



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

**Members present:**

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

**Staff present:**

Mr R Hansen (Committee Secretary)  
Ms M Salisbury (Assistant Committee Secretary)  
Ms A Groth (Assistant Committee Secretary)

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

### **TRANSCRIPT OF PROCEEDINGS**

**FRIDAY, 5 JULY 2019**

**Brisbane**

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### **The committee met at 9.03 am.**

**CHAIR:** Good morning everyone and welcome to the second day of the Brisbane hearings of our inquiry into aged care, palliative care, end-of-life care and voluntary assisted dying. I declare this public hearing of the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee open. I would like to start by acknowledging the traditional owners of the land on which we are meeting today.

My name is Aaron Harper, chair of the committee and member for Thuringowa. The other members of the committee with me today are: Mr Mark McArdle, member for Caloundra and our deputy chair; Marty Hunt, member for Nicklin; Barry O'Rourke, member for Rockhampton; and Joan Pease, member for Lytton. Michael Berkman, member for Maiwar, is unable to be with us today. The committee is a statutory committee of the Queensland parliament and as such represents the parliament. The inquiry into aged care, end-of-life care, palliative care and voluntary assisted dying was referred to the committee on 14 November 2018. The committee is required to report on the inquiry by 30 November 2019. Today's proceedings are similar to the proceedings of parliament and are subject to the parliament's standing rules and orders. The proceedings are covered by parliamentary privilege which means witnesses are protected from legal action in respect of the evidence they 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 remind you that intentionally misleading the committee is a serious offence.

I ask that everyone respect the rights of others to hold and express their views. I also ask that witnesses take care when referring to acts of suicide or euthanasia. This public hearing is being recorded and transcribed by Hansard and witnesses will be provided with a copy of the transcript. All those appearing today have been provided with a copy of instructions for witnesses and we will take those as read. For any media present, I ask that you adhere to my directions as chair at all times. I remind members of the public that they may be admitted to or excluded from the committee at the committee's discretion. Please note that it is a public hearing and you may be filmed or photographed.

**ANDERSON, Ms Rebecca, Member, Elder Law Committee, Queensland Law Society**

**BROWN, Mr Simon, Chair, Health and Disability Law Committee, Queensland Law Society**

**COPE, Mr Michael, President, Queensland Council for Civil Liberties**

**VALLANCE, Ms Sarah, Queensland Committee and the Medical Law Special Interest Group, Australian Lawyers Alliance**

**WHITE, Professor Ben, Private Capacity**

**WILLMOTT, Professor Lindy, Private capacity**

**CHAIR:** I will inform the public today that Deputy Chair Mark McArdle will be taking over this afternoon's session from 12—I know we will be in very good hands—as I have to return to Townsville. I am looking forward to this morning's contribution from each of you. Would you like to make an opening statement and we will then move to questions?

**Prof. Willmott:** I would like to say thanks for the invitation to be a witness before the committee today. I also acknowledge the traditional owners of the land on which we meet. My name is Lindy Willmott and I am a professor of law at QUT and a member of the Australian Centre for Health Law Research. For the past 18 years my colleague Ben White and I have researched almost exclusively in the law, policy and practice of end-of-life decision-making, including in relation to voluntary assisted dying. The views that I express today are my own and I do not purport to represent the views of others at QUT or any other body that I am associated with.

For the sake of transparency, my colleague Ben White and I would like to state our position in relation to voluntary assisted dying. We believe that the current laws should be reformed to allow voluntary assisted dying in limited circumstances. We believe that a law of this kind would promote values that are important in a liberal democracy—values of life, autonomy, freedom of a conscience, equality, the rule of law, protecting the vulnerable, reducing human suffering and safe and high-quality care—and we believe an appropriately drafted law that permits voluntary assisted dying would also protect the vulnerable in our community. Our position is also informed by an analysis of the social science evidence of how these systems have been operating in practice internationally.

This view was reached by parliamentary bodies and ministerial advisory or expert panels in Victoria and WA and has led to the enactment of the Voluntary Assisted Dying Act in Victoria. It has also led to the WA government's statement that it intends to table a bill in the second half of this year to legalise voluntary assisted dying. We have heard much about the Victorian model in the press over recent weeks, some of which has been accurate and some has not. However, from the research that we have undertaken, we believe that this model is the most conservative model in the world, as the Victorian government has claimed. However, we believe that the Victorian legislation could be improved.

My colleagues from QUT, Ben White, Katrine Del Villar and Eliana Close, and I have recently examined the Victorian legislation to see whether it achieves its stated policy goals. We concluded that it did not in some important respects. We believe that the design of the system, including the levels and nature of reporting, may constitute barriers to achieving the stated policy goals. We note that the WA ministerial expert panel has also recommended some departures from the Victorian model which are consistent with the changes to the Victorian model that Ben and I would recommend. Ben and I have drafted a voluntary assisted dying bill. This bill is the culmination of our work in this area and is based on the values stated earlier, as well as our analysis of the Victorian law. We consider it strikes the right balance between providing access to voluntary assisted dying for those seeking it and provides robust safeguards for the vulnerable in the community. Thank you, that concludes my opening remarks and I will hand over to my colleague to provide his.

**Prof. White:** I am a professor in the Australian Centre for Health Law Research in the faculty of law at QUT. I too make clear that the views I express today are my own. Again, in the interests of transparency, I wanted to state my views on voluntary assisted dying. That is that it is possible to design a safe and effective voluntary assisted dying system that respects autonomy and shows compassion for terminally ill patients who would like to die and at the same time that system can also have robust safeguards to ensure the protection of the vulnerable in the community.

Given I am a researcher my approach to this was to start with the ethical issues, including my own values on this topic, and I am also informed by the extensive social science research that has been published in relation to how regimes like this operate in countries overseas. I agree with the points that Lindy has made about the Victorian law which may not be optimal in some respects. I also note that our draft voluntary assisted dying bill represents our thinking on what a safe and effective voluntary assisted dying system should look like.

I wish to add just one point and that is the importance of evidence in debates about voluntary assisted dying. This draws on the work that Lindy and I have done, including with a colleague, Dr Andrew McGee. Voluntary assisted dying involves arguments both about morals and about facts. People can reasonably have different views about morals, the rights and wrongs of voluntary assisted dying. What is important here though is that people are transparent about the values they hold when making these claims because this allows others to understand the values they are relying on and where they are coming from and understand what is motivating the person to hold that view. Lindy mentioned earlier the values that we have articulated and stated publicly as supporting our view in favour of our voluntary assisted dying reform.

Arguments about facts are different. These are claims about whether or not something is actually happening in practice. An example is are vulnerable groups and societies more likely to seek voluntary assisted dying than others. These arguments are not based on values, they are based on evidence. Again transparency about the evidence being relied upon is very important because this allows others to test that claim and whether or not the evidence being put forward in fact supports it. I will make two key points about evidence. The first is that only reliable, trustworthy and high-quality evidence will accurately show what is happening in practice. There are established ways that science uses to establish whether evidence is reliable or not and one is the reliability pyramid of evidence which is included in our submission to the inquiry with colleagues. To illustrate, peer reviewed, high-quality empirical studies are more reliable than anecdotes or media reports which claim what may or may not have happened in other places.

The first point is about reliable, trustworthy and high-quality evidence. The second is that this reliable evidence must also be accurately presented. Cherry-picking of results or selective reporting or presentation of evidence is dangerous. We make this point because both sides of this debate feel very sincerely and strongly about their views, but decisions about permitting and regulating voluntary assisted dying are vitally important for our society so it is critical that we have high-quality debate that is informed by reliable and trustworthy evidence that is fairly presented. Those are my opening remarks.

**CHAIR:** Thank you both very much for your opening statements. We will move to the Queensland Law Society very shortly. You touched on a couple of things there. The Victorian model helps inform us of what potentially could happen in Queensland should we make recommendations, but there were some distinct differences I saw in the recommendations of the WA ministerial expert panel in terms of access. By the sheer geography of the state of WA they have made some recommendations. Of course their bill has to go to the parliament. We are watching very closely in that space as well. I will come back to you, but I wanted to see what the differences were in those two particular models that you said could be improved. Secondly, I noted that you had drafted a proposed bill. Is that on your public website?

**Prof. White:** That is correct. The model Voluntary Assisted Dying bill is available on QUT ePrints.

**CHAIR:** Do you intend to table that today?

**Prof. Willmott:** Yes, we seek leave to table that.

**CHAIR:** Leave is granted. We will return to that shortly. I now welcome Mr Brown from the Queensland Law Society.

**Mr Brown:** Today I appear on behalf of the Queensland Law Society in my role as chair of the Health and Disability Law Committee of the QLS. Thank you for the invitation to appear at this morning's hearing. We have anticipated that the hearing this morning will primarily be directed to voluntary assisted dying matters; however, we would like to make some brief comments on our submissions on aged care, end-of-life and palliative care.

It is apparent from the ongoing Royal Commission into Aged Care Quality and Safety that the current system of aged care does not provide care that is consistently available, safe and of a high quality across the sector. These deficiencies will be compounded in the coming decades with our ageing population. It is therefore essential that a system of aged care be properly resourced and based on a care model that recognises, as well as supports, the rights of older Australians to make decisions and maintain their dignity as they age. Amongst the reforms that will be required are: proper regulation of restrictive practices; implementation of appropriate staff numbers and staff skill set ratios; improved staff screening and training, including in relation to cultural competencies; and improved monitoring of the quality of services provided to our aged population.

The evidence cited in our written submission indicates that Queenslanders do not have sufficient access to palliative care. This problem is even more evident in remote and rural areas of Queensland. We reiterate our call for the development of an action plan to improve palliative care services. Such a plan should be developed through appropriate consultation with key stakeholders with a focus on ensuring timely access to specialist palliative care services for all Queenslanders.

With regard to voluntary assisted dying, the Queensland Law Society recognises that, based on the available evidence, including submissions to this inquiry, the majority view is that VAD should be allowed in certain circumstances. If parliament does decide to enact voluntary assisted dying legislation, the legislative scheme must carefully be considered and have proper regard to the following: the values that underpin the legal principle—and indeed Australian society—of the importance of life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable and reducing human suffering. Eligibility criteria will need to be addressed in relation to the types of health conditions and level of suffering that entitle a person to access voluntary assisted dying as well as appropriate tests for determining capacity and an individual's ability to communicate their understanding of the decision they have made.

It is essential that a VAD scheme safeguards against any assisted dying that is not entirely voluntary; however, safeguards must not be so restrictive as to render the scheme unavailable to many of those it is intended to benefit or to unnecessarily prolong suffering. In particular, any requirement that the person wishing to access voluntary assisted dying must be the first to raise the idea must be balanced against the need for medical practitioners to be able to frankly discuss

end-of-life options with their patients. Further, any requirement for repeated tests of capacity must also account for the possibility that the person's medical condition may contribute to cognitive decline as the illness progresses.

The Queensland Law Society agrees that health practitioners ought not be required to participate in any aspect of the voluntary assisted dying scheme and notes that health practitioners are subject to ethical and codes of conduct in relation to the management of patients wishing to access treatment to which a practitioner holds a conscientious objection. Accessibility of VAD to Queenslanders in rural and remote areas will need to be considered with respect to access to appropriately qualified and willing health practitioners. Finally, an independent body ought to oversee the framework, including receiving reports in relation to all VAD requests and deaths. The Law Society welcomes questions from the committee.

**CHAIR:** I am glad you touched on aged care and palliative care. I know from the number of submissions we have received that there is a heavy weighting towards voluntary assisted dying. I will come back to you with regard to current waiting times. As you have noted, the federal budget recently announced an additional 10,000 national home care packages. We have heard there has been a significant delay in accessing that for Queenslanders. I think the figure we heard yesterday is that there are 127,000 people waiting. That really does put it in perspective. People are waiting up to 18 months to access their package and some people are reportedly dying before they receive their package, which is deplorable.

You have also highlighted the serious issue of ratios within the aged care sector. Our work, along with the royal commission, is to identify how better to prevent delays in the aged-care and palliative care sectors. As we heard yesterday from palliative care specialists, there is a need to improve funding, particularly in rural, remote and regional Queensland. Thank you for touching on that. We are also looking at ministerial oversight bodies in Victoria and the proposed WA model.

I now welcome Sarah Vallance from the Australian Lawyers Alliance.

**Ms Vallance:** I am a medical lawyer, but today I represent the Australian Lawyers Alliance. I am a member of the Queensland committee. Firstly, I would like to thank you for inviting us to attend this hearing. I also acknowledge the traditional owners of the land.

As set out in our submission, the Australian Lawyers Alliance is broadly in support of the introduction of a voluntary assisted dying scheme for persons in limited circumstances. The Australian Lawyers Alliance believes that every life has value. However, with advances in medicine Queenslanders are now living longer and the burden of disease at the end of life is increasing. Queenslanders are also living with chronic diseases that are incurable and impact greatly on a person's quality of life. While most people at the end of life will be cared for by palliative care services, for some of those people palliative care is incapable of easing their pain and suffering. If persons in those circumstances decide that life is too burdensome and they wish to end their life, they should be given genuine choice about the timing and manner of their death. A voluntary assisted dying scheme should not be regarded as an alternative to palliative care, but instead should provide genuine choice for the small group of individuals who seek to access it. Introducing a scheme like this would also be consistent with individual autonomy, which is a fundamental legal and ethical principle in our healthcare system.

In our submission we suggest some differences to the Victorian model, in particular with regard to which persons would be eligible to access the scheme. In Victoria, voluntary assisted dying is only available to persons with a life-limiting illness that is expected to result in their death within six months or, in the case of a neurodegenerative disorder, 12 months. However, as set out in our submission there are circumstances where persons may be suffering greatly from a range of illnesses and medical conditions that may not be progressive and may not result in their death within a particular time frame. However, this does not mean that they are not suffering greatly. For example, they may have tetraplegia or they may have suffered a stroke but it does not necessarily mean that they are expected to die within a short period of time. We believe that consideration should be given as to whether they are eligible to access such a scheme. If so, then the eligibility requirements need to be carefully drafted so that those persons are included in the scheme and able to access it if they wish to.

The Australian Lawyers Alliance is also of the view that it is vital that it is the person's own decision based on their own values and beliefs. The scheme should only be available to persons who have capacity. We do not consider it is appropriate for substitute decision-makers to make a decision on a matter of this nature on behalf of another person. What is meant by 'decision-making capacity' should be very clear in any scheme and consistent with other Queensland legislation. The Australian

Lawyers Alliance is also of the view that practitioners who participate in the scheme should have a minimum level of experience and be provided with training so that they are clear as to how decisions regarding capacity are made. Although the Australian Lawyers Alliance is of the view that a clear process is essential to the success of any voluntary assisted dying scheme, we believe it should not be so burdensome that it in fact does not provide genuine choices to a person seeking to access the scheme and create too many barriers. It should also not greatly increase the pain and suffering experienced by the person seeking to access the scheme. In order to protect vulnerable persons the Australian Lawyers Alliance is of the view that a variety of safeguards need to be implemented, and we have set a number of those out in our submission.

Given there are a range of views and beliefs regarding assisted dying in our community and in our medical and health professions, practitioners who hold a conscientious objection should not be required to participate in the scheme. However, we are of the view that practitioners should refer the person seeking to access the scheme to another practitioner. This would be consistent with the obligations of practitioners under the Termination of Pregnancy Act. We also have a submission about end-of-life decision-making and advance healthcare directives, particularly regarding decisions to withhold and/or withdraw life-sustaining treatment. The legislation that was introduced in 1998 and 2000, which we refer to as the guardianship legislation, is overcomplicated, particularly in relation to decisions to withdraw and/or withhold life-sustaining measures in an advance healthcare directive. The Australian Lawyers Alliance is of the view that the common law promotes individual autonomy but also provides protections if the advance healthcare directive is unclear. It does not appear that common law advance healthcare directives have in fact been protected. The requirements under the guardianship legislation have significantly limited the situations in which a person can make a directive to withhold and/or withdraw life-sustaining measures. The Australian Lawyers Alliance is of the view that a number of changes need to be made in this regard so that persons without capacity are not treated differently to those with capacity in relation to decisions to withdraw and/or withhold life-sustaining measures.

**CHAIR:** In relation to capacity, we continually hear issues raised in terms of being able to make an advance healthcare directive—forward planning, if you like—if they have a stroke or dementia, which is a chronic issue. I see that your medical conditions are broader than Victoria's. The issue of capacity keeps coming up. We need to draw a line in the sand in terms of whether you have capacity or you do not. I was just interested when you said that someone who had had a stroke could potentially apply but they would still have to have capacity.

**Ms Vallance:** Absolutely, yes.

**CHAIR:** We will move on to the Queensland Council for Civil Liberties, and I welcome Michael Cope.

**Mr Cope:** On behalf of the council I thank you for the opportunity to appear before the committee today. The council starts with the position that we need to recognise the needs of those who are suffering from unbearable pain or whose quality of life is now, as far as they are concerned, worthless. We also need to recognise the need to protect the vulnerable. We are of the view that we can have a system which will reconcile both those interests which enables those in our society who are suffering from unbearable pain to be relieved from that pain but also to protect those who may be vulnerable and whose situation may be abused.

In our submission we basically endorse the Dutch system. We do that for two reasons. Firstly, because we do not think the system should be limited to those who have a terminal illness. There are many illnesses which are not terminal which lead to people suffering pain and having a quality of life which is unacceptable and those people also need to be included in this system. We see no relevant difference between those who are suffering in that way from a terminal illness and those who are suffering from an illness which is not terminal. The Dutch system has been around for a long time, I think the Swiss one is older, but is the one that has the most experience and has been developed and changed over a long period of time. One of the features of the Dutch system is that the decision as to whether or not a person's condition can be improved is what you would describe as an objective one in that it has to be agreed to both by the treating medical practitioner and the patient. It is not as it is in some systems finally a decision for the patient. That we think is important in the question of palliative care because we accept that adequate palliative care has to be central to the development of this system.

Having said that, it also has to be recognised that palliative care is not a solution to some of these people's problems. People who have a quality of life which they no longer consider to be acceptable cannot ultimately, in our view, be assisted by palliative care. To those who are worried about the slippery slope, we give the answer that is always given to that which is they have no faith

in people in the future to recognise the same problems that we recognise and that they recognise. They are ignoring the current situation of those who are in pain and cannot have that pain relieved. They ignore the fact that this is already happening except it is going on behind closed doors. They ignore the fact that people already have a right to refuse medical treatment. We would say that a legalised system will be a system of regulation which will control the system and thereby reduce abuses which may be occurring at the present time. Finally, as Professor Willmott has said, there is no good evidence that anywhere where these systems have been established that the slippery slope has, in fact, come into play. In fact, some of the evidence would suggest the reverse. Thank you.

**CHAIR:** Thank you, Mr Cope. Yesterday afternoon we heard from faith based groups that are all reasonably opposed to having voluntary assisted dying in their particular aged-care facilities. What do you say to those people who oppose the legislation? We had one say on record that they would pull out of providing aged-care beds if this was introduced.

