information via stimulating meetings and social activities. We have a bunch of people, about 260 people. The average age is 73 and the balance of male to female is pretty fifty-fifty.

CHAIR: That is good.

Ms PEASE: Good to hear; thank you for that. Today you have said very much that your membership is in support of it and we have heard a lot about voluntary assisted dying. There are two things that I am interested in. Do you or have your group had any exposure to an advance health directive or getting involved in filling out one of those? Have you had anyone come and talk to your group about the benefits of completing an advance health directive?

Mr Fountain: No, I would not think we have had that. The president of the association is here, but the answer is we have had guest speakers on several occasions in certain aspects of the meetings.

Ms PEASE: You would have heard the conversation that it is a really important conversation that should be taking place regularly in our community. Do you have any of your members that do not have the same position that you have put forward and what do you say to them?

Mr Fountain: I think the position we put forward was a very strong majority situation. There were some people for religious grounds and so forth who are against it, but I would have thought it would have been probably 90 per cent pretty clear there. Some of the submissions we have, which I have selected—you probably have them—

Ms PEASE: Yes, I have read your submissions.

Mr Fountain:—were very strong and I think that they made some very good points, in particular on the six-month situation. I think that in most of the cases that I looked at that situation could have been dealt with 12 to 18 months before. With regard to what Professor Cartwright was saying in terms of Canada, there is no period involved. I would think that that is a strong one for us as well.

Ms PEASE: Thank you.

Mr BERKMAN: I take from your submission—I just want to clarify—that your position is that any act for voluntary assisted dying should include provision for people with dementia—that is, for people who do not have current capacity to access VAD. Is that correct?

Mr Fountain: Could you just repeat that again? I think the answer is yes, but I just want to get it clear.

Mr BERKMAN: Sorry, it was too wordy. When someone has dementia, if they do not have capacity, is it your position that the act should allow them to have access to voluntary assisted dying?

Mr Fountain: Clearly, yes.

Mr BERKMAN: You would have heard the professor talking about some of the difficulties in the Netherlands about actually having those advance directives enforced. This is perhaps a question I would have asked the professor if we had more time, but how do you think that might happen?

Mr Fountain: We did not actually deal with that. I did note that we did not have much discussion on the advance directives. I would imagine that a lot of our members would have an advance directive. I am just not really probably equipped to answer that question.

Mr BERKMAN: I completely understand. It is a difficult and technical question. I appreciate that.

Public Hearing—Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

Mr O'CONNOR: As a Gold Coast member, I thank you for taking the time to discuss this with your members and to make such a detailed submission. I wanted to get you to expand on some of these case studies that you have. You had about 10 heartfelt case studies. I do note that some were not for publication, but were there any in particular that you thought would be of value for the committee and the public who are here to hear?

Mr Fountain: I had about five fairly powerful ones which could probably take a minute and a half each. I do not know how we are for time.

CHAIR: Maybe you could just go through one. Make sure that you are reading ones that are able to be published.

Mr Fountain: There are some powerful ones here. I will give you one.

CHAIR: They will be on our public record too, the ones that can be published.

Mr Fountain: This one is on the record so it is okay. It states—

'John, you have Huntington's Disease. Over the coming years your brain and body will decline until it kills you.'

At age 58 this was the shocking news that my relative John had feared he would hear from his doctor.

Huntington's disease is a fatal inherited condition that gradually kills off healthy nerve cells in the brain, leading to loss of language, thinking and reasoning abilities ...

...

... John's condition worsened over the next two years. As a financial adviser, he became concerned that he might start making critical errors with his clients' affairs, so two years later at age 60 he retired.

...

Slowly but relentlessly John's health deteriorated. He had to give up driving and as the muscles in his mouth lost motor function, he found it hard to speak. No driving and the inability to converse freely deprived him of a lot of social contact. Eventually he found it hard to swallow food ... By age 69 John knew he would ... have to be placed in aged care. He became very depressed and once said to his wife; 'I'll cut my throat before I have you cleaning up after me.'

One day, his wife had headed off to golf. John, a very well organised man, took all their important financial documents from the office and laid them out neatly on the table. He then placed the ladder against the outside wall of their house and climbed up.

When she arrived home, John's wife found him unconscious and seriously injured at the bottom of the ladder. we all know that this was not an accidental fall.

As a result of his injuries John spent several days in hospital and then slipped away ...

Clearly the memory of John's medical condition and eventual passing is extremely sad and confronting for his family. The fact that he suffered and deteriorated physically, mentally and emotionally for over 11 years makes this particularly cruel both for John and his friends and family.

Had Voluntary Assisted Dying laws been available at the time it may well have been an option that John, his family and physician could have considered.

That is just one. I have another couple of short ones here.

CHAIR: In the interests of time, they are on the public record and we thank you for that. We are just considering the time.

Mr McARDLE: First of all, congratulations on your submission and the work you put into that in getting the case studies together, which are very important for us. I do not have a question in relation to the committee per se. Did your group submit to a committee on the buyback of freehold title in relation to building unit plans?

Mr Fountain: Not to my knowledge, no.

Mr McARDLE: Chair, I have nothing to question Mr Fountain on, but well done and congratulations to you and your organisation.

CHAIR: Thank you, Mr Fountain. Ladies and gentlemen, we are running behind time. It is a three-hour session and I know we have the next people to speak coming up, but we will have a break for five minutes and then come back.

Proceedings suspended from 1.19 pm to 1.27 pm.

CAMPBELL, Ms Chris, Chair, Australian Care Alliance

EGAN, Mr Richard, Research Officer, Australian Care Alliance

CHAIR: The hearing will recommence. I now welcome representatives from the Australian Care Alliance. Would you like to make an opening statement?

Ms Campbell: Yes. We would each like to make an opening statement and then leave plenty of time for questions. On World Suicide Prevention Day, you as lawmakers can sharply focus on whether your first responsibility is to retain the natural frontier of not endorsing and participating in the suicide of citizens or, alternatively, you can ignore the evidence of the 17 worldwide fatally flawed experiments in jurisdictions where there is state facilitated suicide or euthanasia. You have that evidence in our submission. You have the power to offer a viable, funded alternative to those considering suicide or the lethal injection. You should not feel a sense of inevitability of following the southerners. Rather, we ask that you examine and reflect on the recent arguments given on 39 occasions over the last 20 years when Australian parliaments have rejected their support of suicide. They instead have focused on retaining the medical ethos of first do no harm, which is supported by dozens of international medical associations, including the World Medical Association and the Australian Medical Association.

As a community palliative care volunteer, which is essentially around home based palliative care, I was saddened to hear of the end-of-life anecdotes of the Victorian parliament's people where less than optimal medical or emotional care was provided. To me it was obvious that many MPs felt unprepared for or lacked the personal emotional support during the dying process of their own loved ones, even when it was considered a good death. Suicide is infectious. Suicide contagion is real in jurisdictions that have endorsed it. I urge you to read the evidence in your submissions and on our website. What can you do? What can you do to alleviate the existential suffering of those considering suicide or their family members who think that a person would be better off suiciding? Learning of a poor dying experience for those departing life, as well as their loved ones, requires parliamentarians to have the same resolve to examine evidence as you do on other topics.

We would suggest your recommendations should include the following. One, saying no to state provided suicide or euthanasia. Two, improving the palliative care training of all medical and nursing students. Currently, most students spend two to three times studying beginning-of-life issues rather than end-of-life issues, which take up more of their time than birth. Three, educate the community on what those with a terminal diagnosis may experience during their dying experience, especially when they are accompanied by the very best of palliative care. Their loved ones also benefit from knowing what they may experience as they lovingly accompany a family member while health deteriorates and as they die. Four, increase the research and development of better mental health support of those with a life-limiting illness. Five, provide holistic community based palliative care support that enables people to both live and die well. A financial bonus—and you have magnificent evidence on this—for the state is that community based palliative care is cost effective as it minimises ambulance transfers and hospital admissions as well as futile and burdensome treatments.

Let me give you an example of Betty and one palliative care team that provided holistic support. I say that no confidences have been broken in giving this evidence, as Betty's story was published. Betty was in a palliative care unit when I was rung on a Thursday and asked to visit her the very next day as she felt alone and was not expected to last the weekend. Betty pushed to be discharged home to be cared for by that community based palliative care team. That diagnosis of a few days was categorically wrong because Betty and I shared another 2½ years of life together. This time was well spent as we shared time together at her home when she was feeling too unwell. At other times when she was feeling better we enjoyed time out on daytrips. The multifaceted palliative care team provided far-reaching support. This included nursing care, counselling and many of the things Dr Broadbent outlined to you.

I want to give you five quotes from Betty. She said, 'Being part of palliative care I have been able to avoid ambulance trips and unnecessary hospital admissions. I've been able to remain in my own bed rather than a noisy hospital ward with constant buzzes and beeping machines. I hate going to hospital.' After leaving the palliative care unit and being basically confined to her home and permanently connected to oxygen, extensive support was put in place so she no longer felt isolated, lonely and anxious and yet finding each day incredibly difficult to face. Here is another quote from Betty: 'Family and friends find it really difficult to accept the news you're not going to get better. People continue to ring but visits from anyone other than our family are rare.'

Here is another quote: 'It's hard when you can't get air into your lungs so talking to people on the phone has helped me to manage my anxiety better.' Here is another comment: 'The volunteers and nurses provide me with a sense of security. I know someone is keeping an eye on me and they'll get me help if I need it.' Finally: 'Without them I don't think I would have lived as long as I've lived. They've helped me keep my sanity.' That quote came from 12 months ago. Three weeks ago Betty passed away peacefully, accompanied by family and a palliative care volunteer. She passed away 2½ years after her prognosis was given as days. I say to you really loudly and clearly that prognostication is fraught. Our evidence in our submission in the wrongful deaths category of prognosis provides you with learned journal articles to prove that many prognoses are wrong. I put to you that caring for your constituents requires your really careful attention to the categorical evidence that there can be no safeguards for assisted suicide or euthanasia. I put to you that care for Queenslanders does not mean providing them with lethal drugs endorsed by the politicians.

Mr Egan: I would also like to acknowledge that it is World Suicide Prevention Day and the international slogan for today is 'Shining a light on suicide prevention'. We should consider whether claims that prescribing a lethal poison to a person to be taken home alone, as under the Victorian legislation, with a 10 per cent chance based on Dutch and Oregon figures of it taking two hours or more for the person to die is really the best we can offer a person distressed by a prognosis of possibly six months or less to live. Here in Queensland in your debate, as in Victoria, data from the Coroner enumerating the number of suicides annually by a person with a terminal illness has been used sometimes in a simplistic way to claim that these suicides, unlike all other suicides, are somehow inevitable and could not be prevented—that all we can do is provide a less violent means by making it legal for a doctor to prescribe them a lethal poison.

One Victorian case cited by the coroner in the inquiry there involved an elderly widowed lady who lived alone and was socially isolated. She lamented to a neighbour her inability to read due to loss of vision. I am a keen reader, but did anyone introduce her to talking books? Did anyone encourage her adult children to visit her more frequently? Did anyone else come in for a cup of tea? Sadly, no. She slit her wrists and bled to death in her bathroom. What would change under Victoria's voluntary assisted dying legislation? She could now be prescribed a lethal poison which she could take home alone in her bathroom and perhaps face a long and slow death—still home alone and abandoned. It does not solve any of her problems.

No law permitting euthanasia assisted suicide—whether it has Victoria's claimed 68 safeguards or Western Australia's 102 safeguards—can actually prevent wrongful deaths. Why? Doctors will always make errors in diagnosis—some people are told they have a terminal illness and they do not even have one—and in prognosis, sometimes by years or even decades. Not all doctors know about the latest, most effective treatments. Many doctors know little or nothing about palliative care. Even the very best doctors can miss treatable depression or a lack of decision-making capacity. People with disability report that doctors still share the prejudiced view that a person with a disability would be better off dead and are therefore more willing to agree to a request for assisted suicide from such people.

Most importantly, no set of safeguards could ever ensure that there are no cases of subtle coercion and undue influence in which a person is led to feel that they are a burden on their family and that everyone would simply be better off if they were gone. The Oregon data for 2018 shows that in 54 per cent of cases the doctor reported knowing that the person had a concern about the physical or emotional burden on their family, friends or caregivers as a motivator for requesting the lethal poison. What struck me though was that 15 per cent of doctors said they did not know if the person felt a burden, which indicates the doctor did not even explore this question with the person before writing a script for a lethal poison—they did not even ask whether that was a concern for them.

Assisted suicide advocate Henry Marsh asks, 'Even if a few grannies are bullied into committing suicide, isn't that a price worth paying so that all these other people can die with dignity?' This is the question that anyone considering this issue needs to ask. In my view, the proper tests for a law permitting assisted suicide or euthanasia are the very same ones that we would usually apply to a proposal to reintroduce capital punishment.

CHAIR: Mr Egan, we might not do the comparison with capital punishment. We are talking about this one. Can we move to—

Mr Egan: Sorry, but this is a local point, if I may. Can we craft a law that will ensure that there will not be even one wrongful death, and can we ensure that any deaths under this law are humane—that is, both rapid and peaceful? I am not saying they are the same thing. I am saying logically those two same questions apply and they need to be asked.

CHAIR: Speaking of questions, Mr Egan, we will come to that and, respectfully, thank you very much for your opening statements. I have a couple of questions. I note the irony of it being World Suicide Prevention Day. We have information from the office of the coroner and the National Coronial Information System of approximately seven Queenslanders a month taking their own lives in horrific ways. I did nearly three decades in emergency services and I have seen people take their lives, but when these become published it will shock everyone of what people are doing to themselves. I just think of the irony, where we are talking about World Suicide Prevention Day and we have got people taking their own lives. They were all diagnosed and investigated by the Coroner of having a terminal disease. What do we say to those people for choice?

Mr Egan: Sure. There are lots of studies on diagnosis of cancer and other terminal illnesses as a particular risk factor for suicide and evidence that doctors are missing the suicidal ideation. Oncologists can miss this. Where prevention programs are properly put in place—that is, where oncologists and others are more alert to this issue—then there is depression that can be treated, there are things that can be discussed and put in place. This is what struck me because this was a big part of the debate in Victoria where the figures were 50 Victorians a year. When you looked at the actual cases presented, the coroner was asked in the Victorian inquiry whether anything else could be done and he said no but then a fellow named Jeremy Dwyer was asked the same question. He is from the coroner research unit in Victoria and he said, 'No, if there'd been earlier intervention many of these may have been preventable suicides.'

I would say that obviously we all have the same goal of preventing that outcome of a tragic suicide for this cohort of people, just as we do for every other single cohort of people. I know your Queensland suicide prevention goal is to reduce suicides ideally of course down to zero. We have to work in that direction. We do not solve the problem by just changing the means of suicide, as I say, by giving the person a lethal drug to take home alone, because that is what is under the Victorian law. You get the lethal poison, you keep it at home and you take it at a time of your choosing. Neither under Oregon law nor Victorian law is any witness required to be there when you take it, so people are having very unfortunate deaths as a result of that poison, with seizures and regurgitation. For eight people in Oregon, it did not kill them and they woke up from a coma and so on. It is not the rapid, peaceful death everyone thinks it is.

CHAIR: Thank you. I have a question for Ms Campbell as chair of the Australian Care Alliance. You were formed in March 2018. How many members do you represent, and how many members in Queensland?

Ms Campbell: We have people who are politicians, we have people who are doctors, we have people who are lawyers. How many do we represent in Queensland?

CHAIR: You can take that on notice if you need to. Do you have any idea nationally?

Ms Campbell: Nationally, we would have support of a few hundred.

Mr Egan: Can I just add that it is not essentially a membership based organisation. We are really formed to provide research and to make that as widely available as possible.

CHAIR: What are your qualifications as research officer?

Mr Egan: I am a librarian by training. I have worked for members of parliament, including senators, and I have researched this issue for 35 years.

CHAIR: Thank you. On page 4 of your submission you state—

Is it just about a very small number of people who are imminently dying and are experiencing unrelievable pain?

...

During the proposal phase the focus is almost universally on an alleged group of hard cases, small in number, who, it is said, are suffering unbearable physical pain or other physical symptoms that cannot be relieved by even the best palliative care.

We have heard that by palliative care specialists and we have had thousands of people write to us who deliver care daily—nurses or specialists—and some who will give the other side. You state that this claim is based largely on anecdotal evidence, often from the experience of decades ago. Ms Campbell, a doctor in Townsville who performed palliative care for 40 years, Dr Will Cairns, said that the best palliative care does leave gaps—and he has been practising for a long time—and he was of the belief that people should be given choice at the end of life. What do you say to that, because it goes against what you are saying of anecdotal evidence?

Ms Campbell: My comment to that is in every other area of medicine where people feel they are getting the least optimal care and doctors say, 'At this point in time we cannot give you better than what you're getting at the moment,' we are constantly striving to improve. As medical teams and

research officers in the R&D area—and we have great national health and medical research people—we are constantly striving to improve every other area of medicine that makes people feel that all that is left for them is to commit suicide. We should not be sending a different signal to people who have a life-limiting illness than those in any other area. If we give the signal to those who have a life-limiting illness—and I listened to the evidence of Professor Colleen Cartwright—logically if your mental health does not allow you at this moment to have the best life that you could possibly want and you have a life-limiting illness and you are given the suicide drugs, what is the difference between that and those who do not have a diagnosis?

CHAIR: Okay. Thanks for your response.

Mr BERKMAN: Thank you for being here. I am just interested in your reflections. I assume you were here earlier for the discussion around polling. What is your response to the broad and longstanding popular support for legislation of VAD?

Mr Egan: One of the interesting opinion polls on this was conducted recently in New Zealand. It certainly showed a significant drop once some of the aspects of most assisted suicide legislation was proposed. Clearly, the opinion polls generally posit a situation of unrelievable suffering, and of course most people think immediately of unrelievable physical suffering. There is a gap between that scenario where it says ‘a doctor can do nothing’ and so forth and the reality of assisted suicide as we know now from the data in Oregon and the Netherlands and so on, which has a much broader catchment area. If you start to ask people questions that explore those issues, then support drops dramatically. I am not surprised that that is the answer if you ask that if someone is in unrelievable pain and there is nothing else that can be done whether a doctor should be able to relieve that by ending the person’s life.

Mr BERKMAN: Were you here in the room earlier when we were discussing that particularly recent poll, and it was fleshed out in the professor’s submission, where that kind of loaded language and leading questions, effectively push polling, were not used?

Mr Egan: Yes, and I have seen her analysis of some polls that has been critical of them. She is claiming for this one that it does not have those issues. I have not examined that particular poll, so I cannot comment directly on that. I certainly know from my own experience and talking with people about this that the more they understand of the details of how the legislation actually operates on the ground in places the less support there is for it. For example, with the dementia question it is easy to say, ‘I want an advanced care directive where I say, “When I’m demented, give me euthanasia.”’ Of course, right this week in the courts in the Netherlands is the case of the woman where a drug was put in her coffee to calm her down and she still struggled against the lethal injection and then the doctor got her family members to hold her down while she was lethally injected. That is the dilemma obviously with an advance directive for dementia suicide. Are you are saying your future self wants to be held down when you are struggling to live? There are unresolvable problems there.

Ms Campbell: What might be helpful is if the New Zealand evidence we have just referred to could be provided to you, and we will endeavour to do that.

Mr Egan: We can do that.

Mr BERKMAN: By all means send it through, but I suppose I am more interested in Australian polling than New Zealand as you have described it. It may be of interest.

Mr Egan: I think the illustration is it is the question of what further questions you ask to pursue the issue a bit further and probe into the level of people’s understanding.

CHAIR: Thank you. We are getting further behind the program, so we will extend until 3.30.

Mr O’CONNOR: You mentioned at the outset how it is World Suicide Prevention Day. I want to know how you are drawing this under the broad banner of suicide. In your submission you quoted the statistics that suicide is the biggest killer of 15- to 45-year-olds in Australia. We are talking about very specific circumstances here with end of life and terminal illnesses. I was just wondering how you put that under the banner of suicide in general, which is the biggest killer of young people.

Mr Egan: Sure. It is also a big killer of the older cohort as well. While youth suicide is certainly an issue, there are many cohorts. In my view, in the lists of cohorts of people we should add to our suicide prevention plan should certainly be the category of people diagnosed with a terminal illness or with a chronic illness, because I think they are the people who are at risk of suicide and the same kinds of preventative things need to happen. We need to be ready to be asking the, ‘Are you okay?’ question and to be exploring their feelings about things and to be ensuring that the very best treatments for depression are brought into place. Some of the data on cancer, for example, in suicide shows that the first 12 months after a prognosis is a high-risk period and, if people can be got through

that, then the suicidal ideation often drops away. Why do we say it is the same thing? It does not help to call this 'voluntary assisted dying'. That does not describe either of the actions that are ultimately involved. All legalisation of voluntary assisted dying or dying with dignity in the end means a person is given a lethal substance to ingest at home on their own as in the Oregon and Victorian models without a doctor or any witness present, so in reality it is no different than any other form of suicide. The alternative is that the doctor gives a lethal injection and that is properly called euthanasia. Calling it 'voluntary assisted dying' does not change the reality that the doctor is directly causing the death of a person.

Ms Campbell: I find it really ageist that so often in our community people think it is understandable that people who are older and losing capacity should be given state sanctioned suicide but not so for others whose existential suffering is just as real.

Mr O'CONNOR: So you think younger people should have access to voluntary assisted dying as well?

Ms Campbell: No. I am saying that I do not think that I would have felt like this in my 20s, 30s or 40s, but I do now that there is this sort of ageist mentality in the community that 'you've had your time and we understand if you think you're past it and you've had enough'. Not everybody has the benefit of having families who can give them a hug and love them, and that is where palliative care steps in. People need to feel loved and valued as real people, regardless of whether they can get out and do the shopping trips or go to the coffee shop. We have to say, 'You mean something to me,' and that is what palliative care does but the legislation does not.

Mr McARDLE: I have a comment, not a question. Chris, with regard to the comment that you just made, my wife and I are often perplexed by the ads for retirement villages for over 55s in that once you reach 55 it is all over. They are pushing this barrow further, and that worries me a great deal, but in an ageist society that could be an example—a minor one but still one. Richard, the chair raised a question of the coronial figures—that is, terminal cancer suicide—and they are portrayed as cause and effect, and that worries me. You made the comment that really you need to look at the cases because what happened in each individual case needs to be recognised and to try and bundle cause and effect is inherently dangerous because it can skew what took place in one particular case from another. Would you agree with that?

Mr Egan: Very much so. If you read, say, the Queensland suicide prevention stuff, one of the things it focuses on is that suicide is multifactorial and it is not a simple thing from 'this happened in a person's life and therefore they're suicidal'. There can be all kinds of factors arising from that coronial stuff in Victoria, where I thought the coroner was very simplistic in the conclusion that nothing else could be done in all of these 50 cases a year. Since then, his colleague Jeremy Dwyer has co-authored a paper that examines the characteristics of patients with cancer who die by suicide and it would lead to a very different conclusion than that nothing else could be done. We can table that for the committee.