**Mr HUNT:** That is not what they said, with respect, Mr Chair. They said they would withdraw from the sector if they were forced to participate on their premises.

**CHAIR:** You are correct, thank you, member for Nicklin. I found some of their comments interesting.

**Mr Cope:** As our submission says, we certainly support the right of individual medical practitioners to conscientiously object. It is an interesting question as to whether institutions have a right of conscientious objection. I think the position we have taken in relation to abortion is that they do not, but individuals do.

**CHAIR:** That is the dilemma.

**Mr Cope:** It is. As I say, I think clearly individuals have a right to conscientious objection. On the other hand, I suppose people can choose not to provide a service. I might have to think about that. As I say, in relation to abortion we have taken the position that it is an individual right of conscience and that is what it is. The more I think about it, it is an individual right.

**CHAIR:** Do we go so far, if we do indeed recommend this be introduced into the state, of having an expanded legal framework or a list of those other medical conditions you spoke to in the Dutch system to put some framework around what they are? I know someone else went broader with medical conditions other than a terminal illness.

**Mr Cope:** My understanding of the Dutch system is that they do not have a list, they have a set of criteria which have to be assessed by individual medical practitioners with the patients. I think that is the appropriate way to go. In the end, we are talking about what is the subjective experience of the individual, although, as I say, you have to be careful with subjective experience. It cannot be unregulated because people with these conditions get depressed and depression itself affects how people understand their condition. They can see no way forward. There has to be a balance. I think if we start limiting conditions then you get away from people being able to at least say this condition is unbearable for me and then you start a process, to a degree, of an objective assessment of their assessment of their condition.

**Mr HUNT:** Professor White, you discussed evidence in relation to vulnerable people and that studies have been done into whether or not vulnerable people are more likely to seek assisted dying. Would you concede that that evidence relies on the researcher's definition of vulnerable?

**Prof. White:** On that point I would say I would look carefully at what the relevant studies talk about. What they tend to do is describe transparently the various categories and characteristics of the people who are included in these very, very large studies. They would include various characteristics such as age, gender, the nature of the illness that the person had, whether or not, for example, they were receiving palliative care. There is also, for example in places in the US, demographic data collected about ethnic background as well and there is also data collected about education. For example, when you look at some of the data that comes out of Oregon, the results there talk about primarily being white, well educated and in palliative care. Your question about understanding what vulnerability means, it is important to look closely at these studies to see what categories of people they are talking about. When looking at the studies I think it is reasonably clear and transparent about what groups they are talking about in those studies.

**Mr HUNT:** For example, someone diagnosed with a terminal illness, with a good savings account but poor children who want to leave something for their children and who see major expenses in staying alive, would that person be considered vulnerable?

**Prof. White:** I think that would be an individual case-by-case question.

**Mr HUNT:** What I am getting at, I guess, is that you seem to infer that vulnerable people are not more likely to access voluntary assisted dying.

**Prof. White:** The point I am making is that the large body of social science evidence, which has been published in the best journals in the world, talks about this issue and it specifically asks that question about whether or not vulnerable groups are more likely to access voluntary assisted dying to which the answer is no.

**Mr HUNT:** That goes back to my original question, which is how they define vulnerable in that study. Would you concede that?

**Prof. White:** Those findings do depend on, yes, how they have defined vulnerable, that is right.

**Mr O'ROURKE:** Thank you for being available today. I will ask this question to all of you. If voluntary assisted dying is introduced, one of the eligibility criteria may include the age of a person. I note the Australian Lawyers Alliance supports the common law test of capacity of children to provide consent. What are the views of the panellists in regard to whether a child should be able to access voluntary assisted dying?

**Prof. White:** The draft bill that you have before you which represents our views on this issue we have limited to adults. That is our view based on the balancing of those values, including values such as autonomy and life and others that were listed in Lindy's opening statement. We do note, for example, in places like Belgium where very tightly prescribed access is available for children that it is hardly ever used. For example, in Belgium they changed their law in a very narrow way to permit access to children in 2014. The latest data I am aware of is that only three people under the age of 18 have had access to that regime since that time.

**Prof. Willmott:** Could I also add in relation to previous bills that have been tabled throughout Australia over the last two decades that children are rarely included in voluntary assisted dying regimes. That is relatively unusual in the dialogue in Australia over the last couple of decades.

**Mr Brown:** The Queensland Law Society for this submission looked at 18 as being the presumption where an adult has capacity unless that presumption is rebutted. We did not in particular go into those under 18, although we do recognise that there could be some extenuating circumstances that a review body may wish to look into if an application was brought forward. That would be something further down the track. Our starting point was 18.

**Ms Vallance:** In our submission ALA did say that it could be appropriate to allow children in limited circumstances to access the scheme. We appreciate that there would be a range of beliefs about this issue as well. The test of capacity in the submission is just what the current legal test is. There is no reason why additional requirements could not be imposed in any scheme. In our submission we then just set out some of the protective measures that could possibly be put in place if children were allowed to access the scheme. Overall, we felt it should be considered whether children who would otherwise meet all of the requirements of a scheme should be prevented from accessing the scheme simply because of their age.

**Mr Cope:** Our submission supports access to voluntary assisted dying by mature minors for a number of reasons: firstly, because we have always argued that the decisions of mature minors should be taken more seriously than they are; secondly, because the age of 18 is an arbitrary number—we went along with the Dutch system which is that there is a minimum of 12; thirdly, the pain and suffering of children is no less different than that of adults; finally, of course, we recognise that extra controls, protections, need to be added in the case of children, including extra medical assessment, assessment by people experienced in dealing with children. As Professor White has noted, it has been hardly used in the places where it has been introduced. A fundamental point is we are dealing with people who are assessed, in effect, as having the same understanding of what they are doing as an adult. That is the sort of person we are talking about, a mature minor, a Gillick competent person is the jargon that is used in particular in the family courts. Those sorts of people in our view, who are suffering in the same way as an adult, should be entitled to access the scheme with appropriate safeguards.

**Mr HUNT:** Mr Cope, in your submission under the heading 'Controls on access to voluntary assisted dying', in No. 1 you contend that 'it should be a criminal offence for any person or institution to pressure any patient to die'. Could you expand on what you mean by 'pressure', because pressure can come in all sorts of forms, can't it?

**Mr Cope:** Of course and it is intended to cover any attempt to make a person take a certain course. It is cognisant with the next requirement that the decision should be initiated by the person themselves and that that should be independently verified. I agree with you that pressure could take a whole wide range of things. The idea is that these should be truly voluntary decisions, so I would have no difficulty with the concept of pressure being taken in a broad sense.



**Mr HUNT:** Would you concede perhaps that if legislation for voluntary assisted dying was presented and became the norm in 10 years time people might feel a societal pressure to relieve society or their family of the burden of looking after them?

**Mr Cope:** All we can do is discuss people's individual circumstances. With regard to societal pressure, no-one can address that. It does not seem from the material that I have read that there is any evidence of that. As I think I pointed out in the submission, we refer to some research from Oregon. From a legal point of view, all we could do is assess people's individual circumstances. If some sort of norm were to develop that people should take into account the cost to their family, that becomes a factor which is to be assessed in those cases. If you get a situation where the person is being pressured to do it because other members of the family are pointing out the cost to them, that becomes an illegitimate pressure.

**Mr HUNT:** So that should be a criminal offence then in terms of the subtly of a family discussing that? Have you considered this option? Could that be considered pressure under what you are proposing?

**Mr Cope:** It could become, yes. Just like all other things, you have to look at creating a criminal offence, you have to look at intention and all of those issues, but I have no problem with the notion that a family sitting around a table working on a person, even in a subtle fashion, for a period of time to try to get them to this result should be an offence.

**Prof. Willmott:** If I could make a comment in relation to the burdensome nature and the pressure that that could potentially apply, it has come up in some reports in terms of people feeling pressured to seek assistance to die with one of the reasons being a burden on their family and therefore they want to die for that reason. I think it is really important that we as a community are very compassionate and support people who are approaching the end of life and are obviously suffering and I think it is incumbent upon the community to be compassionate. I know that there are some strategies that are being trialled both in Australia and internationally in that we as a community can be more compassionate and support dying patients, and I think that is important. I also think it is really critical to have top-class palliative care available to everyone at the end of life. Palliative care around Australia is patchy. We have a high standard of palliative care, but that is not available to all people who are dying and it should be.

That said, suffering at the end of life is a really personal thing and there are different factors that motivate people. We know from the data to seek assistance to die that loss of autonomy is one very high factor and not being able to do the things that they want to do is a very high factor. Feeling a burden can be a very personal thing that the person suffers because they have to rely on family to do things that they used to be able to do themselves. It may well be that the family wants to do that to assist the person and it is not coming from the family but it is coming from themselves—that is, they do not want to be in that position—and that is suffering to them. I do not think that should be an illegitimate consideration or an illegitimate factor for an individual person.

**Mr HUNT:** I agree and it is certainly what we are hearing in submissions. We are hearing the word 'burden' a lot. In fact, a submitter yesterday said that amongst her peer group they were talking about wanting access to voluntary assisted dying before they went into residential aged care. There is a whole range of people who submit that they want access to this. I would contend that a lot are vulnerable—under whatever definition we decide to give 'vulnerable'—but vulnerable due to that loss of autonomy, that loss of control or that feeling of burdensomeness, so I agree with you. Briefly back to you, Mr Cope, your submission states under 'Psychiatric conditions'—

The Council recognises that many individuals suffering from psychiatric conditions have the same capacity ...

You go on to say this in relation to depression, I believe. Would you concede that having a terminal diagnosis or losing the autonomy I spoke about a couple of minutes ago or a 25-year-old losing the use of his legs in a motorcycle accident may cause or be an underlying cause of a psychiatric condition such as depression?

**Mr Cope:** Of course, but the submission is directed to people and their sole condition. The underlying condition is psychiatric in that part of the submission. That is not directed to people who have a condition which has resulted in them being depressed. As it says in the first sentence, we are talking about a person where the sole underlying medical condition is psychiatric.

**Mr HUNT:** Right. If somebody has another underlying medical condition which would give them access to voluntary assisted dying under a legislative procedure, if they had underlying depression then that should not exclude them or a diagnosed psychiatric condition as well as—

**Mr Cope:** The point of this bit of the submission is about individuals whose sole condition which they are relying upon to claim voluntary assisted dying is psychiatric.

**Mr HUNT:** Yes, I accept that.

**Mr Cope:** The point is that it is a common thing to say or it is a common view held in the community that people who have psychiatric conditions automatically do not have capacity. We spent a lot of time arguing trying to change that view and against that proposition, so we see no reason why people who have a psychiatric condition—and it is the sole reason—should not be able to access the system, but they should of course have additional medical oversight and special psychiatric oversight in relation to that because, as is noted in the submission and would be the case if you had a physical condition which led you to be depressed, those sorts of medical conditions alter your perception and alter your understanding of whether or not you are going to get better. That is the point of having the extra thing, particularly in a situation where the sole condition is psychiatric. Where it is solely psychiatric, those issues are going to become even stronger we would think.

**Mr HUNT:** Thank you.

**CHAIR:** We will come back for supplementaries if there is time.

**Ms PEASE:** I want to thank everyone for coming in. I really appreciate all of the effort that you have all gone to. It is great to see you here today. Many of the submissions and also many of the conversations that I have with people in my community who come and speak to me about it all have a perception of having the desire to be able to choose to die with dignity and many of them speak about having a living will. I think their perception of what this inquiry is looking at is into a form of voluntary assisted dying. Having said that, people who currently have a living will in place do believe that they have an opportunity to say how they are going to end their life whereas in reality it is an irrelevant document from my understanding. Could anyone comment on that?

**Mr Brown:** By a 'living will' are we meaning an advance directive?

**Ms PEASE:** They actually call it a living will.

**Mr Brown:** A living will, because often people would come to us and say, 'I have a living will,' but what they are really saying is that they have an advance health directive.

**Ms PEASE:** Certainly. Whatever name it goes by, the general public call it a 'living will'.

**Mr Brown:** If it is an advance directive, yes, you can certainly put in place your wishes and directions with regard to certain medical conditions and life-limiting—

**Ms PEASE:** That is treatments, but many of these people in their advance health directive or the living will say if they have a stroke and they lose capacity or if they get dementia and they lose capacity or if they have an accident and they lose their legs or they have some other life-threatening injury such as an acquired brain injury they want someone to take their life. That is what they are making statements about with these living wills and at this point in time in Queensland, and from my interpretation of the Victorian legislation, it still is an irrelevant document.

**Prof. White:** I guess the observation we would make here is that you are talking about advance requests for voluntary assisted dying, because obviously the advance health directive can lawfully refuse life-sustaining treatment and there are some issues about the extent to which those documents are respected by health professionals and also the law that allows health professionals to override them. That is one issue, but you are talking about the issue of advance requests for voluntary assisted dying.

**Ms PEASE:** Yes.

**Prof. White:** Our point on that is that our draft bill, which you have before you, requires the person to have capacity at the time that voluntary assisted dying is provided. We had contemplated the fact that the issue of advance requests is a challenging issue in relation to, as Lindy mentioned, children. The debate and discussion in Australia really has been about competent adults at the time when they are seeking voluntary assisted dying that they have capacity to do that, and certainly our bill reflects that position.

**Ms PEASE:** That is fine, and I understand that. However, my question is this: is there any capacity for that to be taken into consideration? That is really the conversation that I have with people in my electorate and anyone who wants to talk to me about it—that is, they have the opportunity for what they consider to be dying with dignity in that they have a choice. Currently, the legislation in Victoria has fairly rigid rules around how you can and cannot go through that process. Your draft bill is the same. Many people in the community have an expectation that this is going to be something more than it is. The cases of dementia are growing exponentially and that would mean that anyone who goes to the effort of preparing a living will is really doing nothing.

**Prof. White:** We could say that at least in relation to withholding or withdrawing life-sustaining treatment that would have some effect in that regard which would ultimately lead to the person dying. I guess that is a policy question for the committee. There are legal regimes which do permit advance requests for voluntary assisted dying. The Dutch one is one example and, again, this is a useful area where there is some evidence as to how that is used in practice. It is not used a great deal in the Netherlands where advance requests are not frequently acted upon, even though the law does in fact permit that.

**Mr Cope:** I should say that our submission supports this model and so therefore supports that you should have capacity. If you have capacity at the time you make the decision, that should be sufficient. The problem is, as has been discussed, that, even under the advance health directive saying that you do not want to be treated in certain circumstances, although it is a legal document, in practice what actually happens is another matter. Our position is the Dutch position—that is, you need to have capacity when you make the decision about what the circumstances are. We would say that an advance health directive should be capable of being applied to this situation, but what you are saying about what actually happens when you are in that situation I think are two different things.

**Ms PEASE:** Thank you. Sarah?

**Ms Vallance:** There are differences in terms of an advance health directive to access a VAD scheme as opposed to an advance health directive making a decision about the withdrawal or withholding of life-sustaining measures. The ALA does not support a VAD scheme where a person does not have capacity. A person would not be able to make an advance health directive to that effect. There are a number of problems with a formal advance health directive in Queensland. There are a number of requirements that must be met when it is a directive about a decision to withdraw and/or withhold life-sustaining measures. Even if it is valid, a medical practitioner can choose not to follow an advance health directive if they reasonably consider that it would be inconsistent with good medical practice. There are no comprehensive and nationally consistent ethical standards that guide practitioners as to what good medical practice is. In fact, the few tribunal decisions that have considered what that means have focused on whether there is a net benefit in treating the patient. Even if the doctor decides that it is inconsistent with good medical practice, section 66 of the Guardianship and Administration Act sets out the order of priority in how decisions are to be made. There is no section there that allows a doctor to make the decision. If an advance health directive has been made it must be followed. If not, it goes down the order of priorities.

There is also the issue of whether advance health directives are followed in practice. The Metro South Hospital and Health Service has developed a statement of choices form. That is why we think it is very important that common law directives are recognised again. It is an ongoing conversation between someone who is at the end of their life and their treatment providers. Their choices may change, so you want a system that is flexible. Of course you only want a directive to be followed if the person intended it to apply in that particular situation. Our view is that the common law system provided those protections and would work better in practice.

**Mr Brown:** I think we would share Professor White's view as well, that really you would need capacity at the time. Advance health directives have not had a great uptake in Queensland. There is a current review of those processes, as the committee would probably be aware. The other thing is that our members often find in practice that you will do an advance health directive or enduring power of attorney and appoint someone and maybe make a directive in those documents, but when do you review them? Quite often they sit in a drawer. They might be on the Viewer for the Metro South HHS, but is that the current document? There is no register of them apart from certain health services putting them on their electronic files.

We would also advocate that these are issues in general that should be reviewed on a periodic basis. You could have an advance health directive that is some years old, but your views may have changed. Technology may have changed. I do not think we promote individuals reviewing those documents. It is like wills to a certain extent. You think that once you have done them you have ticked the boxes and everything is settled, but it does not always work that way.

**Prof. Willmott:** I have a quick comment in relation to AHDs. I support the comments that have been made. The current legislative regime is not working well in that there are too many restrictions which may mean that, where a person is trying to refuse treatment, an advance health directive will not operate. There are restrictions in sections 36 and 103 of the Powers of Attorney Act that allow doctors to disregard it if it is inconsistent with good medical practice. I do think it is in urgent need of change. I also agree that if the Queensland system acknowledged common law advance health directives that would address some of those concerns as well.

I would also like to make a comment about the Dutch system. That is probably the most liberal system in relation to advance health directives. As Ben said, although it accommodates making an advance health directive for a voluntary assisted dying request, it will only operate in practice if the person, although they may have lost some decision-making capacity, is still well enough to make a request for assistance to die plus the doctor still sees them as suffering. If there is a severely demented person who is quite happy in their demented state, that person would not, even under the Dutch system, receive assistance to die. The Dutch system is the most advanced in that regard.

**Mr McARDLE:** Rebecca, I want to talk to you about elder law. We assume that VAD is for the older population generally speaking, but of course it is not. It is right across the spectrum. Can you give us some idea of the protections that you would like to see in place in any legislation here in Queensland?

**Ms Anderson:** We do need to protect the vulnerable that we have been speaking about already. I think the member for Lytton's comments with regard to dementia and the ageing population absolutely play into that space. That is probably why we feel that there does need to be a capacity perspective and that the advance health directives would perhaps be problematic in that space. You could create an advance health directive in your sixties and then be in your seventies or eighties and living a fairly good life, but because we have had this diagnosis other people might then enact that document and make some decisions with regard to your end of life and it may not recognise how you feel at that time.

Absolutely there is an ageing population. The uptake of these documents is quite low. We also do have concerns about them being understood fully by people even as they are completing these documents. We have significant concerns about people completing forms and not really having an in-depth discussion with the witness, family members around them, their treating doctors and so forth to have a full understanding of what they are saying yes and no to.