CHAIR: That is fine. If you want to produce that, we will get it tabled. Is leave granted? Leave is granted. Thank you. Without debating it and with respect to the deputy chair's comments, we as the committee tasked and asked the question of the Queensland Coroner. They are coronial investigations in each of those deaths; that is the remit of the question. I think the answer is blunt, it is shocking and there is cause and effect as to why people chose to end their life after having been diagnosed with a terminal illness. Notwithstanding how Victoria did it, we asked a particular question and we have got the answer.

Mr Egan: Mr Chair, did you ask him whether anything else could have been done in any of those cases?

CHAIR: We asked a particular question—thank you very much—and we have the response.

Mr McARDLE: I think the other point, too, Chair, is that a committee must always examine the evidence to satisfy themselves as to the veracity.

CHAIR: Yes, exactly. I do not know what the differences are between Victoria and Queensland, but we certainly got the detail that we need. We must respect the views of everyone on what is a very divergent issue, but we do thank you for your time today.

DAVIS, Ms Annette, Private capacity

SMITH, Ms Catherine, Private capacity

SIMONS, Ms Didi, Private capacity

CHAIR: For everyone who is presenting here today—and there is quite a list; that is why we are extending the hearing for some time—these can be difficult discussions that we will have and we are mindful of that. For our next witnesses, given the confines of time, you may hear a ding or a bell just to pull you up so we can ask a question. We do not for a second want to take away the importance of what you are saying, so I want to thank our next group of witnesses for joining us and invite each of you to talk for a few minutes.

Ms Smith: I read the guidelines and it said that you have all read my submission, so I do not aim to read it again but will just make some key points. For me, palliative care is often looked upon as a last resort when all else has failed and therefore its full potential is under-utilised, and we very much heard so this morning from the two doctors first thing. The idea that palliative care is just there for the very end of life needs to change. Palliative care provides so much comfort and information to people in understanding that they have options additional to popular treatments. The revolving door method currently used at A&Es does not work for aged care, the terminally ill and people with chronic illnesses. An individual, holistic approach to their needs should be in place, and we heard again this morning from the first two speakers of how inefficient the A&E is and how much more expensive it is than palliative care or care at home, hence the need for everyone to have a health directive. I found it interesting that the speaker from Gold Coast Retirees was not really up to date with that and I really do feel that it is something we certainly were not aware of until our parents and daughter died. It is something that I know a lot of my friends do not have a clue about and the fact that that is available.

I believe there needs to be more talk in the community about dying. Today I have heard that people are not afraid to die. I would disagree with that and I think family members do not want to let their dying people go, so it is a real taboo subject in western cultures, although it happens to us all at some point in time. Within communities we really need to talk about death and dying and the different options that we have. Too much money is spent at the end of life trying to keep people alive and that this could be better used with those who have a chance of recovery, and you will see in my submission that that applies to our daughter. It was just crazy what they did in the end with her and the money that they spent on her medications, tests and things in the last few weeks of her life. Keeping people alive at any cost and giving people false hope denies the dying person the opportunity of coming to terms with the inevitability of dying.

Too many older people can think of themselves as a nuisance to their families and feel the best decision is to end their lives. My mother had dementia. She went into a community mental health facility. She was anxious and did not know where she was. Thankfully, a few months later she died of a pulmonary embolism. It was instant. She was going for a walk with a nurse to have a hot chocolate at night. When we went to the hospital, the nurse apologised because she had tried to resuscitate my mother but failed. Why? What purpose would it be? I suspect for nurses and doctors there is a dilemma because obviously some family members would want them to be revived and others would not. I do not know whether there is a worry about being sued or what it is, but somewhere along the line we have to have the discussion about when is the right time to die before we go down the track. Lastly, palliative care offers a more humane, dignified, peaceful way of dying. Give that a fair go before you go down the path that is impossible to come back from. Thank you.

CHAIR: Thank you very much, Catherine. Just a comment only before we move on to Didi. We congratulate the AMA. They are undertaking an education campaign of 50 per cent of 50-year-olds to have an advance healthcare directive. That is certainly something that we will take forward in terms of drafting our recommendations. We need to educate people now, not at a time of crisis when their loved ones do not know what to do and what their wishes are. Thank you very much for that. I welcome Didi Simons.

Ms Simons: I did not put in my submission that I did care for my mother before she died and then my 56-year-old brother who died of liver cancer who lived with me for the last 3½ months of his life. I then lived with my dad for four years who died just before he turned 90, so I have that personal experience. My professional experience is in adult education. After my father died, which is nearly four years ago now, I became compelled to learn everything I could about death and dying. I come from New South Wales. I became a hospice volunteer and I travelled the world and studied many different aspects of this dilemma, of which I am still studying. I have come to a similar position, because of my background in adult education, in terms of the real importance of advance care

directives. I live on Tamborine Mountain and am a volunteer with Community Care up there. I talk to the committee and they have supported me to do this work in the community. I have done some talks and I ran a four-week course which I developed myself on helping elders do advance care planning. It was open for everyone, but we got four elders. That is a bit of background about me.

I think education about the natural dying process is so primary in so many different ways in the community. I want to share something that happened this week as an example. I was asked by Community Care to contact a woman who was caring for her husband at home who was in the last stages of Parkinson's because they knew I had this interest. I went to see her and there were several things that happened over the course of my two visits that really bring out a lot of these points. The husband is basically not responsive—hardly responsive at all, just at that point of not wanting to eat and drink anymore. The GP offered for him to be given a PEG, an intravenous feeding tube, and I personally think it is very inappropriate to start feeding someone who is in the dying process in that way. She told me that he had told her previously that he just wished someone would give him rat poison and that he had been asking to die for the previous year. I come from New South Wales where we have community nurses who do palliative care and I am really shocked that they had people from three different organisations coming in. It was very disjointed. All she wanted was for someone to come in for half an hour in the evenings to help her get him into his pyjamas and give him a little wash. When she asked one of the nurses from Blue Care, she said, 'Well, that's when people go to hospice or hospital.' He wanted to die at home and she wanted him to die at home and she was willing to give the help, but she was a 70-year-old woman who had hurt her back trying to help him. She lives on Tamborine Mountain where I come from, so when the nurse suggested that he go to hospice she said, 'But it's a 40-minute drive and I have animals to feed.'

My support is really for—the same as Catherine—community based palliative care. There is a real call for the hospital service, the medical service and the community service to be integrated. More money needs to go to organisations like Karuna that are trying to support people to die at home, which is where they want to die.

CHAIR: Thank you, Didi. We have heard throughout our travels the need for increased community care around palliative care. I take this opportunity to acknowledge everyone in this region on behalf of the committee who is living that horror fire up in the hinterlands right now. We should just pause and reflect at that awful news. On behalf of the members down here, I know everyone would be concerned. You mentioned Mount Tamborine. All up around the hinterland area is under threat right now, so I think we should just take that on board for a moment. Thank you very much for your commentary. I welcome Annette Davis to make some comments.

Ms Davis: Thank you for the opportunity to speak here today. Since making my submission, I have continued to gather information regarding the financial issue in the hope that the information may give me an understanding of why this is happening, as I believe that it is not unreasonable to expect a government approved service provider would at the very least be complying with laws and regulations. An audit was conducted by the commission on the facility in July 2018 and the audit made determinations that the service provider had systems to identify and ensure compliance with all relevant legislation, regulatory requirements as well as professional standards and guidelines and determined that care recipients retain their personal, civil, legal and consumer rights. I asked the ACCC for advice and they advised that it is illegal for a business to charge for a product or service that they do not supply, yet it is happening. I believe that it is of the highest importance that the audits are factual and feel that it needs to be determined if this audit was conducted on dishonest or misleading information provided by the service provider or if the audit process is inadequate.

The financial abuse was reported to the commission 11 months ago and there is no clear information on when it will end. The process with the commission is exhausting and frustrating. I raised the issue with the previous minister. It took five months and many emails before I received a letter claiming that the commission made decisions independently. I could accept this if the industry was meeting a community standard, but as it is not it is concerning. I have written to the current minister and his reply was as defunctive as the previous minister's. I have also written to the Prime Minister twice but only received auto replies. I have contacted every organisation I can find and asked for assistance, but all are unable to help mainly due to their limited capacity and that they would refer this type of complaint to the commission. As that had already occurred, there was nothing that they could offer me.

The commissioning correspondence from the service provider named myself and my parents in relation to the charging of these fees. After this my mother was given a beer with her meals. She had not asked for this or been asked if she would like it. She was just given it, as possibly one of the charges for these additional fees is for beer or wine. This situation caused great confusion for my

mother. I was struggling to believe that any business would operate with such a lack of moral compass and hoped that my mother was incorrect about it, until my brother and his family made a visit to the facility and accompanied my parents to the dining room and witnessed this happen. After that I emailed the commission and the facility and spoke to the manager in person and then the situation stopped. I believe that my parents cannot be excluded from this facility because we have filed a complaint. If that were to happen, where would I go for assistance? I feel that if the commission cannot regulate the service providers in areas that are already governed by law, then it begs the question: why not?

CHAIR: It is interesting to note that we are down here tomorrow and the next few days with regard to Earle Haven to listen to complaints that will come to light as we examine what happened there. Have you given your information or written to the royal commission?

Ms Davis: Yes.

CHAIR: Thank you. Do you want to name the home that you are talking about?

Ms Davis: No, as my parents reside there. I feel at this point their care is utmost. Everything else is secondary.

CHAIR: What information have you received from the Aged Care Quality and Safety Commission? What have your dealings been like with them?

Ms Davis: Eleven months ago I first reported that this was happening. The latest communication was approximately 10 days ago that stated that they are still trying to understand the service provider's response, so nothing really.

CHAIR: Thank you very much. As there are no questions for the three ladies, I just want to deal with an issue. Catherine's first question was, 'Why is there only one woman on your committee?' We welcome Joan being on our committee. Maybe that is a question for the other side. The government members have 50 per cent of women in their caucus, so we are very happy with that. I had to note that one. Thank you very much, ladies. We appreciate your time here today.

MORRIS, Professor Philip, Private capacity

POIDEVIN, Ms Mary-Anne, Private capacity

VAUGHAN, Ms Annabelle, Private capacity

CHAIR: Thank you very much for joining us. I welcome Annabelle Vaughan. Would you like to make an opening statement?

Ms Vaughan: I would. Thank you very much for the opportunity to address this forum on such an important issue. I have read many of the submissions online and the transcripts of the other forums around the state. While I am sickened that there are so many stories of pain and suffering, I am also heartened that there are so many well-informed and educated people who are in agreement with me on this particular topic and that people are willing to come out today and speak to effect change. I, too, have stories that are painful to tell of three immediate family members who died slow and undignified deaths in the last 12 months. All three of my loved ones railed against the outdated laws that prevented them from accessing painless and planned exits from their suffering.

My grandparents, both country people to the core, were both baffled and furious at the denial of the basic mercy that we show farm animals and pets. My grandfather, a proud and independent man, begged for an end to days of sitting incontinent, immobile and helpless in a body that had crumbled around him. My grandmother told me every time I visited her nursing home that she was ready to die and asked why no-one would let her do so. My darling dad, who even with the best palliative care available in the state, was still distressed, nauseous and uncomfortable almost to the end. He was given terminal sedation due to his pain and distress, yet it still took 10 days from when he lost consciousness to when he died. We sat by his side providing what little comfort we could for 10 days. If you have not walked that road, then you have absolutely no concept of how torturous it is. The inadequacy, anger and deep shame that I felt then still burns just as much today as it did when I watched helplessly from my family members' bedsides.

Today I am here to demand that we do better. I am here to make a plea to the lawmakers of this government to ensure that your families and loved ones do not endure the same suffering as mine, that they are not forced to go through the same thing that my family went through. My passionate stance is that it is wrong to deny people the choice to do what they want with their bodies. This battle for body autonomy is one that the women of Queensland already know well and I find it infuriating and disappointing that my right to decide to die and how I want to die is not in my hands. For the most part I am incredibly proud of the standard of health care that we have in this country, yet I cannot believe we still force people to suffer such dreadful deaths. I do not want to be forced to experience the prolonged suffering, pain and dependence that I have seen my family endure.

An overwhelming number of the arguments against changing legislation to allow voluntary assisted dying are from people who reference reasons related to their personal faith. While I fully respect these people's rights to follow their faith and to make decisions about their own lives based on their faiths or values, I fail to understand the assertion that their beliefs should have any bearing on my life or my choices. I hope that compassion and respect for autonomy is something that runs deeper than any doctrine and I hope that it is upheld as a basic human right by all. I hope that this government is brave enough to change our laws to better reflect our country's values of freedom and dignity of the individual and compassion. The real issue here is not death but choice—my choice about my body and my life. Thank you.

CHAIR: Thank you so much, Annabelle. It is something we have heard right throughout Queensland repeated to us—people telling their own personal, difficult stories—and we thank you for sharing that with us.

Ms Vaughan: Thank you very much. I think a really important point for everyone to carry forward is that, no matter how good palliative care is, it is not good enough.

CHAIR: Thank you. I welcome Mary-Anne.

Ms Poidevin: Thank you for the opportunity to address the committee. I want to address two points of my submission—funding for palliative care and doctors' fallibility—and I will address these in the light of my own experiences and opinions that I have formed as a result of my mother's work in palliative care and also a decision of a patient that I cared for as an assistant in nursing a number of years ago. She chose to stop treatment for breast cancer and journeyed to death with huge spirit. They are the reason I am alive today as they taught me to question doctors' decisions and orthodoxy. Some might consider me pretty unlucky, having had three types of cancer and enduring debilitating

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chronic pain as a result of a car accident 15 years ago. However, it has given me a unique insight into the medical system, the lack of appropriate funding for pain management, holistic care and the motivations behind doctors' treatment regimes.

I do not support euthanasia. However, neither do I believe in unnecessarily medically prolonging the lives of people. On three occasions specialists have recommended treatments that would have resulted, if I had followed them, in my life being prematurely ended. Unlike most patients, I had read scientific research and medical papers on the various cancers that I have gone through. I am also strong-minded enough to challenge the doctors. For example, my oncologist twice admitted that my informed choice was correct and that if I had followed his thinking I would have had a premature death. Most patients have implicit trust in medical professionals, especially doctors—and that is to be expected—yet I have discovered their own bias towards certain treatments and 'one model fits all' is not for the benefit of the patient but for simplifying their processes and decision-making. How then can we trust that any recommendation of early death is not motivated by the same reasons and that the patient has been given all options? I know in my case I certainly have not been.

I was on the waiting list for 10 years to see a pain management specialist with Queensland Health. In that time I got to see the psychologist just to make sure I was not going to kill myself. Other than that, nothing happened. I gave up after 10 years and my employer actually paid for me to get some assistance in that area and it is then that I ran into the psychologist who used to work for Queensland Health. She was so frustrated that nobody was getting any assistance because the pain specialist works three days a week that she had left and gone into private practice. It is a small world. During that time when I was in excruciating pain, I would be bedridden sometimes for nine days at a time and I would be saying things like, 'I wish I had a button to press to end it all.' I understand that pain, but it did not actually mean that I wanted to die; it was my way of dealing with it. How dangerous would those words be in a world where human euthanasia is the norm, no matter what the perceived safeguards? Doctors get it wrong now and they are not going to suddenly become infallible with the passing of an act of parliament. Even one life as collateral damage to me is not acceptable.

My experiences have also taught me that, when you allow other people to care for you, you are actually giving them a gift. It is a way of showing love and caring. The palliative care model of holistic care is so valuable in not just life-limiting circumstances but also quality of life. I heard someone mention that earlier as well with regard to illness. I call on this inquiry to recommend making palliative care and pain management accessible to all of the community. Let us get the priorities the right way around and fund research into disease prevention and the relief of pain and suffering so that people do not get to that terrible stage. There is more we can do. When we stop trying to do better, we are a hopeless people. Thank you.

CHAIR: Thank you very much, Mary-Anne. I thank you for being a strong and resilient lady who has fought her own battles with cancer and to be here today to share that. That is certainly something that we are hearing about palliative care need and increasing access to it, so thank you for sharing that. I welcome Professor Philip Morris.

Prof. Morris: Thank you, Mr Chairman, and also thank you to the committee for allowing me to present here in person. I do not have a lot to say—I have given you a very small submission—but what I do have to say I am saying as the President of the Gold Coast Medical Association. I am a psychiatrist who works looking after the care of patients with dementia and many of my colleagues look after people who have terminal illnesses, so this is a territory that we are familiar with. However, I have to say that our members are just as divided as the general community is in terms of those who are very much for euthanasia or voluntary assisted dying and those who may be opposed. I am not trying to say one way or the other that we are totally for or totally against, but I thought I would try to point out some issues from the medical profession that need to be considered.

One of the things that we all know about—not all of us are asked to do this when we graduate from medicine—is a thing called the Hippocratic oath. Some of the older versions have been modified now for different medical schools, but the one that existed from Hippocrates two or three centuries before the birth of Christ says as follows—

I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course.

Of course, this needs to be taken in context. I guess in some ways in years and centuries past maybe doctors might have been used by various governments and others to inflict harm on others. That may be where that was coming from, but you can see from that Hippocratic oath that most of us as doctors do not like the idea that we are going to participate in the death of patients. Our job is to

try and look after patients, keep them well, enhance their function and prevent them from getting sick as much as possible. That is just a little bit of a background to where doctors stand philosophically on this issue. It does not mean that some doctors do not support this or are against euthanasia. However, you will be facing an issue of whether you introduce this into Queensland and you will need to think about how it is going to be done. We have an example from Victoria, but we also now have what you will be looking at in terms of how it could operate here.

My personal view is that I am not a euthanasia advocate, but I understand that there are some situations—and my colleagues on the table here have actually demonstrated this today—that may justify voluntary assisted dying, which is what we seem to now call euthanasia. Yes, it is probably inevitable in some cases that this is an appropriate thing to do. However, who should be making the decision here? What I am suggesting is that this should be a judicial decision at an appropriate level. It could be at a magistrate level or it could be at the Queensland Civil and Administrative Tribunal level where an adjudicator would ask the person who wants to use euthanasia to present their case, or someone could present on their behalf, and this would be open then for others to say, 'I think this is a good thing,' or for people to bring up evidence that this is not a good thing in this person's case. I work in the field of older people and you get situations where individuals are being asked to change their wills by others. People are being coerced; they are being unduly influenced. There is always the possibility that things could be in the mix here that are deleterious to the patient.

It should be an adjudicator or a decision-maker, not the doctor, who decides what happens. The doctors can inform the decision. The patient obviously needs to exercise their decision-making capacity, but the decision-making should be made by an adjudicator, probably in private—that would be the best way of doing it—but where others are given the opportunity to lay information in front of that person or persons to be able to make the decision to give the person the permission to go ahead and have a lethal administration of a drug or whatever else. That is what I will ask you to think about when you are deciding how the procedure should run. It is to take away this very onerous decision from the doctor and place it in a decision-maker's hands where they can be informed by the medical advice and the patient's wishes and then the doctors can, if they are interested, actually undertake the process. Some doctors will agree. Some doctors will say that, no, they are not going to do it, and we should not punish doctors who say that they have an objection to doing this. Thank you very much.

CHAIR: That is an interesting thought for the judiciary to do that. Some doctors have said it is the relationship between the patient and doctor that is paramount in taking them on that journey. We have heard from some providers in Canada who spoke to the committee earlier. That is probably a different tact of putting it into the hands of the courts. I do not know what people would think about that, but I take into account your comments around the oath. As you said, it was centuries ago and we have seen churches modernise their views on things. This is a difficult decision for all of us, but we do welcome your commentary. I will open up for any questions.

Ms PEASE: I do not have any questions, but I do have a couple of comments. Annabelle, thank you very much for sharing your story. I agree wholeheartedly that you have to walk in those shoes, so thank you for sharing that.

Ms Vaughan: Thank you very much.

Ms PEASE: Mary-Anne, I loved your comment that it is a gift to be able to let people help you, so thank you for sharing that with us.

CHAIR: We love having Joan here. She is so compassionate. Thank you, Joan. She has gone through this very thing herself.

Mr McARDLE: Thank you for being here today. I certainly respect, Annabelle, your position and understand what you have been through, probably more than you know. Mary-Anne and Professor Morris, thank you for being here today as well. Professor Morris, there is an argument that having a doctor involved in the process in some way gives VAD a sense of authority to exist in that the doctor is somebody whom we rely upon for medical advice and also rely upon for diagnosis and outcome. Is the court process a method of removing the doctor from that role, because as I hear the argument the doctor's involvement gives euthanasia a status that it would not otherwise have?

Prof. Morris: I have not really put my mind to that particular point of view before. In our society, the involvement of doctors in any sort of process is likely to be a positive. People will see this as having some degree of ethical constraint or ethical support because, generally speaking, doctors are regarded in reasonably high regard by the community. My view would be that the doctor would certainly inform the process of decision-making and would no doubt stay very much involved with the care of the patient, but the decision itself would be taken out of doctors' hands. The reason is that there would be some situations where, let us say, a patient with terminal illness has a big estate—I

am just giving you a possible hypothetical—where someone in the family might be saying, ‘Look, you’re better off ending your life now. You’re just going to be’—whatever. There would be pressure placed and that person may be unduly influenced. At the moment that sort of information is not going to be accessible to a decision-maker to look at the competing interests, conflicts of interests and things of that nature. That is why I think it should fall back to that decision-maker. It does not have to be in a big court. It could be something that is developed under the Queensland Civil and Administrative Tribunal—a much more personalised way of doing things—but it then gives the opportunity that the decision has not been made without any due process about what other options there might be.

Mr McARDLE: Whilst I note your attraction to the Magistrates Court or QCAT becoming involved, I have to raise my concerns about the growth in numbers, the delay in determination, the appeal process and the like that can take some considerable period of time. QCAT is now underfunded by its own report. Though I see your rationale, I really see that as not being a step to resolve the matter in a timely manner. That is a comment, not a question.

Prof. Morris: Fair enough. I just put that up there as a possible example. With this particular issue, it is so sensitive that it may be another way of dealing with it, but the general principle is that the doctor does not take the final decision.

Mr McARDLE: My final point is really a comment, and Catherine Smith raised in her first line, ‘Firstly, why is there only one woman on your committee?’ The chair made the comment in relation to that side of our bipartisan committee having one female member whose opinion I greatly respect and whose intellect I admire. Catherine, can I say to you with the utmost of respect that death is not gender based and neither is pain and suffering, neither is cancer and neither is aged care. It is across-the-board. At the end of the day, my point would be that all of these issues are not based upon gender; they are based upon the lived experiences of everybody here as well.

CHAIR: Thank you very much, Deputy Chair.

Ms PEASE: If I may comment on that, I think that it is important to have a balanced opinion. Males and females do have a very different way that we look at the world, and I think that that was Catherine’s comment.

Mr McARDLE: And I am saddened, Mr Chair, that we have come down, with all due respect to Catherine, to a gender argument in this matter. It should not be.

Ms PEASE: That is unfair.