**Mr McARDLE:** What would you include in the proposed bill by way of protections for elder people or people generally in relation to the misuse of an act of parliament that allows voluntary assisted dying?

**Ms Anderson:** We found that the bill presented by Ben and Lindy is quite a good bill to begin with. We did not find that the restrictions they are proposing are too onerous on this age group, and we found that they do provide suitable protections for our vulnerable cohort.

**Mr McARDLE:** Can the committee take on board that the Law Society endorses the protections contained in the bill proposed by professors White and Gillmott?

**Ms Anderson:** I feel that we support it in principle. We have found that there are a couple of things we would like to have further discussions about. Obviously this is not going to be the final version. I am sure that in time those things will be looked at. We find that this is a very useful bill moving forward from the Victorian piece of legislation.

**Mr Brown:** It is a good start. One of the areas might be to ensure that a witness does not have a pecuniary interest in whatever decision the adult makes. There can be interests if the adult decides to undertake voluntary assisted dying or whether they do not. There could be strengthening criteria about who the witness is. We like the regime where there are a number of steps around capacity. There should be an avenue if people have concerns about capacity—whether it is an application for a declaration to QCAT about someone's capacity—that should be built into any proposed legislation.

**Mr McARDLE:** Unpacking the draft bill, you would say it is a good starting point but not the end point at this point in time.

**Mr Brown:** Exactly, yes.

**Mr McARDLE:** Palliative care has been discussed at great length across this committee. I note that in the Council of Civil Liberty's submission you state, 'In the Netherlands, two-thirds of requests for voluntary assisted dying have been reversed, often as a result of effective palliative care.' Clauses 18 and 23 of the draft bill state that the relevant practitioner must advise the person seeking the declaration of palliative care options. I think it is uniform across the witnesses here today that palliative care in this state needs to be enhanced and perhaps also explained in greater detail as to what it can achieve; is that correct?

**Prof. Willmott:** I think that is very important. I do note that that would mean that a person who is requesting voluntary assisted dying may indeed, if this proposal is adopted, be more familiar with some options at end of life such as palliative care. That may well mean that they do not want to proceed with a request for voluntary assisted dying. I think you have accurately summarised what we are suggesting in the bill.

**Mr Brown:** Yes, we would agree that those options should be made available.

**Ms Vallance:** We agree too.

**Mr Cope:** We agree. That is in the submission.

**Mr McARDLE:** Does that mean that when this committee goes to discuss the issue of voluntary assisted dying and we consider a potential recommendation that a bill be prepared, that discussion takes into account a discussion of palliative care needs as well?

**Ms Anderson:** Yes.

**Prof. Willmott:** Yes.

**Prof. White:** Yes.

**Mr McARDLE:** Does anybody say no? Let me put it that way.

**Ms Anderson:** If I could add one thing. The research that we found from the federal government said that only two per cent of Australians living in aged-care facilities access palliative care. That is in contrast to the fact that 71 per cent of the occupants die in aged care. A substantial number of people are not benefiting from palliative care.

**Mr McARDLE:** I think the other point is that, from what I have heard from the public, there is little knowledge of the value of palliative care or what it can do. Palliative care is not just a week before death occurs; it can be years, as the case may be, based on a diagnosis of a terminal illness and what can flow from there. I think that joining of discussions is very important going forward.

I want to talk about the question of ratios. This has been brought up by the Law Society. You talk about ratios and skill sets on page 2 of your submission. One of the concerns I have is what model would we follow in setting the ratios? I will give you an example of what I am talking about. You may have an aged-care facility with 60 beds and it is aged care alone. Next door is a facility that has 60 beds: 10 dementia, 20 hostel and 30 aged care. They are the same bed numbers, same location, but completely different dynamics. How do you set a ratio in those circumstances? More importantly, who sets the ratio?

**Mr Brown:** That is maybe not a question so much for the Law Society because it is more of a practice issue for healthcare providers. I would say if you have X number funded dementia beds or X number funded general resident accommodation, that ratio would be based on the make-up of your residents. We also heard back from some of our members that—and ratios were thrown around during our discussions—during certain times of the day there are different needs. At night do you need to have two RNs or an EN? I think that is one more for the health providers. As a summary, as you have illustrated, the make-up of the beds and the clientele you have depends on their needs.

**Ms Anderson:** I think you would also have to look at the disability sector and see what they are doing in this regard. Queensland Health has ratios for nursing and so forth. I think you would have to have a look at what other regimes are doing with regard to making sure the quality of care is adequate for people.

**Mr McARDLE:** We may ask Queensland Health those questions as well. I think the distinction between hospitals and nursing homes is vast—absolutely vast—in the type of resident or the type of patient and comorbidities et cetera. I want to go back to professors White and Willmott and conscientious objection. You cover that in clause 38 of your proposed bill. You quite rightly say there that if a practitioner has that objection he or she is not required to perform certain functions (a) to (d). You then say that the practitioner must then disclose the fact that they have a conscientious objection. Then you say—I will insert the word 'must'—and must offer to refer the person. One of the problems I have is this: even though you look at clause 3, leave clause 3 out, in clause 2 what you are saying is that if a practitioner has a conscientious objection they then have to offer to provide information. I find that very difficult to accept because if you have a conscientious objection you are then imposing upon them an obligation—by the way, I can offer you advice as to where to go to. This issue arose in the termination bill as well. Did you mean that they have to offer or if they are asked? I am trying to clarify it.

**Prof. White:** Our intention was that that is required. This provision is based on the Termination of Pregnancy Bill that you are referring to but it is, in fact, less onerous on medical practitioners because under the first bill you mentioned there is a duty to refer whereas in this instance we thought it would be sufficient to provide information to enable someone to have access to that service. The rationale for this is this is the usual way, indeed this is probably less onerous than the usual way that medicine balances the issue of conscientious objection. It respects the choice and conscience of the individual medical practitioner but at the same time if voluntary assisted dying is a lawful health service

then access to it should not be impeded by a person's individual views. This we thought struck an appropriate balance between respecting conscience but also not impeding access to what is lawful health care.

**Mr McARDLE:** Refresh my memory, does Victoria or WA differ in relation to this clause? Does one of them simply state that you can object based on conscience full stop?

**Prof. White:** That's right. In Victoria, and Lindy might talk about Western Australia, the relevant provision basically creates a right not to participate in any way, but that is where the legislation ends. There is nothing further.

**Mr McARDLE:** There is no positive obligation from there on?

**Prof. White:** That's right, and our concern there was that in some instances that may have the impact of impeding access to care. What about in terms of Western Australia?

**Prof. Willmott:** In Western Australia the recommendation is that if a person has a conscientious objection they must notify the person immediately upon their request and, in addition, they must provide sufficient information to enable that person to access information about voluntary assisted dying. They have gone further than Victoria.

**Mr McARDLE:** A bit like your proposal, to an extent?

**Prof. Willmott:** Yes, very similar.

**CHAIR:** Just on the same track as the deputy chair, the institutions that I talked about earlier, what is the viewpoint there when you say your draft bill allows for people to be referred. In the same context, what do we do with what we heard yesterday in regard to some institutions refusing?

**Prof. White:** Our proposal is to strike that same balance. Entities that may have an objection to voluntary assisted dying occurring on their premises do not require them to do so but we do think it is appropriate, again in line with access to what would be a lawful health service, that they offer and facilitate if requested a transfer of care or otherwise access to a medical practitioner who would be willing to provide voluntary assisted dying. Again, striking that same balance.

**CHAIR:** That was clarified. Some of the providers yesterday did articulate that they would transfer. I will go back to the deputy chair.

**Mr McARDLE:** One of the submissions, and I cannot recall whose it was, raised the issue of counselling and endorsed counselling. That was the Law Society, was it?

**Ms Anderson:** Yes.

**Mr McARDLE:** That was also debated in the termination bill and it was rejected through the debate. There is a distinction though between what we are talking about here and termination to an extent. Can you explain why counselling should be part of a bill going forward in relation to voluntary assisted dying?

**Ms Anderson:** The concept was that counselling should be made available but it not be mandatory to take it up. The reasoning behind it was that some people will know their mind and have had this firm view for a long time, other people may need to have some discussion around what they do want to do and what their options are. It was also part of the earlier discussions around whether the counselling might also form part of their consistent views about what they were choosing to do. When we were putting that submission together that was part of whether a future bill might hold something around documenting their views. Perhaps these visits with the counselling and having that part of that might go towards documenting that for them.

**CHAIR:** I started earlier with a question to go back to in regard to the Victorian bill and the proposed Western Australia bill in terms of where you could see improvements. One of the things I note, and particularly coming from our vast state of Queensland with geographical challenges not unlike Western Australia, is the recommendations from that ministerial expert panel talks to not having two doctors but a nurse practitioner and talks to using, I believe—I will have to go back in depth and read it—being able to access via telephone, Skype or any other mode of communication. I think there have been some issues raised at law in regard to doctors using forms of communication in Victoria that could be challenged. Can you talk to some of those points and does your proposed bill go that far?

**Prof. Willmott:** I will deal with your second point first. There have been some media reports over the last couple of weeks about issues relating to Commonwealth legislation which prohibits certain communications. This legislation was passed in 2005 and it criminalises certain activity in terms of promotion of assisted dying through electronic means. There is concern that there is

technically some chance that people carrying on obligations or responsibilities under the Victorian legislation may be in conflict with this Commonwealth legislation which was designed some time ago for an entirely different purpose. There is that technical possibility. It would be useful if that were resolved and it could be resolved, for example, by the Commonwealth passing legislation exempting state legislation from coming within its ambit, I imagine. Our legislation does not address that. That is not an issue that can be addressed by legislation.

The second point you raised was in relation to the health professionals who can actually be involved in voluntary assisted dying. In Victoria they are specialist doctors or vocationally registered general practitioners. Our model largely adopts that Victorian approach. Under the WA recommendations they also contemplated that the possibility that one of the health practitioners who is assessing the person could be a nurse practitioner. I imagine that was done because of the vast state of WA and there were concerns about access issues.

**CHAIR:** Not unlike Queensland.

**Prof. Willmott:** Not unlike Queensland, although I am not sure Queensland is quite as vast. That is something that perhaps the committee might want to consider. At the time we drafted our bill we based on it Victoria as a default model so we did not explore nurse practitioners as a possibility, but if the committee were minded to do that they might also want to look at the experience in Canada, which is also a vast country. They have nurse practitioners there who are able to provide assistance. They will start to have some evidence from how that has worked in Canada.

**CHAIR:** Just to clarify, it would be your recommendation that the committee would have to make some kind of recommendation in our report to get the Commonwealth to amend its 1990 law?

**Prof. Willmott:** I do think that has implications for telehealth. I am not a constitutional expert, but I am not sure that that is something that the Queensland government can do anything about. I imagine it would be a request—recommendation—to the Commonwealth to adjust its legislation so any Queensland legislation would not fall foul of that or anyone acting under the Queensland legislation in a lawful way would not full foul of the Commonwealth legislation.

**CHAIR:** Would you be able to provide the committee with the exact legislation that you are referring to? Can you take that on notice?

**Prof. Willmott:** We are happy to do that, yes.

**CHAIR:** Are there any other viewpoints on that question? If not we will move to supplementary questions. Member for Nicklin, did you have another one?

**Mr HUNT:** It has been covered, thank you.

**CHAIR:** Is there any summarising of today's contributions?

**Mr McARDLE:** Or supplementary comments?

**Prof. White:** I did want to take 60 seconds just to pick up on some of the evidence that was discussed that may have been presented to you along the lines of, for example, societal burden and changing social norms and transforming this into a duty to die. My response to that would be, as I started, what does the evidence say? We now have systems in the Netherlands and Belgium and Oregon which have been operating for some decades. If people sitting in these seats are saying to the committee, 'Where will we be in 10 years? Will this be converted into a duty to die?', a whole bunch of what ifs, my response to that would be, well, what does the evidence say? We have jurisdictions, we have places we can look at and understand how this has integrated into the health system, how this has played out, so we should look very, very carefully at that evidence. By evidence I do not mean assertions such as, 'Look at what is happening in the Netherlands' or 'Look at what is happening in Belgium', I am talking about genuine, real, peer reviewed evidence that has gone through the process of testing. Only then can we be confident about those sorts of claims.

**CHAIR:** Are you able to provide on notice to us that succinct evidence that can back in those claims?

**Prof. White:** I am certainly happy to look at the evidence that is available on that point. My point was actually to people who are saying the what ifs and who are saying where are we going to go.

**CHAIR:** We need to have on it balance.

**Prof. White:** Absolutely, I am happy to do some research and provide information on that, but I think the onus rests on the person making the claim and if someone is making a claim that in 10 years this is what will happen, my answer would be well we have jurisdictions where this has been lawful for 10 years so what would it say.

**Prof. Willmott:** If I could have 30 seconds as well? At the beginning I mentioned that our bill departed from the Victorian model in some significant ways and some important ways and the WA recommendations are consistent in some of those matters that we have raised. If I could just finally mention a couple: one is in relation to the need to obtain permits. The pre-authorisation model under the Victorian legislation we are suggesting is overly burdensome without sufficient safeguards, if any additional safeguard, by requiring that permit process and the WA panel report also did not recommend a permit system.

Secondly, the prohibition on health professionals raising as a possible option voluntary assisted dying, which is section 8 of the Victorian legislation, we believe does not promote high-quality health care and that position was also adopted by Western Australia. The final point I would make is in relation to one of our submissions which is that to promote choice and also to promote safety, the mode of voluntary assisted dying should be self-administration, supervised by a medical practitioner or practitioner administration at the choice of the particular patient. Two main reasons for that are that it promotes choice but also promotes safety. WA did not go so far as that suggestion, but they did broaden the circumstances in which practitioner administration would be available and we urge the committee to have a look at that aspect.

**CHAIR:** Any other summarising points?

**Mr Brown:** The Queensland Law Society would share Professor Willmott's views around whether the person wishing to access VAD should be the one that initiates it and having a restriction on medical practitioners from discussing it. If there is a law that has been validly passed sitting on the shelf why should there be a restriction on medical practitioners providing patients with full options. We would also agree around the issue of permits, whether that is just another layer that may delay someone's suffering in the long-term.

**Ms Anderson:** If I could just add one more comment: We would also have a view that it would not necessarily be specific specialists that would be required. There was a discussion that it would be the ambit of the palliative care doctors who would be dealing with assisted dying, and our view is that it should not be limited to a particular specialty, it should be a doctor who chooses to be part of the program who would then go and get certified to become a voluntary assisted dying assistant in this space.

**CHAIR:** A provider, similar to Canada and Victoria. There being no supplementary questions, I thank you all very much for your contributions this morning. The draft bill is a good starting point and I think it has picked up on some other opportunities to expand or go into another draft, perhaps. There is a lot of work happening in the Western Australia recommendations for their proposed bill. I thank you all for your contributions.

**Proceedings suspended from 10.31 am to 10.47 am.**



**BUCKMASTER, Associate Professor Nicholas, Chair, Queensland Regional Committee, Royal Australasian College of Physicians (via teleconference)**

**STOKES, Dr Kaele, Executive Director, Advocacy and Research, Dementia Australia**

**ACTING CHAIR:** The hearing will now resume. I welcome Dr Kaele Stokes from Dementia Australia and Associate Professor Nicholas Buckmaster. We all have copies of your submissions, so I invite you to make an opening statement.

**Dr Stokes:** Thanks very much for inviting us here today. I am here representing Dementia Australia, which is the peak advocacy organisation for dementia in Australia. We represent people of all ages with all forms of dementia as well as their families and carers and we work with individuals and with families and members of the community to ensure that the voices of people with dementia and their families and carers are elevated in everything that we do as an organisation as a service provider, as an educator and as an advocacy organisation. For those of you who do not know much about the scope of what we do, we run the National Dementia Helpline which is a 1800 number that is available to anyone who has any concerns or questions or requiring information, support and access to services. We also run a range of service delivery programs, most of which are targeted at early intervention, so we tend to fill gaps in the market between more mainstream Commonwealth aged-care support programs. We also do have a mix of Commonwealth Home Support Program funding as well as some other national program funding and we do deliver respite as well on the Gold Coast here in Queensland.

We also run the Centre for Dementia Learning, which is an education arm of the organisation, and that is about working with providers to build capacity within the sector. We run a mix of accredited and unaccredited education to a wide range of people in the sector across the health, disability and aged-care sector, so we target a whole range of different components, and we also do that as part of the bigger consortium known as Dementia Training Australia which runs a wider range of education programs. Finally, as I mentioned, we are the peak body for dementia so we have a range of advocates across the country—that is, individuals who have a lived experience of dementia who are interested in participating in the advocacy work that we undertake by either sharing their stories or participating in focus groups, round tables, forums et cetera, so we have quite a broad array of activities.

**ACTING CHAIR:** Thank you very much. Associate Professor Buckmaster of the Royal Australasian College of Physicians, I invite you to make an opening statement.

**Prof. Buckmaster:** Our college trains, educates and advocates on behalf of about 17,000 physicians across Australia and New Zealand, with a further 8,000 trainee members. We represent a very broad range of specialties, including general medicine, paediatrics, aged care, palliative care and many other specialties that you will be familiar with. I myself am a general physician and respiratory physician working in the public hospital system. Our college has developed a statement on voluntary assisted dying that discusses particularly the issues and risks that may arise in the background of our end-of-life care systems and palliative care system. Because there is a diversity of views within our college membership, many of those views being held very strongly, the college has deliberately taken a position of highlighting issues and making recommendations related to those issues rather than taking a position of support or a lack of support for voluntary assisted dying and our statement to the committee has been guided by that position.

**ACTING CHAIR:** Thank you, Associate Professor. We will now move to questions.

**Ms PEASE:** Thank very much for coming in, Kaele. I really appreciate that and I acknowledge the great work that Dementia Australia does. I am really fortunate that in the bayside we have Glenys Petrie and John Quinn who are well known in the sector.

**Dr Stokes:** Indeed.

**Ms PEASE:** They do an outstanding job of making people aware of people living with dementia and how the community can embrace and work with them. John is a great advocate and a great example of what it is like to be living with dementia and I know that he travels extensively. Having said that, many of the comments that we have had back and the submissions that the committee has received show that people are very anxious about getting dementia towards the end of life and one of their main concerns is to be able to be given an opportunity that, if they are diagnosed and have to live with dementia, they would like to be able to have a choice in terms of voluntary assisted dying. At this current time in the Victorian model people need to have capacity. Can you pass some comments around that?

**Dr Stokes:** Yes. I had quite a bit to do with the early stages of the legislation as it was being developed in Victoria. Dementia Australia's position is neither for nor against voluntary assisted dying, so we believe in the ability for people to choose. Certainly in the initial conversations when the Victorian parliament was looking at the formation of the legislation, there were concerns around the ability for somebody at the later stages of cognitive impairment making an informed decision around that desire to end their life. One of the other challenges of course is that it is very difficult to predict the process of cognitive decline, so it can occur quite quickly in some people and it is a much slower process for others. Dementia is a fatal disease. It does ultimately end up killing you, but it is very difficult to predict that kind of end-of-life period in a very specific way and that is obviously what the legislation was looking at.