CHAIR: Okay. I think it was just a question posed by the former witness. I thank the three panellists—Annabelle, Mary-Anne and Professor Philip Morris.

MUNGOMERY, Ms Linda, Private capacity

MURPHY, Mr Brian, Private capacity

ROGERS, Reverend Sid, Private capacity

CHAIR: I welcome our witnesses, and we will go ladies first this time.

Ms Mungomery: Before I start I just want to make a point about the Hippocratic oath, except I think the professor has left. In the original one it also says they are not to charge their clients, their patients, so times have changed. Thank you for the opportunity to speak today. I have been a registered nurse and midwife. Up until a year ago, along with my sisters, I spent the previous 14 years caring for our mother with Lewy body dementia, complicated further by a CVA, and our father with frontotemporal and vascular dementia. During that 14 years we never felt that caring for our parents was a burden. Our parents died at home. My father was the last to die, just 12 months ago this Friday. In my submission I refer to many experiences using services for my parents. However, I want to focus on voluntary assisted dying. More precisely, I want to make a plea to the committee to incorporate the right to assisted dying even if I and others, who are so determined, should lose capacity according to my predetermined advance health directive.

This has been my consistent, persistent, insistent belief since I was 17 years of age and I have never wavered in this intention, and my experience caring for my parents has only strengthened it. Voluntary assisted dying for the terminally ill needs to make provision for those with dementia. By definition, dementia is a terminal illness and the highest cause of death in females in Australia, the second highest in the overall population. Supporting voluntary assisted dying is not supporting a culture of death; in fact, it comes from a place of compassion. The groups and individuals who seek to impose their religious beliefs on others fail to recognise that we live in a secular society that supports freedom of belief. I fully respect the right of others to practise within their beliefs, but the naysayers do not respect my right to have my beliefs supported. I know this is not simply a religious issue. I know people of faith who support assisted dying and people with no religious belief who would not avail themselves of assisted dying in terminal situations. It is a matter of individual, personal choice.

I also want to make the comment that VAD is not murder and it is not killing. To call it this is the same nonsense as suggesting that consensual sex between adults is rape. The most important thing here is voluntary consent. If that is someone's wishes, we need to respect their right to self-determination. I agree and support adequate pain relief for those dying in extreme pain. I support better care for those at home or in institutionalised care, but for someone like me that is not the choice I want to make. I do not want to live my life if I lose my capacity to self-care because I would view this as unbearable suffering. In saying this, I do not believe that others who require care have diminished or worthless lives. I am saying that for me this is the case. Why should my will not be respected if I do lose mental capacity? Why should I not be heard if I have made a declaration to consent to my assisted death in the case of dementia or neurological damage?

Again, it is important to remember the word is 'voluntary'—that is, self-determined, personal choice made deliberately and consciously, not involuntary, not mandatory, not slip-sliding away, as the naysayers suggest, but voluntary. To claim that giving adequate pain relief negates the need for assisted dying is of no consequence in the case of dementia. I live every day with the fear that I might develop dementia, given my family history and I am now in my 60s. How can someone morally take me and force me into a nursing home if I am able to care for myself? At this point I want VAD. The naysayers also purport to be protecting the vulnerable, yet if a predetermined declaration for VAD is made when one has capacity the vulnerable would always be safe. There are so many safeguards that could be put in place when someone makes this declaration, and I am happy to elaborate on any of these. For instance, a person may have to visit a health professional, whether it is a doctor or a psychologist, perhaps on one or more occasions to be able to articulate that clearly themselves. Additionally, a register could be set up to support this and if people disagreed with having any sort of voluntary assisted dying they could register their wishes on that register.

We deal every day with complex situations like organ donation and transplants. We make and execute wills in society every day. Why should this be any different if managed correctly? A predetermined VAD request as part of an AHD is the safest and surest way to make sure someone's wishes are respected. This could also be used to document one's opposition, as I said, should they never want it, though the default would always be to not enact any assisted dying without a clear, predetermined declaration. I also want to mention that I think the Victorian legislation, and possibly now the West Australian legislation, is inadequate because of this dementia situation.

CHAIR: The point that you made that has been passed on to me after listening to you was the term 'voluntary' and how you articulated that. Thank you very much for that and for your contribution here today. I welcome Reverend Sid Rogers.

Rev. Rogers: Thank you for being here to listen to us. You must be very tired from hearing similar stories, because mine is very similar to Linda's. I have been an Anglican minister for 40 years. I have been retired now for five years. For the last 10 years I was the senior chaplain to the Gold Coast hospitals in not only the palliative care wards but also all of the wards. Daily I dealt with people in extreme existential trauma. Over that period I guess I have been asked by a good 100 people—patients and family members—if I could, and possibly they thought I had the prerogative as a chaplain, to speak to their clinicians to arrange for them to hasten their suffering. Of course that is impossible, but in many of those cases it would have spared weeks and even months of cruel, unnecessary suffering. I hasten to add this was a request from patients in the Hopewell Hospice as well, which is located on the Gold Coast, where I used to attend. This is also not about inadequate palliation treatment or end-of-life care. Our palliative care wards that I have been in or where palliation takes place are simply outstanding. The point is that many people do not want to go to palliative care. This is all about personal choice within a legal framework.

It is also essential that we choose to use non-emotive language. A while ago now I heard a radio presenter use the words 'allowing doctors to kill patients'. This is simply absurd, it is possibly deliberately mischievous and it is certainly misleading. VAD has nothing to do with killing or murder but the fulfilment of the considered wishes of a patient with full cognition who is already dying. Contrary to previous speakers, we should never use the term 'assisted suicide'. Suicide refers to the action a person takes who is not about to die from a terminal illness. Suicide ends a life which is still yet to be lived. VAD is completely different. It refers to an end-of-life decision. These people are in the process of actually dying. Their life, they have determined, is now complete and it is futile for them to continue. Why would a competent adult who is dying and suffering and who asks to die quickly be told they have to die slowly and suffer instead?

In terms of the Hippocratic oath, surely one of the main points is to relieve suffering and it is also to not maintain life at all costs. I have written a bit more about futile medicine in my full submission. To end, to choose VAD is a decision that honours the quality of life rather than quantity. Most importantly in this debate, prolonging death is not the same as extending life. Those who wish to prolong the extreme physical, psychological, cognitive and spiritual pain that I observed daily—excuse me, but I get a bit emotional—with many dying patients and families need to seriously question their motive. Who exactly benefits here? What gives you the right to deny somebody else's well thought through decision to end their life in dignity? VAD is not being legislated as compulsory for all. It is a choice people must make. If you do not wish to have VAD, then that is your choice and it will be honoured. However, you have no right to deny that choice to others who wish to have VAD. Thank you for listening.

CHAIR: Sid, I only have one question before we move to Mr Murphy. We had the Archbishop in Brisbane a few weeks ago and a number of representatives from different churches, including the Anglican, which seems to be supportive of what you are saying about choice and giving people control, yet there was one section of the religious sector that was strongly opposed. As someone who sits in the middle, I find that interesting. This is about people.

Rev. Rogers: Yes, this is about people. What tragically happens is that doctrine supersedes compassion in most of these decisions that the hierarchy have to take. For those people working on the ground like myself—and I trained 60 hospital chaplains in my 10 years as the senior chaplain here—they are dealing with the compassion; they are not dealing with the doctrine. They do not ask a person, 'Do you believe in Jesus?' and then if they do not they do not give them any compassion. That is immaterial. It is the love. It is the golden rule that all our faiths have: to relieve suffering, do unto others as you would have them do unto you. If you want somebody to suffer, that to me is a little bit crazy. Our hierarchy is in a bit of a muddle because they have to toe the line somewhere there, but I hear what you are saying. The other thing of course is which Christianity are you talking about? Are you talking about orthodox, Catholic, Anglican? It is very difficult, but thank you for pointing that out.

CHAIR: Thank you very much for your contribution. Mr Murphy, welcome.

Mr Murphy: Thank you very much. I have a different angle. It is certainly a bit hard. I fully agree with some of the things that have been said today, but I am here to represent baby boomers.

CHAIR: I knew the deputy chair would like this. Can you define BONZA for us?

Mr Murphy: Yes. BONZA is Baby Boomers of New Zealand and Australia. There are about five million of us or a little bit more in Australia and a million Kiwis. I have worked with people from both sides of the ditch and they are both tremendous people, very idealistic—

CHAIR: Thank you for that. Being from New Zealand, I really thank you for that.

Mr Murphy: Yes, and I enjoyed my time over there, too. Getting back to it, I was originally a schoolteacher and a trained change agent with the education department. I brought P-12 to Queensland from New South Wales and was involved with those committees. The change agent thing is what I want to emphasise here. When I first realised the problem that baby boomers were going to cause given our numbers, particularly with aged-care pensions and of course the health budget, I got myself interested and I thought, 'How can we do this differently?' Baby boomers like change. We feel very much about doing it differently from previous generations. We have done that and we have done that very well in our opinion, but other generations do not necessarily agree with that and I respect that opinion.

First of all, I want to talk about those numbers. The youngest baby boomer is now 55, the oldest 73. In another 10 years they will be up to 65 and a lot more of them getting near to the average age of dying now, with males in their early 80s and females in their mid-80s. Heck, that is a lot of people living a lot longer. I sat here today and listened to one of the good doctors mention that there were 40 beds for palliative care and I thought to myself, 'Goodness gracious!' We are talking about hundreds of thousands of baby boomers who are going to be needing palliative care and we have 40 beds? I could not believe it. I was gobsmacked. We have to think very broadly and openly about where we can go with this because it is a very difficult problem. I sat with three of my family—father, mother and sister—as they died. I can tell you that palliative care stinks. It was just emotionally draining. They were dead and I had to sit there and wait for their hearts to stop and hold their hands. I am sorry, but I do not see that as being a great way to go.

As a baby boomer I very much like the idea of euthanasia where someone says to me, 'You are terminally ill,' and I do not care whether it is a legal proxy who has made that decision for me. I am not sure about the legal side of things mentioned earlier, but certainly someone I trust who says, 'Yes, he's terminal; he has to go.' I would like to think that I am in a room with my family—and this is the change agent talking here—and that I could have what I would call the 'last supper' with them where we can sit around and talk about old times, laugh together, hug each other, be supportive and then I disappear out a door and I make the decision of pressing the button. That is what I wish for. There is one other thing I would say on behalf of all baby boomers, and I have worked with hundreds of thousands of them over the last 22 years. I am not here to speak on their behalf, because, I will tell you, they will speak on their own behalf, but I do wish that you can see that they need a choice to go with dignity. I really am worried—and I have to say this to this side of the table—that the LNP has a policy that is not in favour of euthanasia. I really think that your parliamentarians should be given a choice when the time comes to individually decide how they are going to vote on that. Thank you very much.

CHAIR: Thank you very much for your contribution. I will open up to any questions from members.

Mr BERKMAN: I do not have so much a question. I was going to ask a similar question about your differing position as a person of faith, Reverend, from those that we have heard from the Anglican Church previously, but I think you have well answered it.

Rev. Rogers: Yes. I was surprised what the Archbishop said. I am going to send him my submission with a covering email. Yes, I was surprised.

Mr BERKMAN: Short of that, Mr Murphy, you just get bonus points for having the best acronym of the day for your organisation—BONZA.

Mr McARDLE: Mr Murphy, baby boomers rule! It is as simple as that.

Mr Murphy: I will quote you on that.

CHAIR: That is a good way to wrap up this session.

Ms PEASE: There is just one thing I want to say. At one of our hearings in Toowoomba we had a chaplain present and, again, he was a supporter of euthanasia, of voluntary assisted dying, because he said that each and every day he got up and took a tablet which kept him alive for the last 40 years. In actual fact, that is an intervention by the medical industry, so I appreciate your honesty. It must be difficult to have that position. Have you been chastised?