As you said, the legislation is not applicable to people with a cognitive impairment and there is not an ability for people to put their wishes into an advance care plan or to have a substitute decision-maker making those decisions, and there are obviously understandable reasons for that. We do have a number of people in Victoria that we have spoken to who are very disappointed that the legislation excludes them and their ability to put that in place. Of course, there are broader implications for anyone with a neurological disorder or a neurocognitive disease where their cognitive function may be impaired towards the latter stages of their disease process which rules them out from being eligible for that. Since the legislation has come into effect there have been some circumstances in which we are now finding that services are starting to make it clear as to whether or not they would actually support voluntary assisted dying in their facilities. I think the Catholic Church has indicated that it would not be willing to support those practices within its facilities. I am not sure if that extends to aged care as well, but there are some, I guess, unintended consequences in terms of the legislation and the way that it has been implemented.

**Ms PEASE:** Can you suggest a way forward for comfort for people living with a cognitive impairment?

**Dr Stokes:** In terms of legislating for something like this, the power of an advance care plan probably does need to be considered in that context. There are always going to be people who choose not to go down that path and who choose not to undertake a voluntary assisted dying process unless there is some kind of forward planning. A lot of the work that we do with people living with dementia, particularly at the early intervention stages, is around ensuring that they have a good plan ahead of them because most of the time they are getting a diagnosis at a point of crisis and the rest of their care tends to be occurring at a point of crisis such as either being hospitalised or having some kind of physical incident that pre-empts their need to go into residential care or receive some extra form of care. A lot of the work that we do with individuals and families is really looking at the ways in which we can put steps into place ahead of time when the person with dementia is still cognitively able to participate in those conversations and make decisions, and end-of-life care or palliative care—whether that includes voluntary assisted dying or not—should probably be considered in that context.

**Ms PEASE:** Just to change the focus for a moment, in terms of training for staff who are caring for people living with dementia, after an initial diagnosis they would be considered to be palliative because it is going to be a life-threatening condition even though it may be some time away. Particularly for end of life, do the people looking after people with a cognitive impairment require special training?

**Dr Stokes:** Absolutely. There is a couple of things there. Firstly, a lot of people do not recognise that dementia is a fatal disease and nor do they recognise that it is a disease. They just see it as a natural part of ageing, so we are already beginning with a general lack of understanding about dementia. In terms of receiving a diagnosis, often that diagnosis process is prolonged because GPs do not recognise the symptoms or do not feel comfortable having a conversation with somebody. The pathway to getting more thorough diagnostics is not necessarily always in place, so people's experiences of that can be very variable which means they are then not able to access services at that earlier stage.

In terms of end of life, generally across palliative care and end of life discussions do not occur early enough for anybody, let alone somebody with dementia or their families and carers. Some of the work that we focus on is really starting those conversations earlier while the person is able to participate, but literacy of dementia in the aged-care workforce, in the disability workforce and in the health workforce more generally is fairly low. About 70 per cent of people with dementia are receiving some or no care in the community. For those who are on home care services and supports, the majority of staff who deliver those services do not have any formal dementia training. The certificate III, which is the baseline qualification for people working in the aged-care sector, generally does not include a mandatory component of dementia education and it does not even sometimes have an optional component to it either, so it is not even an elective for people to undertake dementia training.

In the work that we do with the workforce and from what we hear from people living with dementia and their families and carers, we do find that an understanding of dementia and how to appropriately support someone with dementia is very much lacking and requires a huge amount of work. We are basically advocating for mandatory dementia qualifications, particularly given the fact that more than half of the people in residential aged care have dementia.

**Mr HUNT:** Associate Professor Buckmaster, in the RACP's submission you acknowledge the divergent views of your membership. You state that that 'constrains the RACP from developing a single position on the legislation of voluntary assisted dying.' It goes on to say, though, that the RACP takes the following unified position and your first point states—

Every patient should have access to timely, equitable, good quality end-of-life care, with access to specialist palliative care where appropriate. These services must not be devalued.

Do you think we are at that point yet?

**Prof. Buckmaster:** Unfortunately, there is no doubt that across Australia and in Queensland there is inadequate access to timely, equitable, good quality end-of-life care. There are shortages and underfunding of specialist palliative care services, both within the community and the state sector, and there is a significant shortage of both. As has been mentioned by my colleague from Dementia Australia, there is a relative lack of good training for end-of-life care, both within primary care and tertiary services.

**CHAIR:** Dr Stokes, I take you to recommendation 7 of your submission, which deals with family members being included in decision-making. I will get you to read it because I cannot quickly find it.

**Dr Stokes:** Recommendation 7 states—

That family members are included in assisted dying decision making with the person's consent and with the proper protections for the person.

**CHAIR:** This relates to someone with clearly diagnosed dementia.

**Dr Stokes:** Yes.

**CHAIR:** We just heard from the legal fraternity, and I do not know if you were here.

**Dr Stokes:** No, unfortunately I was not.

**CHAIR:** We had a discussion about capacity and decision-making. We have received thousands of submissions from people asking for the consideration of neurological diseases such as dementia to be included. We went to and fro with regard to advance healthcare wishes. People can make their wishes known when they have capacity, but the validity of those decisions once you have lost capacity comes into question. There was also a draft bill proposed. I find it interesting that you have asked that family members be included, and I get it because some of the people who are writing to us are asking for that as well. We have received advice that you have to have capacity. If we look at the Victorian model and the proposed recommendations of the ministerial expert panel from Western Australia, capacity keeps coming into it. Can you talk more about that particular issue?

**Dr Stokes:** I think that, as probably has been discussed earlier, someone with a neurocognitive disorder has a window of opportunity to make informed decisions about the future of their care. The way that is recorded and then honoured is problematic, particularly where legislation like the Victorian legislation does not include advance care plans or, indeed, substitute decision-makers in that legislative context. You can understand the legal reasons for that, but it effectively takes the choice away for people who have a neurocognitive disorder, which is what some people have concerns about.

In terms of the conversations we had in Victoria with people with dementia and their families and carers when the Victorian legislation was being debated, some people were in favour of voluntary assisted dying and some people were not. Again it really did come down to individual choice. Under the circumstances where a substitute decision-maker or an advance care plan is not considered to be reflective of somebody's earlier capacity and is not applicable at the later stages where they may not have capacity, then it takes that choice away. That is the challenge for people. It is a difficult one to solve.

**CHAIR:** It certainly is. I do not know if the RACP has a view on the last conversation?

**Prof. Buckmaster:** It is important that people are competent and have capacity to be informed in their decisions. If you have people who do not understand, first of all, what living with dementia entails and what the trajectory of the disease is likely to be, then they are only going to be able to make decisions on the basis of their own education, and that may well be very inaccurate. We obviously have concerns that, if people are making decisions, they are fully informed and they

understand the implications of their decisions. In the absence of capacity, that is very problematic indeed. We know that there exists carer abuse and elder abuse in our society, unfortunately, and we need to be very careful to make sure that there is no opportunity for that in any legislation.

**CHAIR:** I see that page 4 of your submission states—

Legitimate concerns exist around protection of vulnerable individuals or groups. Government, society and physicians must ensure that specific groups have equitable access to palliative and end-of-life care and that relationships of trust are not jeopardised.

I guess that speaks to that point you just articulated.

**Prof. Buckmaster:** It says more than that, because what we believe is also important is that any system or service is able to be extended to all of our population, and that includes geographical distribution. It requires that there must be adequate palliative care services available and that people are given real choices, not just desperate choices.

**CHAIR:** On page 5 you also state—

Patients seeking voluntary assisted dying must be made aware of the benefits that palliative care can offer at the end of life and referral to specialist palliative care should be strongly recommended.

In our report do you think that we should consider a recommendation that the best available palliative care be examined prior to making a decision?

**Prof. Buckmaster:** People need to be given that choice. It is critical that it is not just best available palliative care, but it should be best standard palliative care. The lack of good palliative care availability should not lead people to have to make desperate choices.

**CHAIR:** The availability of accessing good care is something we have heard across Queensland, particularly in rural, regional and remote Queensland. The member for Rockhampton has a question.

**Mr O'ROURKE:** Dementia Australia's submission explains that people at the later stages of dementia due to speech and other difficulties in communicating are often at risk of poorly managed pain. I have two questions. Would a palliative home care package system that sits alongside the federal government's home care package system work well in this area? What additional requirements would such a system need to be suitable for dementia patients?

**Dr Stokes:** I think this flows from Associate Professor Buckmaster's comments. Leaving the voluntary assisted dying part of the equation aside, particularly at end of life there is a fear of the disease itself but there is also a fear that they are not going to receive the appropriate type of care and support they need. Unfortunately, the sorts of stories that we hear and the sorts of things that are coming out in the royal commission demonstrate that dementia is not well supported in mainstream aged-care services, whether that be home care or residential care. There is definitely a shortfall of palliative care services across the board, particularly in regional and remote areas or for populations that may not be Anglo Saxon. For culturally and linguistically diverse communities who may have different cultural practices, a different understanding of death et cetera, those palliative care processes are even more difficult to access.

I think a system that sat alongside the Commonwealth system would be seen favourably by people who require palliative care services. One of the key challenges that we find in the work we do with people with dementia and their families and carers is navigating the system. That is really difficult for them. People do not tend to think in terms of funding buckets. Whilst those behind the scenes do look at it in terms of Commonwealth funding and state based funding, people just look at it in terms of the services that they need to receive. Making sure there is integration between those services and that there is still that coordination piece would be really important to ensure. We have funding to do a couple of navigator trials that are specific to people with dementia in WA and western Sydney working with CALD communities. That is really the first time we have looked at trialling something that supports people navigating the system and accessing the types of care and services they require. I think there would need to be that kind of consideration for a model like that.

**Mr O'ROURKE:** We have had a few discussions about staffing levels and ratios. Do you have a view on whether there should be a minimum staffing level?

**Dr Stokes:** In our submission we have avoided referring to whether there should be a staffing ratio or not. The concern is that, if you have a ratio of registered nurses mandated by legislation and those registered nurses have no experience in supporting somebody with dementia, then the quality of care for that person with dementia is not going to be necessarily better than it is currently. I think that everybody who has interfaced with the aged-care system would argue there needs to be more

staff. We would certainly support that position. There also needs to be more fulfilling career pathways for people to move into aged-care healthcare services, specialisations in dementia et cetera. There needs to be a much broader view of the workforce requirements.

We also find that for all forms of aged care in particular it is not just about the person delivering the care, it is about the cleaner, the chef, the person who is bringing people's meal trays around and supporting them through lifestyle activities. If they also do not have any understanding of dementia and the behavioural prompts that somebody might respond to, then the quality of care is still not going to be significantly changed. That is the kind of focus that we tend to take. It is really about education, the quality of staff and the quality of interactions with individuals that is important. If we are truly looking at person centred care then the staffing levels will be related to that person's needs. There needs to be a multidisciplinary array of staff who are interfacing with somebody to ensure they receive the quality of care they want and have identified together with their families and carers.

**Mr McARDLE:** Kaele, you started by saying that the training in this nation is very poor with regard to dementia. Certificate III is the base requirement and it is not even compulsory to study any dementia knowledge whatsoever and, of course, an RN may not have dementia knowledge as well.

**Dr Stokes:** No, that is right.

**Mr McARDLE:** In a submission made by the Australian and New Zealand Society for Geriatric Medicine they talk about medicines as follows—

Research shows that more than 80 per cent of aged care residents with dementia receive psychotropics ... even though as few as 10 per cent might benefit from them ... and only 10 per cent of the psychotropic drug use for neuropsychiatric symptoms in patients with dementia is fully appropriate ... while others might experience severe side effects such as stroke, falls or even premature death.

Tying the two comments together, your comment and that quote I just gave you, is the quote an outcome of lack of knowledge, do you think?

**Dr Stokes:** I think it is. It is also a lack of connection between different parts of the health and ageing sectors. Certainly in relation to the use of antipsychotics we would wholeheartedly agree with what has been read out in that statement. There is a chronic overuse of antipsychotics and they loosely get grouped as chemical and physical restraint. Whilst the legislation and operational guidelines et cetera at the Commonwealth level specify that they should be used as a last resort, it is clear that they are not. There is a disconnect between what is deemed to be good practice, because the majority of clinicians when you talk to them say that their use of antipsychotics generally is not particularly useful or appropriate for people with dementia and yet we still see those sorts of rates. There is a disconnect somewhere in the system in terms of the way they are applied and certainly the conversations we have had with family members and some people with dementia that are in particularly residential care settings show that there is not really sufficient engagement between the GP or the prescribing doctor with the aged-care providers and then the person themselves where they are able to participate in that conversation and/or their families and carers. That kind of consultative collaborative approach to care just does not seem to be in place.

Often families report that when antipsychotics are prescribed for their loved one they are either not informed at all, which actually goes against the legislation that there is not that kind of informed consent process being put in place, even if it can occur after the medication has been administered, that those conversations either are not occurring or that they are occurring in a context in which the provider is presenting it as there is no choice in this, we need to administer this medication. GPs are often reporting that they do not have a full background of the individual and they are being brought in in an emergency situation to calm a particular behaviour down, that they will prescribe under those circumstances but then the review process does not seem to be occurring. Providers will say that they are just following the prescribing instructions of the general practitioner or the specialist that has provided that. There are a lot of missed opportunities for there being a more collaborative decision-making process.

**Mr McARDLE:** Would you say that the use of chemical restraints is more widespread across the aged-care sector than just in the dementia section?

**Dr Stokes:** I am not really sure about the aged-care sector more generally, but certainly for people living with dementia, particularly where they have changed behaviours or BPSDs, behavioural and psychological symptoms of dementia, because there is a lack of understanding in the workforce about other ways of interacting with somebody or addressing a particular changed behaviour, the resort is to go to a chemical intervention. Having a more well-trained workforce that actually understand how to support people's changed behaviours through other mechanisms, diversionary

tactics, the way that they talk to somebody, body language, simple things like that, can—not in every circumstance but in an awful lot of circumstances—ameliorate the need to look at other interactions or other interventions because you can change behaviours through the way you interact.

**Mr McARDLE:** Would you say a certificate III holder is not qualified to deal with dementia patients?

**Dr Stokes:** I do not think that is necessarily the case given that the majority of the workforce are generally certificate III trained. There are some basic fundamental components to dementia education that would ensure that those engagements can be meaningful. I think the key thing for somebody at a certificate III level, and I am sure my education colleagues would probably have a more informed view on this, would be for them to understand when to elevate the care needs of somebody to their managers, so not necessarily be making medical decisions or behaviour related decisions but know when to escalate those.

**Mr McARDLE:** A patient with dementia accessing voluntary assisted dying, you would support that as a principle—provided they have made the direction beforehand?

**Dr Stokes:** We support people's choice to have that option.

**Mr McARDLE:** Can I tease it out a bit. A person pre dementia signs the directive that if I do develop dementia I should then access voluntary assisted dying. Somebody at some point in time, a doctor, has to make the assessment that the person is at that point, but is that the only question? Is a second question is the person now with dementia living a life that for all intents and purposes where they are happy? It is a very unusual word to use, but I want to try to distinguish is simply getting to a point of having dementia the trigger or does there need to be more assessment of the patient before that directive is put into effect?

**Dr Stokes:** I think there needs to be more assessment. Quality of life is always difficult to define and it is very much based on the individual's perspective and perception of what quality of life is, but I think then that maybe becomes the core of the conversation around what are the quality of life measures for me as an individual. When I can no longer eat or drink, is that what I define to be the end of my quality of life? Is it if I am not able to eat without aspirating, is that how I define the end of my quality of life? I think probably that initial conversation needs to look much more deeply at what those measures are which again, as I say, is still a complicated process to work through but I think there are some metrics that quality of life could be determined by.

**Mr McARDLE:** Is that where the discussion with the family becomes very important in the pre and post position of the patient, shall we say?

**Dr Stokes:** Absolutely, yes. I know we do have incidents where there is elder abuse and that family members play a large role in that so obviously there still needs to be safeguards in place to ensure that that is not occurring. The best care outcomes by far for people living with dementia, particularly at the advanced stages of cognitive impairment, tend to be when the family is involved because they know the person the best and they know what their likes and dislikes are and how to work with care staff to ensure that their quality of life is maintained.

**Mr McARDLE:** In many ways they can make a judgment call on whether they believe their loved one is in a state where their quality of life is still positive.

**Dr Stokes:** Yes, that is right.

**Mr McARDLE:** Professor Buckmaster, you make comment on page 6 of your document that you do not believe a medical practitioner should be required to refer a patient on if they have a conscientious objection to voluntary assisted dying.

**Prof. Buckmaster:** That is correct. In relation to that, we believe that if you have a mandatory rule for many physicians that would be an impossible ethical dilemma. Having said that, they should not be hindering patients accessing such services and it is important that there is the ability for the patient and their family to access information as to how they could have alternative referral pathways.

**Mr McARDLE:** What you would say is they cannot positively refuse to provide information?

**Prof. Buckmaster:** That is correct. Having said that, that should be at the level of providing guidance to the patient as to where they can find information about such services. They would not be able to be directed to actually provide an opinion on those services otherwise it would be very difficult for those practitioners to practise.

**Mr McARDLE:** You would then recommend a central information source or scheme be put in place that patients can access to obtain information as to which facility or which practitioner can assist in that regard?

**Prof. Buckmaster:** That has been our view on the basis that obviously the actual register of practitioners needs to be quite carefully protected to avoid harassment from those in the community particularly who hold strong views and who at times direct those views towards individuals.

**CHAIR:** As there are no supplementary questions, I thank you both for your contributions today. It is deeply appreciated in helping inform the committee going forward.

## **PERRON, Mr Marshall, Private Capacity**

**CHAIR:** For those members of the audience and those watching the live stream, Marshall Perron was a member of the Northern Territory Legislative Assembly for 21 years from 1974, serving as minister for much of that period and chief minister for eight years. He is also the architect and sponsor of the first voluntary euthanasia law, the Rights of the Terminally Ill Act 1995 in the Northern Territory. Welcome, Mr Perron. Twenty-something years later you are seeing advances now in what you started. On our record your act was probably the first legislative change in the world in regard to legalising euthanasia. I will let you speak to what is happening two decades later in Victoria, Western Australia and what we are considering at the moment. You have a depth of knowledge on the subject and we welcome you here today. Would you like to make an opening statement?

**Mr Perron:** Thank you, Mr Chairman. Thank you for your comments and I thank the committee for the opportunity to address you today and for specifically the time that you have allowed me to do this. My written submission only refers in passing to the case for VAD—I will use that term, if I may, to save a few words. I will leave the subject of the case for to others who are more qualified by way of personal experience than I am. My comments today are given on the basis that the committee may accept the need for law reform and move on to consider what form it should take. I gather from evidence this morning that the committee is getting to that point, if it has not been there for a while.