Rev. Rogers: Yes and no. You learn who your friends are, I guess, because this is, as Brian said, a new way of thinking and the Hippocratic oath is 2,000 years old. Are we going to be governed by something like that or are we going to move forward? It is the same with the church. We had it with the marriage debate. That was a huge rumpus.

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Ms PEASE: Absolutely.

Rev. Rogers: We should have a referendum about this, shouldn't we?

Ms PEASE: No, let us not. Thank you very much for your honesty.

CHAIR: Yes, and I want to thank you for your years of work of looking after people who have been terminally ill and dying. I thought you really articulated that point very well.

AWABDY, Ms Anne Marie, Private capacity

CLAYTON, Mr James, Private capacity

TAYLOR, Mr David, Private capacity

CHAIR: I welcome each of you. Mr David Taylor, I invite you to go first.

Mr Taylor: Thank you, Mr Chair and the committee, for inviting me to speak today. Strong opinions and emotions continue to consume the debate on voluntary assisted dying, or VAD as it is known, and it seems the issue can benefit from some crystallisation. The team with the most players want VAD to be available as an option if needed but yet in no way prescribes it for those who do not want it. The minor side does not want it for themselves and, what is more, they do not want it for the big team either. It is not a matter of palliative care, or voluntary assisted dying. It cannot be just that minor groups are able to impose their particular creed on the community at large, in this case denying a very personal choice to those in the most distressing and painful predicaments imaginable. They just do not get it that we are not all alike and some of us simply do not want to be humiliated or suffer. Sure, there are a number of hurdles on the way to VAD legislation, but our politicians and their advisers, including those presiding here today, are justly qualified to nut out the detail of duly considered consent statements which authorities need to get before compassionate end-of-life procedures can be triggered, so that the vulnerable are protected.

Of course a new act will not be perfect, but nor are most of our existing laws; otherwise people would not regularly be killed on the roads by dangerous drivers or be harmed at the hands of negligent doctors or hospitals, yet I hear no-one calling for the abolition of the statutes governing such matters because of inherent dangers. Consequently, it is disingenuous for opponents to parade the idea that any VAD legislation may be seriously unsafe. Very few people actually want to die. It is only when pain management and lifestyle regimes fail them that their thoughts turn to VAD because, for some, palliative care is either not effective or simply not their preference.

Is there any palpable humanity discernible for a caring culture to learn from grandma's obituary that she passed away, aged 86, after a long illness bravely endured when, with a little compassion, we could be reading that she passed away peacefully, albeit a couple of months earlier? This is a question which, in the 21st century, a secular society should not have to answer. Thinking people know VAD will come about and by helping it happen sooner rather than later numerous Queenslanders will be spared much torment, and those instrumental in assisting the enactment of these changes should feel justly proud that they made a significant contribution to humanity. Please: if you still doubt this course, shut your eyes and imagine being trapped in your own racked body, lying for just one hour in the geriatric bed of a stroke crippled elder, or a chronic emphysema sufferer struggling for every breath, or a late stage Alzheimer's patient, and then open your heart to compassion. Thank you.

CHAIR: Thank you, Mr Taylor. That was beautifully articulated. I welcome Mr James Clayton.

Mr Clayton: Firstly, my wife and myself applaud the fully transparent way in which this inquiry has been conducted. Thank you for placing it out in the open as you have done. Our interest is VAD, voluntary assisted dying. My age is 90 and my wife is 85, so I think we can claim to be fully interested in that, probably as the principal actors rather than bit parts. We feel confident that we can expect the inquiry to recommend—and I am not sure wherever they go from that—at least initial legislation to consider a formal act to consider VAD in the parliament. I am sure the committee will by now be well aware of the very strong support from what we might call the quiet Queensland majority. Obviously the well organised vocal minority groups, as always, will make the most noise, but that should not dictate the action.

I am not aware, nor have I studied it, that legislation previously passed in any overseas jurisdiction with regard to voluntary assisted dying has had to be withdrawn or even tightened since it was enacted. In fact, more often than not, it seems the opposite. It seems the legislation has been relaxed since first enacted. This does not indicate to me any wholesale abuse of the schemes as they have been prescribed. There will always be problems; of course there will be. There will always be mistakes. Perhaps one will lose a few people to family schemes. However, overall it would seem to me that those voluntary assisted dying schemes already in existence are working. It concerns me that prominent parliamentarians like Campbell Newman and Daniel Andrews have now both changed their views on voluntary assisted dying after experiencing very painful times with their own families. It surprises me, frankly, that such prominent and intelligent parliamentarians would not have looked through this in a better fashion and that only when they have experience directly of what happens then do they say, 'Oh, these people are right after all.'

For my wife and myself it is not all about severe pain at the end. In fact, for us it is more about the total loss of quality of life. We have all seen and experienced in our own family people who have lost all ability: they have lost their functions, they have lost everything really, but they are not in a coma so it is not a question of pulling the plug. They have got to remain in that situation and yet they have no quality of life of any sort. To us good palliative care is important and family support is probably even more important, but the scheme is still voluntary so it is entirely up to the person who is going to be affected.

I would just share with you—I had not intended to but I will because so many other people are sharing personal things—the death of my father. It goes back many years and was, indeed, in another jurisdiction. He was dying of cancer of the pancreas, terminal. Sixty days at most. He wanted to die at home. My mother wanted him to die at home. He had lost all control. He was totally bedridden. He was dozing on and off but fully conscious, but mostly he was aware of the problem with his cleanliness and his dependence. A proud man, he now had no quality of life of any sort. I said to the doctor, 'Is there any way we can hurry this along?' He said, 'James, you shouldn't ask me that. You know the law. There is nothing I can do. You know that.' Anyway, just before he left he said, 'Here's a box of painkillers. They're very strong. The dose is on them, but be careful, because if you overdose it could bring quite a reaction. The dose might be two, but if you were to make it four or six you could even lose your father, so you be very careful.' Well, my father died that night and the doc said, 'Make sure you destroy those pills that I gave you.' We have all faced and seen this type of thing during our lives, or many of us have. I could quote other situations. What we are asking for now is to some extent legalising part of what already goes on. That is all I have to say. Thank you.

CHAIR: Thank you for sharing your story. In relation to your opening statement congratulating the committee for taking this out in the open, it was the resolve of the committee—we were offered to go overseas and talk to other jurisdictions and we have them coming to us—to hear from Queenslanders. We have travelled the state, and we are probably three-quarters of the way through it, to hear stories just like yours.

Mr Clayton: You have done a very good job so far.

CHAIR: Thank you very much. Anne Marie, I invite you to make some comments.

Ms Awabdy: Do you have my correspondence?

CHAIR: Yes.

Ms Awabdy: I would like to thank you very much for allowing me to speak. I have a Queensland story to tell. I would like to suggest, as members of the committee, as politicians, that if any of you got a terminal illness tomorrow and had a number of months to live I think that there is a very good chance that you would all get very excellent care in our private hospital system because that is what I have seen with many people and that was my expectation of care in Queensland. However, I have a situation in my family where my husband went from the private hospital system to have a very particular type of surgery that was only available in the public system. Unfortunately he had many surgical complications and he got stuck in the public health system. As a nurse of many years in the private health system I was absolutely shocked and devastated to see just how shockingly bad the care was in the public health system.

I am here today because I have seen too many people being made to feel like an unwanted and unworthy burden by the Queensland Health system. We are talking about bringing in assisted suicide to a Queensland Health system that is in constant crisis. This year we have seen ambulance ramping out of control and major neglect in rural health services. We have elderly patients hoping and praying to die before they get sent back to their nursing homes where they are neglected. We have younger patients hoping and praying to die before they get shipped off to be parked—and they refer to it as being parked because they get the message that they are no longer welcome, they are not getting any treatment, they are just dumped somewhere in ghastly subacute hospitals or sent home to rot away for months, often without any access to a qualified doctor.

Today Queensland Health is not given the funding priority it needs to provide good care. Euthanasia will certainly save some money, but it is not a morally appropriate response to Queensland's urgent need for better health care. We currently, right now, have many vulnerable patients who are made to feel like an unwanted burden. They are being pressured by health services. They are being told to choose the cheapest options. So long as our system is severely under-resourced and there is an ever-increasing number of health rationing decisions to be made, then it is both unrealistic and illogical to even dream that any number of safeguards will adequately protect vulnerable patients from being coerced into accepting unwanted assisted suicide.

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I had the experience of standing by helplessly watching for months while my husband underwent the most disempowering and soul-destroying treatment in the Queensland Health system. There was no way for him to access good care in the public health system. This was due to health pressure, resource pressure and the health rationing was confirmed to me in a letter I received from the then CEO of the PA Hospital. He wrote to me, and I quote Dr Richard Ashby, 'There is an obligation on the hospital management and senior clinical staff to ensure that billion dollar entities like PA Hospital operate efficiently for the greater good of the greater number in the community.' It seems our clinical staff have become advocates for the health budget when their role really should be advocating for patients. The rest of the letter was very insensitive, extremely irrelevant and grossly inappropriate as correspondence to a grieving family. I firmly believe that the letter was intended to both belittle me and to intimidate me from speaking out further.

I also wrote to him about what I perceived to be the extremely arrogant and defensive attitude of the senior palliative care doctor at Metro South Health who refused to take my complaints seriously, even when attending a conciliation meeting organised by the Health Ombudsman. I later wrote to the Health Ombudsman regarding that experience and I received a letter from the Health Ombudsman to say that although we have charters of patient rights these do not provide any instrument under which the Health Ombudsman can take action. In other words, the health services know that there are absolutely no repercussions for poor care when it comes to terminally ill people and they are free to do whatever is most convenient for them and whatever is best for their budget.

CHAIR: Thank you very much, but we are out of time. I appreciate that you have written that out. If you have more, we can table it if you want to provide that. I am very sorry that you went through the experience that you did.

Ms Awabdy: I do have more and I would just like to say the response from the health minister at the time was that he excused himself from any responsibility or authority regarding health care, saying that health services are statutory authorities that are independently controlled—in other words, not the health minister, not the Health Ombudsman, not the health services, absolutely nobody cares and then when there is a problem with health care for a terminally ill person there is absolutely nowhere to go. The safeguards are not working now and there is no way in the world they will work if we introduce euthanasia.

CHAIR: Thank you very much, Anne Marie.

Ms Awabdy: Because I was so distressed, I did not get my submission in on time so it has therefore been rejected. I would appreciate if you would accept that submission.

CHAIR: We can do that. Is leave granted? Leave is granted. Thank you very much for that.

Ms Awabdy: Thank you.

CHAIR: Thank you to each and every one of you for your contributions today.

CANNARD, Mr Graham, Private capacity

McCUAIG, Ms Julia, Private capacity

REINBOTT, Mr Graeme, Private capacity

CHAIR: Welcome. Julia, would you like to start with an opening statement?

Ms McCuaig: Good afternoon. I am here today because in 2014 my beautiful mum, who was also my best friend, was diagnosed with terminal cancer and she did not have a good death. She was given six months to live, of which she lived for only four. I was by her side throughout that time and I have seen things I cannot unsee. We had quite a few conversations about her wish to die. Her biggest fear after losing her dignity was that someone would intervene if she got the chance to go. She would tell anyone who came into the room that she was not to be resuscitated or given antibiotics. She kept asking the one question: 'It's my life. Why can't I choose to end it?' I used to watch her staring out the window and wondered what was going through her mind, although I have a pretty good idea.

We were incredibly fortunate to have the absolute best of palliative care, which I know is not the case for everyone. My mum spent quite a few weeks throughout her illness at Dove Cottage in Caloundra and this is also where she died. I cannot stress enough how wonderful they were to both of us, but they could not give her the one thing she wanted. I let my mum down the day she pleaded with me to help her end her life. I said, 'No'—not because I did not want to help end her suffering but because my hands were tied by the law and I was terrified. I know the fact that she asked me this caused her further pain and distress, which she certainly did not need, but she was desperate. My mum was a lady and she was also a Catholic and she was strongly against suicide. My parents raised me to be a strong, independent woman and a good person with morals, values and respect. I am proud to say that I am my mother's daughter. She taught me to stand up for what I believe in. I consider it a great honour and privilege to have been by her side during her final months, but it should not have been like that.

I do not like to talk about myself, but I want you to know the effect that has had on me. By the time my mum died, I weighed less than 50 kilograms, I felt like I was constantly living on the edge, always fearful of what would happen next while trying to keep it altogether and stay strong for mum. I did not even cry when she did die; I just felt such relief for her. It was finally over. It has been over five years since I lost my mum and I am still not able to hold down a full-time job, although I am working on that. I used to be incredibly capable and reliable and I held some very high-level positions. I now suffer from incredible anxiety, PTSD and frequently disrupted sleep. I do not socialise much anymore and I get completely overwhelmed by things that I previously would have thought of were trivial. I am a very positive person and I work extremely hard to overcome all of this. I can honestly tell you that, throughout this entire time, I have never been suicidal or wanted to end my own life, but I have struggled figuring out just how to live my life again after what I saw. I am also incredibly fearful of what my own future holds. What if this happens to me? What happened to my mum could happen to any one of us.

I also sat with my dad when he died about 10 months after my mum. He was in a nursing home and he had Parkinson's disease. He was not in any physical pain and he did not want to die, so voluntary assisted dying would not have been a choice my dad would have made. That is the whole point: it is about having the choice. In closing, I ask that you please do not feel sorry for me but use this opportunity you have been given to make a difference, help to bring this legislation in so that others do not have to experience what I have. Allow us all the right to choose; ensure there are safeguards so that the vulnerable, lonely and depressed are not taken advantage of; and, if there are those who wish to see their suffering as a gift, let that be their choice and let us all move forward and live our best lives.

CHAIR: Julia, thank you very much. One thing that was not apparent to us when we began this journey nearly a year ago was that people were coming and sharing their very personal experiences and it has been fed back to us that talking through those experiences has helped them move forward. I think your mum, Anne Roslyn McCuaig, would be incredibly proud of you today. Thank you. Mr Graeme Reinbott, welcome.

Mr Reinbott: Thank you, Mr Chairman, and I thank the committee for this opportunity. I am representing my family today. I am also a member of the Gold Coast Retirees whom you heard from earlier and, of course, I am a baby boomer. Since writing my submission No. 1,101, some matters of importance have come to my attention—that is, two influential groups in our society have spoken out in an attempt to stop legislation giving us freedom of choice in the matter of voluntary assisted dying.

There are medical practitioners—doctors—who support voluntary assisted dying, including groups of doctors. However, the peak organisation for Australian doctors, the AMA, has opposed such legislation. While this is disappointing, put into context it is understandable that the Hippocratic oath limits the way some doctors think on this important matter. However, when we accept death as an inevitable part of life, the Hippocratic oath loses some of its relevance. The AMA in its position statement of 2016 acknowledges that laws in relation to voluntary assisted dying, euthanasia and physician assisted suicide are ultimately a matter for society and government. Thankfully, that is why we are here today.

The other group trying to exert its influence is, of course, the churches. In my submission I said the case in favour of voluntary assisted dying is all about two words: respect—allowing others to have their choice in end-of-life decisions; and compassion—allowing the individual to decide for themselves when enough is enough. Being brought up as a Christian and being a practising Christian for most of my life, respect, compassion, love and caring were synonymous with what I was taught. How is it possible for the church to turn its back on these things of which Jesus spoke? If church leaders want to preach to their people about the sanctity of life and other doctrinal matters, that is fine, but freedom of religion surely does not mean imposing these beliefs on others.

Ultimately, this is a matter for the people and you, our government. The people have spoken, with more than 70 per cent of Australians in favour of voluntary assisted dying. We now ask you, our politicians, to have the courage to follow through with legislation to legalise voluntary assisted dying. Thank you.

CHAIR: Mr Reinbott, thank you very much for your contribution. Mr Graham Cannard. Welcome.

Mr Cannard: Thank you very much and thanks to the committee for doing the job you are doing and bringing it out into the public. My story is one, like we have heard from other people, of loss. My father died in 1999 of lung cancer. He was in a small country hospital where everybody knew everybody. As is our family tradition, I sat with him and my brother—my older brother and only sibling—and we watched him die a death, which was not really pleasant. I will not go into too many details, because I am sure we can all imagine somebody in that situation. He did, however, wish that he could take his own life at one stage, especially after he went to hospital. He then went into a coma and was out of it for a couple of days. He then woke up and said, 'Where AM I? What AM I doing?' I told him. He said, 'Oh.' I said, 'I didn't think you would have another yarn, dad. You've been very crook and more or less in a coma.' He said, 'I would like to repeal that wish to die.' He said, 'I didn't know anything of the last couple of days and the fact that I'm sitting here talking to you again is a real bonus to me.' That was one attitude of one family member who passed away about a day after that.

Three years later, I lined up again as the primary caregiver for my mother. She died of liver cancer in the same little country hospital. On the night she passed away, once again with my brother and me taking turns in sitting by her bedside and being with her, a good friend of mine and the nurse on duty said to me, 'Graham, you don't want to be here tonight. She's going to die of liver cancer and it's a horrific death and you will never unsee it.' She tried to drag me out of the room, but I would not go. What I proceeded to watch was the most horrific thing, which has replayed in my mind many times. That was like 15 years ago—or whatever it is—but it is the last memory you have of that person and you just cannot unsee that stuff. She was of the mind that she did not want to talk about being sick. She just wanted to go to hospital when she lost control of her bowels. She comes from the time of dignity and the fact that, as I was a son, she did not want me doing that, so we respected those wishes.

Fast-forward another two years and my only sibling, my 45-year-old older brother, was diagnosed with advanced rectal cancer, which was a terrible disease to watch. The difference between him and my parents was that he was 45 years old. He did not smoke. He had healthy lungs. He had a healthy heart. What it took him to die was absolutely horrific. He tried to beat it. He battled boldly. He took some alternative pathways, which did not work, and then when he got down to about 40 kilos and being six foot two he said, 'I'm just going to die now and I'm going to suit myself how I do that.' There were two other primary caregivers—people who assisted me who were not related who helped—and we left him a mortar and pestle and a jar of jam, which was his wishes. He crushed up his OxyContin—80 milligrams—and his sleeping tablets and he took them without us in the room, because did he not want to involve us.

Unfortunately, because his heart was so good and his lungs were so good, his heartbeat went down to four beats a minute and he did not die. We were then left with no medication for him and we had to take the unwanted alternative of taking him to the hospital and calling the ambulance, which we did. My last memories of my brother and the last thing he told me when I was rubbing some ice

on his lips after they had taken the drip off him two days previously were, 'Just effing kill me.' That is the last thing my brother said to me. Two nights later he passed away in considerable pain with all the help that was available and the OxyContin really could not ease his pain. Once again, as the only family member I was left. I just see that the whole three of them were different, but the thing remains the same. I ask the same question as the good Anglican minister: why would anyone be denied a quick, painless death, a humane death and compassion to be shown and wishes to be followed? Thank you.

CHAIR: Thank you very much, Graham. People are still carrying these memories from years ago and they live with them. We have heard it right throughout the state. I thank each of you for sharing your deeply personal stories. I do not have any questions. No-one has. Thank you very much. We appreciate it.

D'HAGE-CRAIG, Ms Carla, Private capacity

FRUGTNIET, Ms Deborah, Private capacity

HUNTER, Mr Mark, Private capacity

TREBBLE, Ms Shawna, Private capacity

CHAIR: I welcome our final speakers for today's hearing. Mark, you are outgunned by the ladies. You have been sitting patiently, like everyone else has, so I am going to ask you to go first.

Mr Hunter: Thanks very much. Just a little history, I am a past CEO of a local hospice. I have experienced dying in a hospice, in a palliative care bed in a large Brisbane hospital, and in an aged-care facility. I recently went to Dr Nitschke's event at Robina on voluntary assisted dying by choice rather than by a medical model and I have recently written a play that demonstrates our need for the discussion of dying and death in our society. It is set in a hospice. I want to die—well, we are all going to die in some way—but I am not sure whether I want to die in Queensland yet. I want to make two points. I want to advocate for hospice being a viable choice, because I think death is a choice, and I want to advocate for the need for education that promotes discussion on dying and death.

In advocating for hospice, it is a difficult situation because we only have three hospices in Queensland—we have outreach services as well—whereas if we compare that situation with New Zealand where they have 31 hospices then it becomes a viable choice. In actual fact, in New Zealand a significant percentage of people who die as a result of age die in a hospice. Hospices are homelike. They have specialist consistent nurses and nursing and a dedicated skilled volunteer workforce. It is a whole-person approach. It is highly responsive and a flexible environment. When I was writing the play I was discussing with one hospice nurse and she was sharing how flexible a hospice is when she said to one of the residents there, 'What is it that you want to eat tonight?' He said, 'I'd like a dozen oysters,' so she organised a dozen oysters and that is what he got. The hospice environment is a rather remarkable environment. Love and compassion are the drivers and the focus is on quality of living and a dignity while dying.

I want to move on to this issue of promoting discussion and the reason for the play that I have written. It just recently had a shared professional reading to an audience of about 80 and I received almost 250 pieces of feedback which were in support of the concept that we need to get discussion around dying and death in the community. My goal would be to have a play followed possibly by a Geoffrey Robertson hypothetical where we can cover such issues as cultural diversity when it comes to dying and death, including dying and death from our Indigenous perspective.

There are basically two points to my submission. One is that we need to promote and develop more hospices so that it becomes a viable choice in Queensland, along with the other choices that we have heard—the medical assisted dying process and, for those people who want it, the choice based approach to voluntary assisted dying. I think we need to have hospices and we passionately need to have a process or a commitment to complement the legislation that is going to come out where dying and death is discussed comprehensively by the community. Thank you.

CHAIR: Thank you very much, Mr Hunter. Two points: I think you have hit the nail on the head in terms of hospices. You did mention that there are three. We have information that seven are funded in South-East Queensland. I am from the regions, so I flagged that immediately because I think we could all do with more, and that is part of what we are seeing. There are many small community based hospices that we have found that are operating in, for example, Toowoomba and, member for Caloundra, we visited Dove Cottage. There are a number of really small ones that are getting some co-funding as well. I do not think we actually landed on the exact number, but there is always a need for more I think.

Mr Hunter: I am aware of those three. I think we need more for hospice and end-of-life services to be a viable choice.

CHAIR: The other thing, and congratulations on writing a play: have you heard of death cafes and death dinners?

Mr Hunter: I have run death cafes for Hopewell, yes.

CHAIR: They have just started in Townsville. They are not morbid by any means, but we had someone present to us about it a few weeks ago and I will just share with the audience what they are about. You do not start your meal until you have done your statement of choices or advance healthcare directive or at least begun the conversation. We need to actually start talking about this early, not at a time of crisis. I congratulate you on your work. I think it is magnificent, so well done.

Mr Hunter: Thank you.

CHAIR: We will now move on to Deborah.