For the past 20 years I have observed closely the slow progress of attempts to reintroduce VAD in Australia. I believe some of the reluctance by politicians to embrace the issue, despite the massive public support and humanitarian need to act, is the mistaken belief that legalising VAD is a very complex, hard thing to do. In fact, it has been considered too hard. Committee members could be forgiven for thinking that, considering the mountain of evidence that has been presented before

I want to present an alternate view, a pathway through the noise that comes with the reference that you have before you. The starting point is a clear picture of what such legislation aims to achieve. Everyone knows how to kill themselves. People are doing it every day, mostly violently and always alone. Even more people fail in their attempt, some making their plight and remaining life even worse. A tranquil death can be achieved. However, the ideal means to do so, the Holy Grail, is denied us by government decree.

Basically, all VAD legislation does is permit a tiny minority of competent adults to briefly possess a currently banned substance and indemnifies the doctor who supplies the substance and, in some cases, for helping the person administer the substance. All the fuss we hear about how legalising VAD is going to fundamentally change society as we know it boils down to changing the relationship between two people—two consenting adults.

Legislators wanting to move forward need to decide three things. First, is there a group in our society whose plight is so irretrievably bad that they reasonably want to end their lives—individuals who should be allowed access to the product currently denied them? If the answer is yes to that question—and it clearly is—the second step is to define the group. Does an applicant have to have a terminal illness or does eligibility extend to the incurably ill? The third step is deciding on the nature of assistance allowed—whether the patient must self-administer the medication, as in Oregon; or can a doctor administer but only if the patient cannot, as in Victoria; or can either the patient or doctor administer contingent upon agreement between them, as in the White-Willmott draft bill, which I will mention again shortly? Once those three decisions are made, the rest of the safeguards exercise is simply 'tick the box': how many witnesses do you want, cooling-off periods, psychiatric examinations, permit applications, forms to be filled in, the involvement of interpreters, second opinions et cetera et cetera?

Obviously there are several models to guide you on these matters. There is no right answer. They will all work. Opponents will do everything they can to overregulate and complicate the process. They will argue that there should be witnesses to witnesses. Resist them. Their aim is to make the law unworkable. If you do undertake the exercise of preparing a draft bill, I urge you to keep foremost in your mind the individual the legislation is designed to help. Most of the safeguards are not aimed at helping the patient. They are designed to keep everyone else comfortable—that no-one will get access to the prohibited drugs who parliament deems should not have access. It is too easy to load up the gauntlet of safeguards the already suffering applicant has to navigate to get the relief they desperately seek.

Lastly, I want to say that having studied every VAD bill and been involved in all of the campaigns for their introduction in Australia I consider the draft bill drawn up by Professors Ben White and Lindy Willmott, whom you heard from this morning, is the best I have seen. It is superior to the Victorian law and to the proposals by the Western Australia expert panel. That actually does not



surprise me. I have known Ben and Lindy for a long time and I regard them as probably the most informed people in the nation on the detail of this subject. The principal reason for believing that their bill is superior to the others is summated by the fact that, firstly, there is no estimated 'life left period' specified in their bill; that either doctor or patient can administer medication; and, thirdly, and importantly in my view, that the doctor must be present during administration, which was also a requirement of the Northern Territory legislation when it existed. That is the end of my opening remarks. Thank you, Mr Chairman. I would be very happy to answer questions.

**CHAIR:** Thank you very much, Mr Perron, for your opening remarks. Going directly to your submission, we have heard from some palliative care nurses who look after terminally ill patients, and we have received written submissions. We have heard from some palliative care specialists like Dr Will Cairns in Townsville, who is a VAD supporter after 40 years of treating people in palliative care. I was interested to read on page 3 of your submission—

The palliative care response to intractable pain and suffering is terminal sedation, a medically controlled process that is utilised close to the end of life, commonly without the explicit consent of the patient. In order to avoid accusations of intending to hasten death, the delivery of sedatives and analgesics is slowly titrated upwards, which means that control of pain and suffering may take some days to achieve. As nutrition is with-held, it can take up to two weeks for the patient to die.

That has been articulated in a substantial number of written submissions. You go further with the sentence—

Terminal sedation is, in fact, slow euthanasia.

I had a conversation yesterday with palliative care specialists sitting at the table and I concluded the same—that is, when you provide a cocktail, as they described it, of drugs, the end result is death. There was some debate over whether that could be termed as 'slow euthanasia', as you have put it here, but my conclusion after listening to them is the result is death. Clearly providing choice and compassion to someone who is terminally ill before going into this process is something that you would stand by in terms of us considering voluntary assisted dying in the legislation in Queensland. Do you want to speak to any of that at all?

**Mr Perron:** I am not quite sure of the actual question, Mr Chairman, I am sorry. I ask you to direct me to the point of what you are asking me.

**CHAIR:** In the deliberations yesterday I concurred that them providing those drugs is indeed what you have written here. Terminal sedation is in fact slow euthanasia.

**Mr Perron:** Yes; I understand, Mr Chairman. This has been a part of the debate forever of course. In fact, there is very little change in the debate today than that which took place in the Northern Territory 24 years ago. Very few things have changed over that period of time, except that public support has gone from about 75 per cent to 85 per cent. On the subject of whether terminal sedation is in fact what we advocates say is actually slow euthanasia, some palliative care experts of course will agree, but the majority of the palliative care industry defending their position will take objection to that terminology, so I think it is one of those issues where we just leave it. We say it is slow euthanasia. We do not understand why it is okay for somebody to die over days or weeks when they can die in minutes when the object is the same. If terminal sedation is commenced, I add with the concurrent decision to withhold nutrition—food and fluids—then there is only one possible outcome and to me there is only one possible intention, and that is the death of the patient. We probably will not win on this argument. It is sort of a semantics about terminology.

**CHAIR:** No, I was just interested in reading that. As a comment only, it is preceded by page 2 where you say 'doctors who act compassionately'—and we had this discussion yesterday—'to relieve intractable pain and suffering by accelerating death', and that is what I was trying to get out of the conversations yesterday. The end result is death and bringing it forward. They maintain it is about relieving suffering at end of life but, again, it is semantics I believe. We will open up for questions. I call the member for Nicklin.

**Mr HUNT:** It might be semantics to you, but I would suggest that the statement that the death of the patient is intended is where they would take tremendous offence. I accept that death may occur, but it really comes down to that one word, and that is 'intent', and that was what was made clear to us yesterday—that is, when they are providing palliative care what their intent is, and therein lies the difference, and I do not believe that is semantics at all. I believe that is quite clear.

**Mr Perron:** It is really a matter of the law, I guess, and the law says that if the intent was not to kill the patient then the doctor in a double effect means that the palliative care administrators are not in breach of any law and that is how it is happening today in my view. Dr Roger Hunt from South Australia—whom you may have heard of; he is a palliative care expert of many years standing and an advocate for voluntary assisted dying and I think is on the expert panel in Western Australia and Brisbane

was involved in Victoria as well—makes the point that the absurdity of the current situation as a palliative care person who has administered terminal sedation to patients is that while in your mind you might flash back from a genuine intent to relieve suffering, which it is, there is then an occasional hope during that period of days or weeks that death will hurry up. He makes the point that the law is absurd today—it is incoherent I think is the term Ben White uses—because you are swinging between abiding by the law and technically murdering another individual by your intent during the course of that process. No-one knows because these things are going on inside your head. Again, I think this debate is almost—I am sorry to disagree—about semantics because we know the facts of what happens in terminal sedation and we advocates say that it is a completely unsatisfactory response to intractable suffering.

**Mr HUNT:** And there are palliative care specialists who would disagree with that. Certainly they did not just talk about the legal requirements; I think one of them said yesterday being able to sleep at night. Morally within themselves, as you suggested, in their mind what their intent is is clear to them.

**Mr Perron:** Yes. Sorry, but was there a question there?

**Mr HUNT:** No, that is okay. I am finished. Thank you.

**Ms PEASE:** Thank you very much for coming in today and thank you very much for the great work that you have done. I am wondering if you could perhaps enlighten us with what the Rights of the Terminally Ill Act 1995 looked like.

**Mr Perron:** Yes. At the time there were no real models to go by when I decided to introduce legislation as a private member's bill and, having done some reading on the subject, I decided that the case for legislation, if it was limited to competent terminally ill adults, was a very clear case in my mind—a case of compassion. It was an argument that I could win. I believed that a competent terminally ill adult ought to be able to have the right to say, 'I've had enough. I want to go now. Can you assist me with the appropriate drugs?' You would never win the religious argument, but for the rest of the community I believed I could win the argument, and in fact I did. That left unsaid of course the other categories where you could say, 'If competent terminally ill adults can have it, what about people who are not adults, under 18s? What about the incurably ill and not the terminally ill?' I did not have the answers to those questions. Some questions are too hard, and you have spoken this morning about the problem of dementia and the possibility of advance directives that cover that.

In the Northern Territory I limited very much the legislation to competent terminally ill adults and the Northern Territory community had the debate very thoroughly. We were a small community of 25 politicians. Our electorates were only about 4,000 or 4,500 constituents in each. We were very responsive politicians. Even back in those days, even though the subject had not been on the agenda at all basically like it has been in Australia for some years, the community very quickly embraced it and the politicians very quickly got to know all of the arguments on both sides. In fact, it is interesting that very shortly after the draft bill was released there was an extraordinary outpouring of emotion from across Australia. It was almost like you had scratched society and it started to bleed. All of my colleagues and I were inundated with letters and calls from people desperate to tell their story. It is the story you have been hearing because I have read a lot of the submissions that have come before you.

In the worst cases, people have had to kill a parent. They had to respond because they watched their loved ones suffer to the point where they could not stand it anymore. They have had this information bottled up in the family for years. It has been happening ever since, and I am talking about 1995. There was an extraordinary outpouring not just from Northern Territorians, it was from across the country. There were letters you could not get through without choking up. That convinced me that we were on the right path. At that stage it would have been easy to pull out and say, 'It's all too hard,' but by that stage—some weeks after the draft bill was released—the opposition started to mobilise. I caught them completely by surprise. Once the churches and the AMA got a bit of traction they came back pretty savagely with their counterarguments. They were all of the same arguments you are hearing today.

We debated it thoroughly in the community. Individual MLAs polled their electorates, as Mr McArdle has also done, and they received a very clear message as to what they wanted to do. The legislation very narrowly passed the second reading. We went through a long committee stage and finally it was passed into law by a vote of 15 to 10. Very sadly, it was not allowed to stay on foot very long. It was on foot for nine months. Four people used it to die—one Northern Territorian and three from interstate.

If I made a mistake, it was probably not putting a residential requirement in the legislation. I did that for a good reason. I believed I was only legislating for my jurisdiction, which was the Northern Territory, but it seemed to me somehow wrong that if someone visited the Northern Territory and took ill in some way and was in a bed with the same condition as a Territorian, one entitled to voluntary euthanasia—it was full voluntary euthanasia, not just assisted suicide—and the person in the bed next to them was not, if the basis of this legislation is compassion then it should apply to anyone who was in the Northern Territory. For that reason we did not put in a residential requirement. I think that fact probably aggravated opponents in Canberra more than anything. It was stated that ‘you’ve legislated for the whole of Australia’. I suppose you could have said we were legislating for the whole of the world, because we were not stopping a Japanese tourist from taking ill in the Northern Territory either. However, that may well have made the difference between the legislation surviving or not, because it was only lost in the Senate by two or three votes. I think it was 35 to 38 in the Senate.

**Ms PEASE:** What was the catalyst for you to present the private member’s bill? Was there a personal reason?

**Mr Perron:** I have been asked that question about a thousand times. The answer is completely unsatisfactory to journalists particularly, because there is no terrible trauma in my history or someone close to me dying badly that led me down this path. I simply always believed for as long as I can remember that anyone who is suffering and close to death ought to be able to say, ‘I’ve had enough. Can I go now?’ I probably picked it up in a movie. It would not have been television, because the Northern Territory did not have as much television as you guys down here back in those days. It is just something I have always believed.

I had been in parliament a long time. I had been a minister for most of that time and a chief minister for a lot of that. Upon reflecting on my time in politics, most everything I had done up to that period—and we thought we did some pretty good things up there—could have been done by anyone else just as well. I have no particular expertise; I am not qualified in any field. I wanted to do something that was significant, that would make a fundamental difference to the lives of my constituents. This had always been in the back of my mind, so I did a little bit of research. In fact, I read a document that was so powerful I dropped it. I put it down and I said, ‘I’m going to do this.’ It was by Associated Profession Kelga Kuhse, an academic in Melbourne. I am not sure if she is a doctor or a professor, but she is a wonderful woman who presented a paper on why voluntary euthanasia should be legalised. To me it was such a powerful, logical argument that I just felt, ‘I’m going to try this.’ I was not at all sure that I would get the legislation through the parliament. I thought that even if I did not, I may advance the day when someone else would pick up the cudgel somewhere in Australia and move the matter forward. To me there was nothing to lose. By chance I almost made it, as it were.

**Ms PEASE:** You did for a little while.

**Mr Perron:** Briefly. Nine months.

**CHAIR:** It is excellent to have you here. One of the things I consistently ask caregivers who appear before us is: have you had people say, ‘I ought to have the choice.’? Have you had people ask if they could just end it? ‘I’ve had enough. It’s time to go.’ From my interpretation of the people who have come before us, the majority have experienced that in their clinical practice.

**Mr Perron:** Yes. At the end of the day we are only offering choice; it is as simple as that. I describe it as a law that does not require anybody to do anything. If you do not believe in VAD, live your life as if it does not exist. I know that is an oversimplification because a conscientious objector may have to say to a patient who asks if they would assist them, ‘No, I will not.’ Therefore, it is a law that does require someone to do something, but it does not require them to specifically act against their conscience.

**Mr McARDLE:** I also share the chair’s admiration for the fact that you are a man who has a very strong principled belief with regard to this matter and I congratulate you for that. You made the comment in your opening words that this was a bill that affected a tiny number of adults. That worries me a little bit because it seems to imply that if the number is small, it is okay. If the number is larger, that is the question mark. When a bill or an act of this nature impacts one person or 100, the question becomes a moral judgement, does it not?

**Mr Perron:** Let me respond this way. I will start from another end. People have said that politicians should act on this issue because 85 per cent of the community wants them to. I consider the 85 per cent simply a political bonus. I believe this legislation should pass if five per cent of the community wants it because it is an option to be taken by those people who want the option. We legislate for minorities all the time.

Getting to your point as to whether legislation would be good or bad based on the number of people who might use it, I use the term I did in my opening remarks. The facts seem to show that very tiny numbers of people will ever use the legislation, whether it is full voluntary euthanasia or whether it is assisted suicide. I think in Holland the figures have grown and about four per cent of deaths are now assisted deaths under their regime, whereas in Oregon I think it is 0.2 per cent of deaths. Those figures are readily available to you. There is a huge discrepancy which probably reflects, to some degree, the culture of those places. It might also reflect the legislation, because in Oregon it is hugely restricted to orally taken assisted suicide, whereas in Holland it is full voluntary euthanasia. You do not even have to be terminally ill, of course. You just have to be suffering badly.

I am not sure if I am answering your question. To me, the fact that in Holland the numbers grew for a while, I believe, and then levelled out and may be growing a little again now—some of the academic studies have reflected that people have been more comfortable with the option available to them and therefore more people are considering it an option available to them. While some would argue that is a bad thing, from my point of view—providing all of the applicants meet the criteria laid down—if they are all trying to avoid that futile period of suffering right at the end of life then the numbers do not bother me at all.

**Mr McARDLE:** I think we differ, because I still think you are relating it to few numbers therefore make it viable. I am not suggesting that I propose, oppose or support. I just do not like the idea that numbers are the criteria for a bill of this nature to be passed. I think that is a philosophical battle going forward.

**Mr Perron:** Let me say that I do not disagree with you. I do not at all. The criteria is purely whether people meet the criteria laid down in legislation. If they do, the numbers are the numbers whatever they are.

**Mr McARDLE:** The numbers do not matter, do they? If it is right—

**Mr Perron:** You are right. Exactly; they do not matter.

**Mr McARDLE:** You also said that there was a concern that passing this legislation or a legislation would not fundamentally change society. I think those are the words you used. I am not convinced that a bill of this nature being passed would not fundamentally change our society. Again, that may well be a point of personal debate between us, but also I do not think that is a basis to pass a bill of this nature.

**Mr Perron:** I am not sure if I put in the words ‘change society for the worse’, but that is really what I was trying to imply. The doomsayers in this debate had won up until Victoria. There have been 30-odd bills introduced in Australian parliaments, and I have watched every one of them go down. In many cases they have gone down on what Andrew Denton describes as FUD—fear, uncertainty and doubt. That is promoted brilliantly by its opponents; that is, basically that society will be changed forever if we embrace the paradigm where one human can assist another to die. They say that that is a fundamental line we should never cross. Of course we crossed it long ago when we started training our military to kill people. To suggest that life is sacrosanct in every circumstance is simply not true.

**Mr McARDLE:** I accept that. Let us go to the bill by the professors, which I think you are quite familiar with. Let us expand on that bill. Do you believe that a bill which may come to the parliament should also incorporate a pre dementia directive as well? That is, a person without dementia can issue a directive that if he or she develops dementia they should still qualify for access to VAD?

**Mr Perron:** Personally, I cannot see it happening in my lifetime. However, personally I indeed wish that I could see it happen. I believe that before we get to that stage we will move from terminal illness to the terminal and incurably ill, the quadriplegics and so on who beg to be killed by anyone who comes anywhere near them. That is an easier step to take than the one where somebody is assisted to die after they have lost competence. One of the South Australia bills did propose such a system of advance directives so that if a person lost competence after they made that request, their request could be fulfilled. It was one of the bills that failed. There have not been many attempts to do exactly that. There have been very many interesting attempts to be unique with legislation to cover an issue, a couple of which I could run through in my final remarks if I get a chance. Sorry, to step back.

I heard the debates this morning about dementia. I relate these things to myself and my family. We have no evidence of dementia or cases in the past, but personally if I am diagnosed with early stage dementia at any time—hopefully not—I do not believe that I am prepared to ever let the disease take its course. That leaves me with only one option, and that is to act very early in the piece. That

brings me to the point I was going to say if I had the chance. You probably realise that there are hundreds of people across Queensland who are preparing for their demise at their own hand because it has taken so long for politicians to act. There is a desperate search for information on how to die peacefully by your own hand. You have to do it alone, of course, and there are ways you can do it if you do your research. I know of a number of people who have assembled the necessary equipment, all because there is no legislation that they can put any hope on yet.

**Mr McARDLE:** My final question is this: there was a professor who was aged 104 who went to Switzerland, I think it was.

**Mr Perron:** Yes.

**Mr McARDLE:** He did not have, as I understand, a disease or any form of illness. Would you go so far as to say that a person who—it is only my paraphrasing—had reached a point in their life where they no longer desired to live without an impairment should access VAD?