Ms Frugtniet: Thank you very much for the invitation to speak. I am speaking as a proud daughter-in-law and on behalf of my mother-in-law and the rest of our family. My father, Hilton, is 80. He is in full-time care now with advanced dementia in a care facility just around the corner in Arundel. The dementia has been a long event for dad, for mum and for our family of 10 or more years. He was a proud soldier for Australia and has done a lot for our country and has offered a lot to the community. What I have seen in the last 10 years, and certainly in the last 12 months, is that that has not been paid back to dad. Mum cared for dad as long as she possibly could in their home. They moved closer to medical services to make it easier for both of them and to be closer to us, their kids.

Unfortunately, nine months ago dad was deemed far too much for mum to care for at home and that is because, in our belief, the in-home services are just not adequate. Mum was firstly put through a rigmarole of invasion of privacy and made to feel like she had to answer for things that she should not have just to get the care. Dad is a gold card holder. As I said, he fought for our country and has been an upstanding citizen for his 80 years, mum also. The first thing we saw was the rigmarole mum was put through. I can imagine how a person of 70 years of age, if she did not have the support of her kids and grandkids around her, might struggle with that or how that might challenge them and I fear for those other elderly people who are standing on their own because, honestly, that is our first issue—that is, the problems that they have been put through to get the help. Then there is the issue of not being able to care for him in their home because the help is just not adequate and having to take dad and put him in a care facility. That is really obviously heartbreaking for mum and the family, but we then had to look at mum's health. It was just simply not viable for her to do it because a high-care dementia patient will end in both people being unwell. We had to consider that.

I can only speak from our experience and that of those that we have been in touch with in the same facility, but unfortunately the care is nothing short of neglect at times. I compare it to our young people in child care and the ratios that they are given, the requirements for dietary nutrition, the requirements for reporting and the communication. I cannot see any comparison between the elderly and young people in terms of the standards being the same. In my eyes, these people at 80-plus with high-care dementia, or even younger unfortunately, are neglected.

We have seen things like dad being bedridden, but he has bed sores because he is not turned enough. We were late for today's meeting because mum was with dad because he was having a seizure. When mum said to the RN, 'What is going on here?' she said, 'That's because he hasn't been turned.' He had not been turned for 24 hours. We have had to write the time on the back of dad's nappy pants to prove that they are not being changed. I have had to insist on his bed being changed because it was filthy. Mum has to take food up. Mum is 70-plus years old. She is up there for 16 hours a day sometimes because there are not enough staff.

We have just had Earle Haven—the walkout at Earle Haven. Two nights later we were in a very similar situation. Other patients' families were there and were refusing to leave because there were two people to care for 40-plus high-care dementia patients. I waited for an hour to help dad get to the bathroom because we cannot do it on our own. In that time they had another patient next door on the toilet and they are saying, 'Just stay. Just stay,' because they could not be in two places at once. This is not okay for our elderly.

CHAIR: No, it is not.

Ms Frugtniet: The connection between VAD and this is dignity and respect. These people deserve more dignity, more care and more respect, so I would ask that that be the consideration moving forward.

CHAIR: Thank you very much, Deborah. Did you say Eden was the name of that? Do you want to name that facility?

Ms Frugtniet: Mum will not thank me, but it is St Vincent's in Arundel. If I could just make a comment, we have so much respect for the care staff up there. They are loving and nurturing and want to do the best, but their hands are tied. This is a higher management issue.

CHAIR: You said you were not here earlier today, but we talked to the fact that the committee has now been tasked with inquiring into Earle Haven over the next two days but also tasked with the Health Transparency Bill, which is to bring in nurse-patient ratios in aged care and place the impetus, I guess, on private facilities to report so people can know what levels of care are being offered. That is before us as part of the remit of what we are doing. It is another piece of important work, but we do thank you very much for your contribution.

Ms Frugtniet: Thank you for your time.

CHAIR: I think your dad would be pretty proud of you being here today speaking up. Good on you.

Ms Frugtniet: Thank you.

CHAIR: Much like Julia before, I think he would be really proud. We will now move on to Carla.

Ms D'Hage-Craig: Thank you for the opportunity to speak today. I am here today to show my support for voluntary assisted dying. My father, Kenneth James Parr, passed away in 2017 at the age of 61 after a short but aggressive battle with cholangiocarcinoma, a rare cancer of the bile ducts. With a survival rate of only two per cent, a lack of research and no cure on the horizon, he tried everything he could. He was given a terminal diagnosis in April and he passed away on 30 June, very thoughtfully for tax time! My family watched my father suffer for three months. However, the last week of his life was by far the most traumatising for us all. He begged us to help him end his pain. He said he could not take it anymore, and that still haunts me to this day. He knew he was in for an agonising and absolutely humiliating end.

My father was an incredibly dignified man. He was an upstanding member of society and somebody who spent his whole life helping others, never complaining. To that end, we had to explain to him that he needed to learn how to tell us about his pain on a scale of one to 10 because he used to say things like, 'Yucky,' which you cannot really judge. My father was afraid of death, mainly because he did not want to leave his loving wife and his daughters but also because he was cognisant enough to realise what was happening to him. A common argument made against VAD is the belief that it is up to God to decide when we die. I, along with the 30 per cent of Australians who subscribe to no religion, believe that it would be absolutely discriminatory to base this law on the beliefs of a shrinking number of Australians. Queensland is a secular state and I believe that religion has absolutely no place in this debate.

The second common argument is that the current pain relief and palliative care is adequate enough. After my dad learned how to explain his pain on a ratio of 10, four days before he passed his pain hit a constant 10 out of 10, and not for the first time. By this stage he was well versed in the routine. He had to wait for more morphine and pop as many additional over-the-counter medications as he could while sucking on his 15th fentanyl lollipop for the day—something that I did not even know existed. His pain was not manageable. His pain was unbearable not only for the family members but you could see in dad's eyes he was suffering. Until you have sat across from your father as he loses control of all bodily functions, becomes aggressive, which he never was, continuously terrified because the medication that is meant to ease him into a gentle death is giving him vivid hallucinations to the point where we had to put a laser pointer in his room to guard him at night, and then you have to watch as he coughs up what looks like black tar as he suffocates slowly, I do not think that anybody should assume that what is available currently is making the end of life peaceful or comfortable in any manner. At the end of the day, why should we be satisfied with adequate care?

For the first year after his passing, I was haunted by the experiences that my father had gone through—these have not left me—and the fact that he felt completely helpless. As somebody who had dedicated his whole life to helping the community, nobody could help him. Voluntary assisted dying would not have been murder or taking away his life, especially in that last week: there was no life left. He was a shell of the brilliant person I had known.

VAD is not about ending life. It is not that black and white. It is about ending humiliation and suffering. It is about giving people like my father the choice to end when he wanted and how he wanted to. My father did not want to die at home. He did not want to put that pressure on my family, so he died at St Vincent's hospital in Brisbane. They were absolutely loving to him but, at the same time, there were often cases where we had to wait over an hour for pain medication. I do not think that my father could have gripped my hand harder without breaking it.

These are the things that I have to manage and deal with for the rest of my life. I now suffer from depression, which I am managing. My husband also suffers from this. My mother has been the one who suffers the most. She has had to move out of her home and is now living in a unit, which is not her preference at all. She has had to quit work as a teacher, which she thoroughly enjoyed. I have watched her struggle with everyday life. My father did absolutely everything. He doted on her. Her learning how to do things like cook and clean and help and take the train—those are things that she suffers with. Every time something like that happens, she is reminded of the fact that her husband died in such a horrific way. In those last three months, there was not an opportunity for my dad to do things, because he was so terrified of anything happening to him. He went to Sydney one week. Two weeks later, he was dead. It was too much for him, because the pain medication available just was not suitable. That is my submission.

CHAIR: Thank you. I offer our condolences on the passing of your dad. Much like Deborah, I think that he would be pretty proud that you were sitting here talking about this and sharing this with us. Thank you. Ms Shawna Trebble is our last speaker for the day. Welcome.

Ms Trebble: I am the last speaker, but I am also the only person who has stood up to you to talk to you about being against euthanasia. I also want to state before I start that there are only six countries in the world and six states that are for euthanasia. I am going to give some statistics in my speech in relation to some of the things that have been dealt with, but they are actual statistics from Belgium and the Netherlands.

Currently, we are our brother's keepers, which means that we basically help and bless and care for our fellow men following the biblical mandate of loving our neighbour as ourselves, much like our volunteer firefighters are now doing in Queensland. If we change the law so that it now becomes legal to kill someone, where does it stop? Right now, euthanasia will be allowed only for the physically terminally ill, but if we open this up it is a legal minefield and there will be no safeguards to making legal euthanasia applying to all groups and all populations who decide at that particular moment in time that they want to suicide, or those who are in authority by power of attorney choose to kill without consequence.

In the Catholic Church it is still considered a mortal sin to kill someone. The Bible declares it a sin in 1 Corinthians 3:16. Why is that? Because life is considered to be a gift from God and we are stewards of that gift. Our actions also impact others. Euthanasia is a self-centred act that violates the genuine love of not only oneself but also that of family, friends, neighbours and even acquaintances. There is a huge societal impact of killing oneself on family, friends and acquaintances. I do not really think that this has been discussed or evaluated much, but it is a huge issue. It is well known that suicide leads to suicide. My right to choose also directly impacts on other people.

In Belgium, they have had legalised euthanasia since 2002. Each year, the statistics go up by 27 per cent. If we agree to kill those who are physically terminally ill, what about those who are long-term mentally ill? Again, in Belgium two per cent of those who are euthanased are psychiatric patients. What about those who consider themselves too old but are unhealthy and want to die? Are we going to assist them in their suicide too? Where does the line stop? To me it is a very slippery slope and one, if we go into, that will dramatically change society for the worst. Last year alone in Holland, 440 people chose to die through euthanasia for minor issues such as incontinence or hearing loss. That was up 50 per cent from the year before.

Euthanasia also opens up the whole area of power of attorney abuse. If euthanasia is legalised, children who have powers of attorney will be able to now legally knock off their ageing parents so they can get their inheritance earlier than bother with the responsibility of caring for them. Also, what about family members who have children with severe disabilities or terminal illnesses and who are tired of looking after them? How can the law safeguard against situations so abuse of the most vulnerable does not happen? Personally, I do not think that there is any way that the law can safeguard this. Already, the abuse of the elderly is such a concern to this country that currently there is a royal commission into it. This has been a huge concern overseas—in Europe. Holland has had a major shift recently in the interpretation of their law, which as one member says continues to just expand and expand the whole area of euthanasia. It now endorses the killing of dementia patients, and children in no age group can die through euthanasia with the help and support of their parents and a psychiatrist or psychologist.

Medically speaking, if the patient is in severe discomfort and is terminally ill, the doctor is allowed to up the morphine or medication so that the patient dies much sooner and in relative comfort, thus I think we already have the ability for those who are terminally ill to die in comfort and we do not need to change the euthanasia law. Currently, the doctors are bound by the Hippocratic oath but, if we allow them to kill, that normally goes against what a doctor is there for. It opens up a whole host of other areas for doctor abuse.

CHAIR: Thank you, Shawna. Thank you very much. I am sorry to pull you up on time. If there are no questions from the committee, I thank all three of you. We have to respect the views of everyone on this journey. I think, having the last few days in the back of my mind and in listening to people today, the message that we are getting is that this is an issue that is above politics, I hope, above religion, I hope, and it is about people. I want to thank everyone for being here today. Sir, I am going to close the proceedings, but I am happy to talk to you. We are well over time. I thank everyone who has been here today observing and listening to the contributions of everyone here today. I now declare this public hearing closed.

The committee adjourned at 3.53 pm.