**Mr Perron:** I find this one of the hardest decisions to really have a view on. I knew well of the case you mentioned. It is hard not to have sympathy for a man who lived so long that no-one who ever meant anything to him was alive and he was suffering a whole series of age related ailments, may I suggest deterioration, but none of them terminal. Life had reached a point where it had no meaning for him whatsoever and he had full capacity, full faculties of course. I just think it is politically unacceptable to suggest that we could include such situation in legislation at this point in time. I think in another 30 or 40 years when the world's population gets to about 10 billion there will be a different attitude in society towards people who want out for a variety of reasons, but today I just think it is a subject that is off the agenda.

**CHAIR:** Thank you very much for your significant contribution over the decades. Would you like to make some closing remarks?

**Mr Perron:** Could I make a closing remark on one issue, if I could. I am very pleased to see that Western Australia has moved down this path. I advocate that legislation should contain one special clause, or at least not prohibit a particular action, and that is what I call intravenous self-administration. The expert panel in Western Australia has, it seemed, picked up on the point that if we allow doctors not only to prescribe but also to prepare a patient for self-administration, in the legislation's wording, that would almost eliminate completely the need for a doctor to assist someone to die directly because today, of course, with technology you can activate a syringe driver with a blink of an eye, let alone a finger or any body movement. It would seem to me that the problem with regimes that only require self-administration a la Oregon leave the patient in a position where if you cannot swallow in that case then you are out of luck. I believe Oregon has an amendment coming forward for the first time in 20 years to allow intravenous administration.

It would be something that should be in any legislation that is considered because it will remove a doctor from having to act personally. It will allow the patient to take control of the situation in virtually every circumstance that I could imagine that someone would be competent. You can normally blink an eyelid even with advanced MND. Please bear it in mind.

**CHAIR:** Thank you very much for your contribution. It is certainly helping our committee in its considerations going forward. The deputy chair will be taking over this afternoon's session and that will be with the Public Advocate and representatives from the Human Rights Commission.

**Proceedings suspended from 12.04 pm to 12.46 pm.**

**BALL, Ms Julie, Principal Lawyer, Queensland Human Rights Commission**

**BURGESS, Ms Mary, Public Advocate, Office of the Public Advocate**

**HOLMES, Ms Neroli, Deputy Commissioner, Queensland Human Rights Commission**

**ACTING CHAIR:** I formally reconvene the hearings and offer the chair's apology for not being here this afternoon. We have copies of your submissions, but I would invite you to give a five-minute opening statement and then we will ask questions.

**Ms Burgess:** I want to thank the committee for inviting me to give evidence today in relation to these very important legal, health and social issues. Before I commence, I would like to acknowledge the traditional custodians of the lands on which we are meeting today and their elders past, present and emerging. I acknowledge any Aboriginal and Torres Strait Islander people who may be in attendance at the hearing today. I will also take this opportunity to briefly re-state some of the key issues that are the focus of my submission.

For the benefit of the committee and those who are not familiar with my role, the Public Advocate is an independent statutory position under the Guardianship and Administration Act. My key role is to undertake systemic advocacy to protect the rights and interests of people with impaired decision-making capacity. People can experience impaired decision-making capacity as a result of a range of conditions, including intellectual disability, acquired brain injury, mental health conditions and age related conditions such as dementia.

I am going to limit my comments today to two key issues, although my submission did cover a number of issues, including: young people with disability residing in aged care; a narrower regime for reporting deaths of people in aged care to the coroner than would apply to people receiving NDIS funded services; issues around decisions to move older people into aged care; and the need to fund advocacy services for older people who are the subject of guardianship applications so that they can express their views and have them meaningfully considered. I also raised issues around end-of-life care for people with impaired decision-making capacity, the general lack of knowledge of the law in this area and the absence of a consistent statewide approach to advance care planning and enduring documents which has resulted in the development of a potentially confusing range of advance care planning documents available to Queenslanders.

The two issues that I want to cover today relate to voluntary assisted dying. I do not profess to have a particular expertise in this area. I have read many of the other submissions. Certainly there are some very well-developed positions the committee has to consider. The point I would like to make is that any future legislation enacted should specifically require that a person must have capacity to request to die voluntarily. Further, while I support the concept of advance care planning for people to express wishes about their care and treatment after they have lost capacity, at this point I think there should be no provision in any legislation that is enacted that would allow advance care planning documents to operate to allow people to request voluntary assisted dying after they have lost capacity.

The other issue I want to speak to the committee about today is the use of restrictive practices in residential aged care. I do not think you have received many submissions in relation to this, but I am aware that the Queensland Law Society has raised it in their submission. I raise it because of its currency in terms of the royal commission, recent very disturbing media reports about the treatment of people in aged care, especially those who have challenging behaviours, and also because the Commonwealth government announced changes to address these issues which came into effect just this week. I want to explain to the committee why these changes are, from my point of view, wholly inadequate for addressing the issues around the way restrictive practices are being used. These changes also potentially create problems for Queensland agencies.

Restrictive practices can include a range of treatments of people, including detention, seclusion, restricted access to objects and physical, chemical and mechanical restraints. They are all types of restrictive practices that are currently used in the aged-care sector. They are routinely used in residential aged-care facilities across Australia, despite studies indicating that they may result in negative physical and psychological impacts on the person who is being restrained. They can constitute a breach of the law and human rights. The use of these practices has become such a customary aspect of the aged-care system that people have stopped questioning whether they are appropriate or lawful. The current situation in Australia is out of step with most other modern western democracies. Other countries, including New Zealand, the United Kingdom, Scotland, the USA, most provinces of Canada and most European states of the European Union, have formal legal frameworks regulating the use of restrictive practices in aged care.

Earlier this year, in response to those distressing media stories that I spoke about earlier and the evidence before the royal commission, the former aged care minister, the Hon. Ken Wyatt AM, committed to the improved regulation of chemical and physical restraints in residential aged care. However, the recent changes to the Aged Care Quality Standards and the aged care regulations which commence this week amount to little more than tinkering with a system that still leaves aged-care residents without proper legal protections and the system essentially unaccountable. We need appropriate regulation so these practices can be used within a proper legal framework that nominates an appropriate and accountable decision-maker and provides for appropriate review reporting and the protection of rights. The model should also include guidance to ensure that, when these practices are necessary, the least restrictive option is used for the shortest time possible and that it is applied in accordance with best practice standards. These are all characteristics of a model of restrictive practices recommended by the Australian Law Reform Commission in its 2017 report *Elder abuse—A national legal response*.

My concerns about what is happening to people in aged care have also been compounded by some material I have seen filed by the Commonwealth government with the aged care royal commission. The royal commission has a website where it posts all of the exhibits that have been filed with the commission. They are available to the public. There is an options paper on that site which was prepared by the minister's Aged Care Clinical Advisory Committee. It provided advice to the minister that consent to restrictive practices can be implied if the clinical circumstances and the proposed medication is discussed with the consumer and/or the substitute decision-maker 'before or at a reasonable time after prescription'. The circumstances outlined by this committee suggesting the way consent could operate do not amount to informed consent either in law or under any definition of that term in the healthcare sector. It is a legal and logical nonsense to suggest informing a person or their decision-maker after the event that the person has been administered a drug could be construed as obtaining informed consent for the purposes of administering the drug.

This committee's paper goes on to recognise that formal or implied consent is 'currently not commonly obtained by prescribing practitioners' in the aged-care sector. What this means is that many of the medical practitioners who are prescribing medications to chemically restrain aged-care residents are routinely doing so illegally. It is unlawful to administer any medical treatment to a person without their consent, except in an emergency. The concerns raised by the problem of prescribing practitioners not obtaining consent should also ring alarm bells when we consider that in the context of the committee's further acknowledgment that there is 'a problem with the overuse of antipsychotic medications and benzodiazepines in residential aged care', with about 90 per cent—90 per cent—of the current prescriptions unable to be justified. That is advice from the aged care minister's own clinical committee.

I think it is reasonable to comment that it looks like we have a crisis in this space in aged care. On 6 April this year, just prior to the announcement of the federal election, the then minister instructed his department to progress the options that had been put forward in that options paper, including the option dealing with the issue of consent. It is not clear what stage the investigation of this new approach to consent has reached at the Commonwealth departmental level, but I plan to write to the federal minister to make inquiries about where that is at and what direction has been given to the sector. As far as I am aware there has been no formal direction in this space, so the issue of consent is still floating unresolved. It is a complex legal issue, and aged-care providers need clear direction to be able to do what is right.

Another document prepared by the minister's Aged Care Clinical Advisory Committee for a meeting to discuss regulatory measures to reduce the inappropriate use of restraints was also filed with the royal commission. It states that Commonwealth law could require informed consent to be obtained but be silent on the process which it says is set out in state and territory laws. It suggests that the Commonwealth's approach to this very difficult issue is to rely on state appointed guardians and advocates to make decisions about restrictive practices in residential aged care without setting up an appropriate legal framework for these decisions to be made and also without consulting state guardians and advocates about the approach that it is taking or giving them an opportunity to air their concerns or to identify the potential impacts on their operations of these decisions now apparently defaulting to them.

I am aware that it has begun. This week the Public Guardian began receiving requests for consent to restrictive practices in aged care for people they have guardianship for. This is completely out of the blue for them. Considering what we now know about the problem of physical and chemical restraint in aged care, it is reasonable to anticipate that changes introduced by government, especially

the new and potentially dangerous definition of informed consent that seems to be floated, are unlikely to achieve the desired objective of reducing restraints in aged care and may actually result in an increase in inappropriate prescribing practices.

We all have the fundamental right to be free from physical restrictions and to our own bodily integrity. These rights do not diminish with age or infirmity. If any of the restrictive practices used routinely on aged-care residents was used on any other person in the community, those responsible would be liable to be charged with a criminal offence. We as a community should be outraged by the poor treatment and practices that we have allowed to proliferate in parts of the aged-care sector. After the evidence given to the royal commission, the Australian government can no longer deny knowledge of the poor treatment and care that is occurring in residential aged-care facilities as a result of inadequate standards, oversight and regulation. It has an obligation to protect the legal and human rights of older Australians in aged care. Today I respectfully request this committee consider raising these concerns with the Commonwealth government and call for it to act as a matter of urgency to address these issues.

**Ms Holmes:** Thank you for inviting us today to speak with you. Can I also acknowledge the traditional owners of the land on which we meet today and pay my respects to elders past, present and emerging. The Human Rights Commission, in making its submission in relation to the voluntary assisted dying portion of this inquiry, does not intend to make a submission on where parliament or the committee should land on the substantive matters raised in that regard. We make our submission solely to draw to the committee's attention the various human rights relevant to voluntary assisted dying. As a background, you all will be very familiar with the fact that the Queensland parliament passed the Human Rights Act 2019 and that the human rights in that act become operative on 1 January 2020. While the act is not yet in force in relation to this committee's deliberations, the parliament in passing the act has made a clear statement about the 23 rights it specifically seeks to protect and promote, and it is to those rights that we refer in our submission.

In essence, there are a number of rights that are relevant. An analysis of them suggests that, in relation to voluntary assisted dying, there is no one identifiable right that necessarily requires the legislation of voluntary euthanasia, nor is there one identifiable right that prevents it providing stringent safeguards are instituted. From a human rights perspective, the option exists to support legalisation of voluntary euthanasia practices provided that sufficient safeguards are put in place to prevent arbitrary, including discriminatory, deprivations of life. There is the need to have strong safeguards to protect against potential abuse. It is for parliament to consider the rights and to find an appropriate balance of the rights if it chooses to act in progressing the notion of voluntary euthanasia.

If legislation is to proceed, depending on the provisions' relevant rights that will probably need to be considered in a statement of compatibility, which is the new methodology that is in the Human Rights Act for parliament to consider human rights when legislation is brought before it, and it is similar to that in the recently passed Victorian model of voluntary euthanasia, the rights that will be engaged are recognition and equality before the law, the right to life, protection from torture, cruel, inhumane and degrading treatment, freedom of thought, conscience, religion and belief, freedom of expression, privacy and reputation, protection of families and children, and our new right in Queensland, the right to health services. Of course, we also need to consider the convention on the rights of persons with disabilities which contains specific obligations in relation to people with disability, particularly equality before the law.

Briefly, the right to life does not require a state to ensure a person's life is protected when this is against the express wishes of that person. In voluntary euthanasia, the state's obligation to protect life must be balanced against the right to personal autonomy which is contained in the right to privacy. If voluntary euthanasia is legalised, the right to life requires the legislation to contain strict safeguards against abuse. We probably already have a system of passive euthanasia in Australia. In relation to that, to subject a person to medical treatment against their will without their consent possibly may be cruel, inhumane and degrading treatment. My colleagues just related to that in relation to aged care when you receive medical treatment without your consent.

The disability convention makes it clear that people with disability are entitled to the same rights to life, health, physical integrity and personal autonomy as people without disability. If they wish to, they can also make their own decisions providing they have the capacity to do so. In terms of equality before the law, if a bill is passed or legislation is considered and there are eligibility criteria such as age limits, citizenship status or exclusions on the ground of mental illness or disability as referred to by my colleague, this right is relevant and a proportionality analysis will be necessary. The Victorian legislation excludes people under 18 years of age, people who have not resided in Victoria for a certain period of time and people who have mental illness or disability from making that decision. That



is discrimination on the grounds of all those criteria, but it may be relevant to discriminate in that regard when you look at the issues with the vulnerability of those people or people moving to the jurisdiction simply to avail themselves of a right to voluntary euthanasia when they may not have a clinical relationship with a medical practitioner who can appropriately support them through that decision-making.

Article 26 of our new Human Rights Act in Queensland provides that children are entitled to protection of their best interests. This is a relevant consideration in deciding what age voluntary euthanasia might be appropriate to allow. If the committee is particularly interested in the discussion about that, I refer it to the Victorian statement of compatibility on human rights about how you balance that right. I can refer the committee to the precise pages where they considered that. Of course, the right to freedom of thought, conscience and belief requires a conscientious objection provision in the legislation that will allow medical practitioners who do not agree with the euthanasia provisions not to provide that service to patients.

Freedom of expression was discussed in the Victorian statement of compatibility. It can be impacted if the legislation contains a prohibition on GPs or others initiating a discussion with a patient about voluntary assisted dying. That legislation does have requirements that say it cannot be raised by a GP, that you have to wait for your patient to raise the issue with you. There are other provisions in the legislation about people not initiating those discussions. Of course, that does put a limitation on freedom of expression but, again, that might be an appropriate limitation on that right. Again, I can refer the committee to the Victorian committee's charter analysis discussion of that point if it is interested. If the committee is interested in knowing more about the particular human rights considerations in relation to that matter, the commission is very happy to assist with that.

**ACTING CHAIR:** Thank you, Ms Holmes. Ms Ball, any opening statement from yourself or would you rather defer to Ms Holmes?

**Ms Ball:** No, I will defer.

**Mr O'ROURKE:** My question is to the Queensland Human Rights Commission. Your submission notes article 7 of the International Convention of Civil and Political Rights and in particular freedom from cruel, inhumane or degrading treatment. The committee has heard of numerous cases of people suffering in their final weeks after medical treatment has been ceased and of a patient being left by their medical practitioners to die by nil by mouth. We have heard instances of this taking up to 17 days. Do you think that instances of people dying like this could be in breach of article 7?

**Ms Holmes:** It is discussed in the statement of compatibility of the Victorian health minister when she introduced her legislation to the Victorian parliament. She came to the view that that right was not engaged in that legislation. That sort of issue is more about the right to privacy and personal autonomy. In her analysis, being able to control what happens to you as a person and making decisions about your personal autonomy comes under the right to privacy provision of the human rights legislation. She felt that that protection from cruel, inhumane and degrading treatment in her analysis of the rights that were engaged was not engaged by the bill, but her concern was where treatment was continued without a person's consent. The third limb of that particular provision—cruel, inhumane and degrading treatment—does specifically speak about medical treatment without full and informed consent. That would be where that right would be engaged. Certainly what you are talking about is a relevant consideration under human rights considerations, but the relevant right would be the right to privacy which is actually much broader than the concept of privacy would suggest. Those sorts of long, painful deaths certainly raise that right and a consideration of how that right pertains to that experience.

**Mr O'ROURKE:** In terms of aged care, there have been many reports of appalling instances of abuse occurring in aged-care facilities over the recent years. Do you think that article 7 could be in breach in those situations?

**Ms Holmes:** Our article 7?

**Mr O'ROURKE:** Yes.

**Ms Holmes:** Seventeen? Oh yes, most definitely. Of course, our Queensland Human Rights Act pertains only to public entities under the management and control of Queensland parliament. I am aware that about 15 aged-care facilities are managed by the Queensland Department of Health. When our commission is considering which public entities we need to educate about these human rights and make them think about these human rights when going about their daily business and operating their facilities, that right is certainly one that would be at the forefront of our discussing that right with those sorts of entities so that they are fully aware of how that might pertain to the things

happening in facilities. I not really aware of how well managed Queensland's facilities are. I hope they are very well managed, but of course those 17 or whatever number aged-care facilities that are managed by the Queensland government would have this right applicable to them. Unfortunately, until we get a Commonwealth human rights act in relation to the other facilities, unless they are under the control of the Queensland executive, these human rights whilst they should apply to them will legally not be enforceable in that regard.

**Mr O'ROURKE:** It is disappointing that it is not broader.

**Ms Holmes:** Yes. There have been lots of discussions about how important human rights are and we are a federation. Each state has control only over the matters they have control over, but I know that a lot of people we speak to in the community would love to know that we have a set of human rights that are universal to everybody in Australia and that are very similar to each other. Whilst each state and the Federation has its own agenda on how they want to pass that legislation, I think most Australians feel that they have human rights, even though they do not, and would want our human rights to be similar across every jurisdiction. Certainly, it should not really matter which aged-care facility you are in and who is running it. Your human rights should be the same no matter where you are.

**Mr HUNT:** You mentioned in relation to voluntary assisted dying the importance of the right of a doctor to be able to conscientiously object to taking part. Would legislation that then requires that doctor to refer to an alternate service that that doctor knows would provide that service impact on their rights? Would it be incompatible, particularly with say someone who works for Queensland Health, with our human rights legislation?

**Ms Holmes:** It may be. There are so many different models that the parliament can choose to consider if it chooses to go ahead with drafting legislation. The Victorian model has been very conservative in its approach to that issue in that it has basically said that there is no requirement on medical practitioners who do not wish to refer to be required to refer. I think they have also said that they should not be imposing their view on a patient. Again, there are some restrictions on their freedom of expression but also protecting them for their religious beliefs. That is the model that is operating in Victoria. I do not know how controversial or how debated that particular aspect of it was, but that is the model that they have followed in Victoria but it certainly engages in rights.

**Mr HUNT:** Thank you. Mary, I wanted to explore decision-making capacity with you. First of all, could you explain to me the difference between the Public Advocate and the Public Guardian?

**Ms Burgess:** We are both agencies under the Guardianship and Administration Act. The Public Guardian has a role where she is appointed as the substitute decision-maker for people who have been found to have impaired decision-making capacity and require decisions to be made for them. My role is a complementary role that is only involved in systemic advocacy. I do not take complaints and I do not represent individuals.

**Mr HUNT:** Your submission states—

Existing guardianship and power of attorney legislation does not allow for particular decisions to be made by substitute decision-makers, including, for example, consent to marriage, the making or revoking of a will, voting, the termination of a pregnancy, sterilisation or organ donation.

Does that relate to the Public Guardian not being able to make those decisions on behalf of them?

**Ms Burgess:** Yes, or anyone else appointed as a private guardian for a person. They cannot make those decisions for that person if those decisions do need to be made. Particularly in relation to special healthcare matters, there is provision under the act for an application to be made to the Queensland Civil and Administrative Tribunal to consider and make the decision.

**Mr HUNT:** So they can substitute and make the decision that way?

**Ms Burgess:** Yes. There is a very formalised decision-making process with built-in safeguards around that. I should also clarify that when I made my submission we were unaware that there is one case in Queensland from 2003 with the former Guardianship and Administration Tribunal where Judge Lyons was sitting and she formed a view that a guardian under the act could make a decision in relation to restrictive practices. That was outside of the disability restrictive practices regime, so it was in relation to a person who was in the mental health system. My reading of recent academic research on the subject is that the law in this space is unclear and is certainly not consistent from state to state in Australia. I think there was a recent decision against the Public Advocate in South Australia where there was a finding that the Public Advocate could not make decisions approving restrictive practices of people under their care, so it varies across the country. While we do have a

precedent from 2003 in Queensland, at the time that Judge Lyons made that decision she did remark twice during the judgement that she thought it would be useful to have a decision of the Supreme Court on the issue, so we have a decision but it is a lower court decision or a tribunal decision.

**Mr HUNT:** Your recommendation 1 states—

Any future voluntary assisted dying legislation must include the necessary safeguards to ensure that only people with decision-making capacity can access ...

Obviously there would be a wide scope of ability to make decisions, so is that a declared position?

**Ms Burgess:** Exactly. When Neroli was speaking to you about the exemptions in the Victorian legislation, I was thinking that I would like to clarify that my view is that we should not as a blanket approach be denying anyone with certain types of conditions from being able to access voluntary assisted dying. I think the decisions have to be made on a case-by-case basis about whether the person has the capacity to make this decision in these circumstances.

**Mr HUNT:** Determined by a medical professional?

**Ms Burgess:** And an assessment by the appropriate tribunal or whatever agency can make the decision about whether a person can proceed with voluntary assisted dying. From my point of view, my role is to advocate for people to be able to exercise whatever decision-making capacity they have to the greatest extent that they can. I would be cautious about just listing a range of conditions where you would want to exclude people. It should be on an individual case basis. Considering the nature of this kind of legislation, it seems to me that that is not an onerous requirement considering the really important issues it is dealing with. It should always be very much a case-by-case basis and the fundamental starting point should be that the person has capacity to make the decision. That is a fundamental starting point in every legal proceeding really. We just do not turn our minds to it because it is a given in most cases. Capacity is presumed, but when we are in this space there will be people with conditions where the issue of capacity will have to arise. It seems to me that that could or should be considered in every circumstance. That would then allow more people with conditions that may impact their capacity, but not necessarily prevent them from making this decision, access to this treatment. It would be less at risk of being discriminatory as well I think.

**Mr HUNT:** Thank you.

**Ms PEASE:** Thank you very much for coming in. Mary, I would like to go further with that line of questioning the member for Nicklin was going down. With regard to enabling people to have access to voluntary assisted dying, if they have made it clear that they wanted to have voluntary assisted dying, at what point do you determine whether that can be enacted? For example, they have made a decision at the early stages if they have a cognitive impairment and the condition progresses. Can we look back at their original request? You are saying they should have access to it, so at what point do you say, 'Sorry, you don't anymore'?

**Ms Burgess:** I think at the point that they are making the decision for the death to occur they have to have capacity.

**Ms PEASE:** The death to occur at the beginning? Let us say they have been diagnosed and they are one year in. Can they hold off and say, 'I want to have voluntary assisted dying but only when my capacity deteriorates,' or do we allow people who have been given a diagnosis of dementia the ability to have access to voluntary assisted dying immediately although it is not an impending death?

**Ms Burgess:** I think this is a really complicated issue. We looked at the submissions that this committee has received and we could see that many of them were from people whose family members had progressed to a state of a loss of capacity and significant deterioration in their health, but really from their point of view the person was not there anymore and their view was that there should be some capacity for the person to be able to die. The problem is that is no longer voluntary assisted dying. When you have past the point of being able to make that decision yourself, it is no longer voluntary on your part. We explored a number of scenarios in our office about how it might play out if you were to allow people to make an advance care planning document, for instance.

I was familiar with a woman who developed Alzheimer's disease. She was very physically well and able but lost her capacity some years before she died, but she was very physically active and very mobile. I thought in her case—and she is not an isolated case; it is very common for people to still be engaging once they have essentially lost capacity or forget who they are or who their family are but are still able to engage in conversation and live a life—'How do you decide to enact their wishes after they've lost capacity when they're still walking and talking and seem to be engaging?' Do you have to round them up and tie them to a bed and administer it? Who is going to do that? We

have to be really careful about how we might choose to go down this track and open this door because it creates some really difficult situations if we are not really careful about how we test them in practical terms and in real-life terms.

I need to return to that point that when we are talking about voluntary assisted dying it can only be voluntary if you have capacity at the time of your death to make that voluntary decision. At this point that is our thinking. I heard Marshall Perron speak this morning and he said in 30, 40 or 50 years we might have a different view of this. I think this is one of these areas where you might want to start small and go down the track of the simplest approach. There are so many risks and variables and thorns in this, so maybe it would be best to keep it as simple as possible to begin with so that we do not run the risk of situations developing that were not anticipated and that challenge all of our thinking in terms of what the legislation was intended to achieve. The other reason why we take this very firm line on capacity is that across human history we have a very bad history of euthanasing people who have capacity or physical capacity issues and we do not—

**Ms PEASE:** Sorry, but can you repeat that?

**Ms Burgess:** We have a bad history. Humanity has a bad history of treating people with disability badly such as killing babies at birth and subjecting people to treatment and testing that is in breach of their human rights. You have to be really careful if you open the door to people with capacity issues or disabilities of sorts being admitted to voluntary assisted dying, unless you can be absolutely certain that the person themselves is making the decision to voluntarily end their life.

**Ms PEASE:** Thank you. I have a question for Neroli, and I spoke about this earlier today. People have come and spoken to me and in the submissions people have gone to a solicitor and written up a living will. Some of them call it an advance health directive. They have made it quite clear that at some point if they have an accident or they have an acquired brain injury or they develop a cognitive health condition they want to end their life at that point. If that is not followed, is that a breach of any human right?

**Ms Holmes:** I am probably not the best expert to ask that. I would suggest Lindy Willmott and Ben White might be better people to speak to about that. I would think it is that balancing of rights. You have autonomy, so you have your privacy and you can make directions and make decisions about yourself, which is a very strong human right. If you lose capacity at some stage, then there are countervailing rights as Mary has said. You can always, if you have capacity, say that you do not want medical treatment. It is very easy in that situation to say, 'I don't want medical treatment,' and it is harder if you have lost capacity to say that you do not want health treatment any longer.

**Ms PEASE:** The point I am getting to is that with an advance health directive you are able to put in there that you want to stop treatment knowing full well that that is going to result in your death. Is that not the same?

**Ms Holmes:** If you do not have capacity at that time it is more challenging, I think.

**Ms PEASE:** My point is it is not about capacity, because what my point goes back to is at the beginning when you complete the advance healthcare directive you make it clear that you want to either stop all medical treatments, you want to not be fed, all you want is pain relief. Is that not, in effect, when you have capacity? That can be enacted when you are in hospital. I know that there has been some discussion around that, that it is not always followed, but generally that is what people would go to look at. Is that not, in effect, the same as giving a request to seek a lethal injection at some point into the future?

**Ms Burgess:** Can I interject? I think the difference is that in the first case that you are describing it is a person exercising their right to privacy and bodily integrity, saying I want to be able to refuse treatment in certain circumstances. The second around voluntary assisted dying is requiring someone to actively do something to end your life. That is the distinction between the two.

**Ms PEASE:** I guess my distinction is that you are actively doing something by saying, 'Don't give me any treatment and don't give me any food.' That is fine. I know you are probably not in a position to answer it, but I guess the crux of the question is that it comes back to not having capacity and yet you have completed the advance health directive when you have capacity and therefore that is enacted, which is no more treatment, no food, only pain relief, but at the time when that is enacted you do not have capacity, but that is still considered okay.

**Ms Ball:** I think the difference is though that when that happens there is still someone who is making the decisions for you. There is a decision-maker, whether that is the family or some other guardian. You have expressed the wish that you do not want that to happen, but ultimately it is up to the person who is making the decisions for you whether or not they follow that.

**Ms PEASE:** I would again go back to that may well be the case with your desire to seek voluntary assisted dying. I will not take up any more question time.

**Ms Burgess:** I completely recognise what you are saying here. It is a very vexed issue. They are very close but I actually think the argument is that they are not quite the same. I attended a presentation that Ben White did for the Queensland Law Society around this and we had a very interesting discussion on this issue and they can tease that out. It might be worthwhile you asking them to clarify this further.

**Ms PEASE:** It is fine. I am seeking your opinion. We have already had them here today.

**Ms Burgess:** I do think that one is being able to refuse anyone doing something to your body, the other is asking someone to actively do something. One is letting nature take its course, the other one is intervening actively to end someone's life.

**ACTING CHAIR:** I want to take that point up a bit further. As I see it, the person has capacity and says if I get to a point do not feed me, do not provide me with medication. That is a negative outcome. If the same person says if I get to that point a positive step I want you to do is to give me an injection or some sort of drug. Isn't the root the person making the call? Isn't the person determining what is to happen as opposed to us focusing on what happens? Isn't the core the person with capacity saying negative or positive? I think that is what you are getting at too. I am lost in that. We tend to be forgetting that it is the person who makes the call. That person has not differed. It is the process beyond that that differs. We will let it go for the time being. If a bill comes before the House we will debate it further.

**Ms Holmes:** They are very complex issues. It is difficult and this is where it is so good that committees like this tease these issues out and think these issues through.

**ACTING CHAIR:** Ms Holmes, you referred to passive euthanasia. What do you mean by that?

**Ms Holmes:** This is a term that is used by the Australian Human Rights Commission in their very considered paper that looked at this. That is really making that statement that I do not want any more treatment so it is really where you are withdrawing treatment and saying I don't want any more treatment.

**ACTING CHAIR:** It is a negative consequence, not a positive action.

**Ms Holmes:** Yes.

**ACTING CHAIR:** Ms Burgess, you referred to restrictive practices and you mentioned that 90 per cent of drugs that are given are of limited or no value in relation to dementia patients and/or those who have impaired capacity. We heard that figure a bit lower from a geriatrician as well, equally concerned about the use of these drugs, and then someone mentioned that certificate III holders working in aged care with dementia patients often do not have the capacity to understand a dementia patient, what they go through or to interact or to assist them. Would you agree with that?

**Ms Burgess:** I am not familiar with all the details of the certificate III training but I have read the reports and recommendations around the need for better training for aged-care staff. I think part of what has happened in aged care is that their skill set is probably limited and the resourcing more generally is limited and that combination of factors means that you tend to resort to the simplest response to challenging behaviours. If you can get someone who will write a prescription and you can give someone medication then that is much easier than restructuring your service model that involves actively engaging people daily in various activities and having particular routines and daily activities that keep people engaged but may take a bit more time and resourcing to do and also a more highly skilled workforce.

Certainly the papers that I have read, including to the Productivity Commission some years ago, all seem to raise this issue around training. I think it was the Productivity Commission that made some very specific recommendations about the need for better training in aged care. When the royal commission was announced I think some of the frustration in the sector and those hoping to see positive change was that there had been so many reviews and reports already in this space that had laid out a pretty clear blueprint for reform, that looked at staffing and skill sets and restrictive practices and a whole range of issues and they really just needed to be pulled together and taken forward and acted on. The work has been done in the training space is my view and, yes, I think primarily what we are seeing here in the restrictive practices space is a lack of resources and a lack of skills.

**ACTING CHAIR:** Do you correlate that drug use to the lack of skills?

**Ms Burgess:** I think so. It is a bit larger than that though. It is a lack of looking beyond what we are doing now to something that could be better. I think it is more than just a lack of skills. Organisationally the service providers need to be thinking bigger and better and different because we

are expecting more. The baby boomers are coming into aged care and they are not going to go quietly, and they should not because people should not have been having these things happen to them. I am fairly positive that we will see change because there will be larger numbers of people going in, they will have better health, they are likely to live longer and they will have more money—at least some of them. I think those factors in themselves will cause the system to shift. I think that is part of what is happening. Why are we talking about these things now? Why are we having a royal commission? Why do we have an inquiry into Oakden? People are realising this is wrong and things have got to get better. The real problem with it all is that ultimately all this costs money and we have to decide where we want to put our money. I think that is the answer.

**ACTING CHAIR:** Is it a matter that what we thought was aged care 30 years ago is no longer society's desire? It is becoming more a health service or a health hub in so many ways and is that an outcome the royal commission may well come to, in your opinion?

**Ms Burgess:** That aged care is really a health service?

**ACTING CHAIR:** Yes. Years ago you went in there, you were 65; two or three years and you may have passed on. Now, with dementia, comorbidities, an older population base, living longer, is the aged care service evolving into something that we did not see it becoming 10 or 20-odd years ago, which means more training, more money, more expertise et cetera?

**Ms Burgess:** That is probably true. I think what is happening, and I have read this in a number of publications, is that we are seeing people going in older with far more significant conditions that require a lot more care, medical care as well as behavioural management, and I think that is contributing to the problem. What is happening is people are living longer and they are living well up to a point and then they are coming in and they are quite ill. People do not tend to live very long in aged care. I am not talking about retirement villages and places like that, I am talking about where you are getting that kind of higher-needs care that we refer to as residential aged care. I think you are right. I think we are seeing people living longer and being maintained with medications and other things with conditions that maybe they would not have lived so long with in the past and so I think it is changing.

**ACTING CHAIR:** That would mean the training regimes for those who work in that new aged-care model must move with that as well?

**Ms Burgess:** Yes.

**ACTING CHAIR:** The current practices in relation to certificate III, which is the lowest level of training available, may no longer suit a new model going forward?

**Ms Holmes:** I think that is right. It is a new challenge for us and we need to really reconceptualise the model and reconceptualise how we support it financially and what expectations we have of what is good service and what is good practice in those places.

**ACTING CHAIR:** This may be outside your province, but I am going to pose it anyway: does it mean a new financial model as well? You have the Commonwealth and the state and a massive grey area between the two. One blames the other and the other one blames the other one as well. Prime Minister Rudd reviewed the medical funding arrangement. Is it a matter that the funding model we have now needs to be looked at if we are going to transition into a new model of care with the added involvement of more education, comorbidities, et cetera?

**Ms Holmes:** I would think so and I would think we really want to make sure that we are not spending the money poorly. We want to make sure that every dollar that we are spending is important, that we are getting the best we can for the money that is being utilised and it is being effectively and efficiently used and we are getting the best—the taxpayers and the citizens—from the services that we hope our parents will have and that we will have when we, if we ever should, end up in an aged-care facility ourselves.

**ACTING CHAIR:** Ms Burgess, you have a comment?

**Ms Burgess:** I would not pretend to have the expertise to talk on the funding, but what I can talk about is that we do hear quite frequently stories about the argy-bargy that goes on between our mainstream health services and aged-care facilities where people have a deterioration in their condition and they may need medical care, but there is a view that those people who are brought from nursing homes are bed blockers. I think we need to get really clear about what care we expect and how we view people in terms of their entitlement to medical care past a certain age.

People are entitled to be administered medical treatment that would be given in ordinary circumstances if it is good medical practice and, of course, that can vary depending on the person's age and infirmity and all those sorts of things. People are also entitled to be able to access the medical

care that keeps them comfortable and free of pain. I am aware that there have been many conversations before this committee about the issue of the accessibility of palliative care and the lack of good palliative care being available in aged-care homes. I think that there needs to be more of a conversation about how we give people a good wraparound model of care so that they do not get transferred to hospitals if they do not need to but they can still access medical care that is appropriate to their needs and/or that they are accessing palliative care that keeps them comfortable and gives them some quality of life as they age. If we do that better, and I am sure people have been saying this to you all along, you will have fewer people seeking voluntary assisted dying because when you see these stories coming out of aged care who in this room wants to go in? It looks frightening. It looks like you check your rights at the door and that is the end of it. It should not be like that. It is not like that everywhere, I am not suggesting that, but the stories that we have heard are worrying enough for people to think, 'I cannot even imagine the prospect of my life becoming like that.' We do not want people to be seeing aged care as that. As Neroli was saying, we should be able to provide a better quality of care that gives people a better quality of life than just sitting in a bed staring at a TV.

**ACTING CHAIR:** Time has expired, ladies. Thank you very much for your time in coming here today. It has been a pleasure.

**DE ZUBICARAY, Professor Greig, Assistant Dean (Research), Faculty of Health, Queensland University of Technology**

**YATES, Professor Patsy, Deputy Vice-Chancellor and Vice-President (Research and Innovation), Queensland University of Technology**

**ACTING CHAIR:** Thank you for your time today. We have a copy of your paper. Could we please start with an opening statement and then we will go to questions from the committee?

**Prof. Yates:** Thank you very much for the opportunity for us to present to this really important inquiry. By way of background to understand where I come from, I have a couple of decades of experience as a nurse, a researcher and an educator in palliative care. That has given me lots of opportunities to understand a lot about the system and lots of privileges in terms of being able to undertake research and learn a little bit more about how we can improve it.

In my opening statement I want to provide a little understanding of some of the work that I have been doing and then I am very happy to answer any questions that about. Some of the main work that we are involved with at QUT with our partners is around workforce development. I have a very strong interest and I am very interested to have a conversation with you around workforce development. From funding through grants from the National Palliative Care Program for over 10 years now, we have had the opportunity to develop underpinning curriculum that can be embedded in undergraduate courses for all health professionals. We have had a lot of success at defining the capabilities that every health professional should achieve no matter where they go to work—and I am not talking about specialists; I am talking about every health professional—and trying to work with course providers to embed those principles and concepts. We have developed some learning resources to help educators achieve that.

More recently, we have extended that program beyond universities to the VET sector. We have developed similar sorts of programs for diploma level enrolled nurse programs and we are just starting to work at the certificate level to understand how we might use our learnings to adapt to core programs that enable people to understand what everybody should know. That is one piece.

We also do a lot of work around continuing professional education in this area. One of our programs—again, funded through the National Palliative Care Program—is a program called PEPA, which is a program of professional experience in palliative care. That is really targeted at people who are not specialists but who work in an acute care setting, or in aged-care setting, or in the community, to have an immersion experience in a specialist palliative care setting.

I am also involved with the ELDAC program. That program, again funded through the Commonwealth, is about improving end-of-life care for older people in both residential and community care settings. We are now two years into that program. That program has four main streams of work. One is around embedding tools and resources to help aged-care providers, embedding some digital solutions to have access to information and, on the ground, we have employed what we call our partnership facilitators who are working with aged-care providers to see how you can build a link between an aged-care service and a specialist palliative care service to build capability. It is quite an innovative program. As I said, we are two years into a three-year funding program.

I am also involved with PCOC—the Palliative Care Outcomes Collaboration. That is an important national program for specialist palliative care in the sense that it is around measuring and reporting outcomes. Part of that program has enabled us to understand what we are achieving and where there needs to be quality improvement. That program is about measuring outcomes on a routine basis, feeding that information back to service providers and helping them identify solutions to make some improvements. I am happy to submit an additional report from the PCOC team, which provides a lot of information about where we have gaps in services.

That is just a flavour of a number of things. We are also fortunate to have a National Health and Medical Research Centre of Research Excellence in End of Life Care that is led through QUT. As part of that, over the past five years we have had the opportunity to test different models to understand what services might look like across a range of different settings. As you can see, I am involved in lots and have a real passion about how we can improve end-of-life care.

**ACTING CHAIR:** Thank you very much. Greig, do you want to make a comment?

**Prof. De Zubicaray:** I would quickly point out that Professor Yates is being quite modest when she describes herself as being involved in these areas. She has, in fact, senior leadership roles. She is the director of many of these national and state centres and her international reputation is lauded. We are extremely proud to have her at QUT. As a former head of the school of nursing and now a Brisbane



deputy vice-chancellor and vice-president of research, you can understand just how proud we are. In terms of this inquiry, you could not have a better person to speak to the state of research internationally and statewide.

**ACTING CHAIR:** Thank you very much, Greig.

**Mr O'ROURKE:** We have heard a lot about the challenges of delivering palliative and aged care in regional and remote areas. Besides the training of staff, do you have any other suggestions as to how we can do that better and any guidance in that?

**Prof. Yates:** It is a big issue for Queensland. I think there are better ways in which we can network services—specialist services and non-specialist services—through the use of technology. There is good evidence out there, both in some small studies in Australia but also overseas, that shows that technology enables us to provide good outcomes. I think there is a lot more that we can do with telehealth—by using remote monitoring and connecting patients and their carers more effectively.

I think it is about the capability of the workforce as well. That does not mean that it is about everyone being a specialist. So long as people have the capability to know where they need to refer on and know where to get that support, we can often deliver good outcomes in a team approach. I think it is about the integration of services. I think it is about the linking of our services. Obviously, to make that work there have to be the appropriate mechanisms, incentives and funding models. It is easy in principle. Everyone says, 'Integrated care,' but it needs the right structures to enable it.

**Mr HUNT:** I have similar questions about research and where we are going with palliative care into the future and best practice. With your knowledge of what is available around the world, is there somewhere that we should be looking to for best practice? What are some of the technological advances that are helping? Not only remote Queenslanders but also inner-city Queenslanders are telling us that they would prefer to die at home and have access to services. That brings with it the lifting, the care, the syringe drivers, the equipment—all of those things. Is that getting better with technology? Is the research going that way?

**Prof. Yates:** In terms of your first question about examples across the world, I think that the best examples that would relate to Queensland really come from those systems where they have the ability to work across sectors. I think that one of the biggest challenges we have is making the connected care piece. They are some of the best examples. Having said that, I think that in Australia and Queensland we do pretty well with palliative care. When we look across the world to find solutions, we often find that we are doing pretty well. As much as we have a long way to go, there is not a lot that we can easily apply. I think it is the connected care.

In terms of your question about getting better ability to provide quality care at point of care, it is interesting that there are some good bits of research happening but I think there is so much more potential around technologies that can apply to end-of-life care. I do not think that technology has been a space that people have really used. I think that is partly because people worry that it is not just a technical thing—'If we start talking about technological solutions, are we going to take away the person-centred side of that?' I do not think there is anything further from the truth. I think that goes to how you train our workforce to realise that that is the future of health and aged care. It is using technology, but it frightens people, because they think that you will take out the person side of things.

I cannot identify any specific examples of where there is great innovation except at the point of providing immediate information about patient needs—some of the technologies around understanding patients, patient reported outcomes and using patient reported outcomes through technological solutions to drive how we plan our care and how we bring in the right services. That is probably where it is happening the most but, in terms of things like how do we lift people, how do we use the right equipment and devices, I think a lot more work could be done there.

**Mr HUNT:** Is there a place for palliative care in enhancing the quality of life as well?

**Prof. Yates:** Absolutely. Again, there have been some huge trials over the past 10 years that have identified without a doubt—and there have been systematic reviews of these trials now—that, when you have the early integration of palliative care, you get better outcomes in terms of quality of life. In some cases, some studies of some populations have showed not only better quality of life but also, in fact, improved survival and length of life—both better quality and longer time with loved ones. The evidence on that is really clear in very robust studies.

**Mr HUNT:** How is research funded? Do you have any concerns if voluntary assisted dying legislation is enacted in Queensland whether that might have an impact on future research or funding?

**Prof. Yates:** I have been around long enough to know that in about 2004 the Commonwealth invested some dedicated funding for research. They provided that to NHMRC to allocate to particularly capacity building. That was really good. At that time it meant that a lot of people had the opportunity to do PhDs and develop their research careers. The great thing about that was that they put a number of other things around it. You had to collaborate with other people.

That provided a really good base for researchers across the country. We all worked together pretty well, and to do good research it has to be of scale. Of course, that was one-off special grants and now you have to compete, as you should, with other researchers on merit and quality. There are some challenges with that, because by nature end-of-life care research is messy. Often times when you go to funding bodies, they like nice, neat trials. Of course, it is not the space that we work in. I do think there needs to be some prioritisation sometimes, because in standard schemes it does get very difficult to compete with nice, neat controlled trials.

In terms of your question about the introduction of voluntary assisted dying, my issue is that we need that fundamental base of good quality care. That just has to be a given in how we ensure that that is part of whatever systems we have. With the introduction of legislation, that would include ensuring that our workforce is really confident and prepared in all settings to be able to live with different options that might be available.

**Ms PEASE:** Professor Yates, you have been talked about already this morning. We all were anxiously awaiting your arrival, so thank you both very much for all of the work that you do. No doubt you will continue to contribute. You talked about training, an area that I have spoken about today, particularly around people living with dementia and some specialised training for people working in that sector. Is there much uptake of ENs, personal care workers or RNs taking up that training, or is it easier for them to learn on the job? What is your position?

**Prof. Yates:** I think that it is both. There are skills and capabilities. You need to understand what the evidence tells us about how to manage and provide best care for people with dementia. Yes, you can learn some of that by experience, but you need that solid understanding of what the evidence tells us is increasingly emerging. We know a lot more now about care for people with dementia and how to support people who might be having particularly challenging symptoms. If you are a care worker in an environment and are not equipped with that toolbox of, 'Well, these are the strategies I can apply', I imagine it is pretty overwhelming. We know that it just escalates the problem and it gets worse and worse. I think it is a bit of both. It is about understanding the principles and the evidence and then being able to apply it.

**Ms PEASE:** I guess the same would apply across all the different sectors, whether it is aged care, palliative care, people with cognitive health conditions. Should it be a mandatory requirement that people working in those sectors have a certificate or some sort of training in that area?

**Prof. Yates:** I believe that there should be. The level of that requirement does depend upon context. One thing that we try and promote about workforce development is that sort of tiered approach. It is understanding that everybody should know something, because you might come into contact with it. That something might be awareness, knowing how to refer or knowing that immediate need. If you are working in a setting where you have a little bit more intensity and complexity, you need a higher level of capability up to a specialist sort of level. We have designed our programs to get the right outcome at the right level as best we can. Yes, I do think that there is a certain level for everybody in those settings and that that will become increasingly important with the increasing number of people living with dementia.

**Ms PEASE:** And across the whole sector, people have greater expectations as well. One of the things about which there has been a lot of discussion is setting staff-to-patient ratios. Do you have a comment or a position on that?

**Prof. Yates:** Yes. I have a nursing background and am involved in another capacity around the introduction of the nurse-patient ratios in the public health system in Queensland. Again, the evidence in that space is very clear, that if you have the right capability of your staff that your outcomes are better. I have just come back from the International Council of Nurses conference last weekend where they presented the latest evidence. Again, it very clearly says that if you have the right level of staff you have reduced mortality, reduced morbidity, improvements in costs and savings to the system. We have not tested that in aged care, but I do not see any reason the principles would not still apply. What those ratios would look like still need to be worked through, because obviously again it is a different sort of care setting than the acute medical-surgical. Without a doubt, it is essential that the complexity of care requires a registered nurse with that advanced clinical decision-making skill and, yes, with a support team so that everyone does not need to be there. There needs to be at least a minimum if we are to get the right outcomes.

**ACTING CHAIR:** Thank you for coming today, and it is wonderful to hear your voice, Professor Yates. You are a beacon for many people who have spoken of you in very high, glowing terms. You made the comment in relation to palliative care that as a nation we are doing pretty well. I accept that statement. Are we educating the public sufficiently as to the existence of palliative care and the worth of palliative care because, with all due respect, we can have all the academia and academics we want but, if it is not out there, it may as well be somewhere else completely?

**Prof. Yates:** Absolutely. Some of our biggest challenges to achieving good quality end of life are people understanding that we all will die and that if we prepare appropriately that time of our lives may be managed more effectively. Yes, in answer to your question, the community does not put enough emphasis in terms of we can normalise that understanding. How do we do that? Obviously it is not about hitting people over the head with it. It is about appropriate education programs so that people see it as a normal part of life. A brief answer—absolutely, we do need to do that.

**ACTING CHAIR:** A bit like vaccinations. The more we talk about it, the better the outcome will be.

**Prof. Yates:** It is normal. That is about then being sophisticated around what are the moments at which we have those conversations, how do we best do it and those sorts of things.

**ACTING CHAIR:** That is my next point, too. If a person is going to consider voluntary assisted dying, should palliative care not be part of that conversation going forward? Is it not an essential ingredient for a person to make a determination?

**Prof. Yates:** Absolutely. People need to know what all the options are, that it is not an either/or, that this is all part of an end-of-life journey. It is a normal part of life and people need to be as well informed as they can of all the possibilities.

**ACTING CHAIR:** You might be aware of professors White and Willmott's draft bill where they talk about palliative care by way of the first practitioner and the second practitioner ticking off, shall we say. Is it the case in your mind that if palliative care is explained as to what it can do, that that can deter a person going down the road of voluntary assisted dying? Is that the worth of palliative care in that discussion?

**Prof. Yates:** In my own experience, I think that people understanding the value of palliative care does change how they view their options. Again, I think that, fundamentally whatever legislation is introduced, the key to that has to be as much information for people as possible to be empowered to understand what the possibilities are.

**ACTING CHAIR:** This committee needs to discuss the relationship between palliative care and VAD. We really cannot have one without the other to give a patient all the information to come to an informed determination. Do you agree with that?

**Prof. Yates:** Yes, absolutely. You cannot have one without the other.

**ACTING CHAIR:** You are aware of the Queensland Health Palliative Care Services Review key findings document. In fact, I understand you may have co-authored the review referred to on page 14.

**Prof. Yates:** Yes.

**ACTING CHAIR:** I make clear that that has not been published publicly; therefore, be careful what you say. For this committee looking at palliative care going forward—and for the public as well—should that review be published?

**Prof. Yates:** It is a summary of a lot of the evidence that is out there. Some of the challenges with any of this is that, again, it is not nice, neat and precise. It is written more as an academic document, but I think that it provides a good summary of the evidence. I always worry when people put figures and it gets interpreted out of context in different ways but, nonetheless, as a good summary of the evidence that is what was our intention.

**ACTING CHAIR:** Do you think the public should see that document?

**Prof. Yates:** Yes. The contents and the key findings within that are important. It really is a summary of what I would be talking about in any sort of setting and context.

**ACTING CHAIR:** Be careful as it is unpublished at this point in time, but did the review that you co-authored make recommendations, or was it a review of literature that then gathered that together in a peer review manner?

**Prof. Yates:** Our review was a summary of what the existing literature sort of tells us. In that sense, it sort of summarised and synthesized what was out there.

**ACTING CHAIR:** I think the review that we have here that has been public is a little bit frustrating, because there are no recommendations contained in the document. From my perspective, there was limited data or an understanding of where we are with palliative care. Though it is made for us to look at, I would rather get the nuts and bolts so that we can then look at that information and recommendations contained in a document that goes through it properly and we can utilise the content. Do you agree?

**Prof. Yates:** I can provide the information from the PCCC (Palliative Care Outcomes Collaboration) report. I think that goes to some of the issues around our use of the Peacock data to estimate things like what is the demand in the future for palliative care. That was put up in the last couple of days on the Peacock website, so it is publicly available. It says for example things like how many potentially predictable deaths there are in Queensland, about 63 per cent in 2017. Again, the estimates use models from the literature about how many of those people would need palliative care. The figures that are estimated from the Peacock data are around one-third of those people. It also provides that summarised outcome data that I was mentioning about how our specialist services both in hospitals and in the community are going against the benchmarks which the sector has set for itself around quality palliative care.

**ACTING CHAIR:** Is that document with you now?

**Prof. Yates:** Yes, but I have scribbled on it, so it might be better if I send you a clean copy.

**ACTING CHAIR:** Thank you very much indeed for your trouble, I do appreciate that.

**Prof. Yates:** Thank you again for the time.

**Proceedings suspended from 2.14 pm to 2.21 pm.**

**MITCHELL, Dr Geoffrey, Professor of General Practice and Palliative Care, University of Queensland**

**WINCH, Associate Professor Sarah, Head of Discipline and Medical Ethics, University of Queensland**

**ACTING CHAIR:** We have your papers before us. Before we ask you questions please make a statement of about five minutes duration in relation to the papers.

**Prof. Winch:** Thank you for the invitation. I thought I would use part of my statement to explain my background. I am an associate professor in charge of the ethics, law and professionalism stream at the University of Queensland, Faculty of Medicine. I am also a healthcare ethicist who works nationally. I do some international work and I also work locally. My most common area to look at is end of life. I also work in the death literacy space. I hope that you have heard a bit more about that today. That is where we work with community on their understanding of end of life, so I do Death Cafe, Death Over Dinner, those sort of things, and I have also written a book for the general public about how to get a good death. I really try to work across the spectrum. I do research in the area of futile treatment with Lindy Willmott and Ben White, so I have done that sort of broad work as well.

When I was thinking about what we would look at and what we need to respond to in terms of an ethical approach to this, we look very much at statistics and what is happening. We consider evidence as well as principles. For that reason I was really interested in the notion of choice, because choice—autonomy, the ability to do what you like—is a really fundamental thing that we want. It was then that I became concerned with looking at people's understanding of end of life, what death looks like, the provision of palliative care and what would seem to be quite uneven access to high-quality palliative care considering the amount of fear that has been driven in the community about the need for VAD. Dr Stephen Duckett has just done a good review—and we have spoken about this—about the amount of fear and pathos in stories.

I just heard a throwaway comment on the ABC the other day that 'everybody knows all dying is terrible'. I thought, 'Hang on a minute.' I have a nursing background originally. I have seen an awful lot of dying, including during the HIV-AIDS crisis. Maybe I am the common denominator—I hope not—but dying is not terrible and it does not have to be terrible. I am getting a little confused about how people can make a good decision about this and the amount of fear that is out in the community now about death and dying. That is very concerning to me. Your ability to make a choice is about your knowledge of things, it is about your access to things and it is also about your emotions. I think that these are some of the things that hopefully will be addressed going forward.

**Dr Mitchell:** I have worked in this area from a practical perspective and from an academic perspective for 20-something years. I am a GP in Ipswich. I was involved in the establishment of the West Moreton palliative care plan, part of which includes a hospice in Ipswich that has been functioning now for 25 years. I am also an actively practising GP, so I come to it from a very pragmatic perspective. I am also the cofounder of an international primary palliative care network which has looked at the whole issue of where primary care fits in to end-of-life care, and I have been instrumental in getting primary care mentioned in end-of-life statements at the WHO. The European Association for Palliative Care now has a standing committee on primary palliative care. The whole purpose of that is that end-of-life care should be available at the highest quality for all people, in all situations, for all elements of a person's persona—physical, psychological, spiritual and practical—in all countries.

In fact, that is not the case we have at the moment. We have been incredibly successful at minimising or eliminating the diseases which take people early and in midlife. We say that we save lives, but in fact we do not; we defer death. The only thing I can guarantee is that every person in this room is going to die—it is just a case of when and how. When you think of it like that, we focus enormously on deferring death, but what we are doing is becoming victims of our own success. We now have a rapidly ageing population that is all going to die pretty much all at once. The rate of death is going to more than double in the next 30 or 40 years. The system that we have in place focuses not on the majority of people who die, but the minority. If you are over 70 and you die, 19 per cent of you will die of cancer. Eighty per cent of specialist palliative care patients have cancer, so the question is: who looks after the rest? The rest are people who die of multimorbidity, frailty, dementia and organ failure. That is everyone's business. It is a mixture of primary care, aged care, aged-care facilities and generalist specialists, so people like geriatricians and general physicians.

The problem is that our health system is set up in silos. In a tertiary hospital you have a cardiology ward, a respiratory ward and a renal ward. If you are unlucky enough to have all three of those diseases how are you looked after? The question then is if we are focusing on that, who makes  
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the decisions within the system? What are we doing to try to take advantage of the expertise that is out in the community, where we do this on a daily basis? I have done a lot of work on testing models of care which allow that to happen. That has been quoted in our submission. I know that it can work, but the focus has to be from the hospital. It is too hard for GPs to take carriage of running this sort of thing. In order for that to happen you have to have hospitals and health services willing to give it a go. At the moment, hardly any specialist in any hospital has any interaction with primary care and community based care.

Aged-care facilities in particular I will touch on. The death rate in aged-care facilities is very high. We have a Commonwealth-state divide which means that the funding for these facilities is the responsibility of the Commonwealth but if that fails, and I can give you a couple of examples of how, then these people end up in the state system in the hospitals. That can be avoided. For example, I have just finished a review of an education service in Ipswich run by palliative care nurses going into aged-care facilities evaluating and working with the facility to maximise the quality of the palliative care that is given for people who are dying there. That dropped admissions per annum of those who died from 42 per cent to 18 per cent. Of those people who did go to hospital prior to this service being instituted, more than half of them stayed in hospital until they died and after the service only 20 per cent stayed in hospital and died. The difference is extraordinary. All it took was education and coordination. That is the sort of thing that I think the health system ought to be looking at.

This relates to the first two elements of the terms of reference. I have not talked about voluntary assisted dying but our position is that until that kind of service is available and that death literacy is actually something that is generally available to the whole population, then the need for voluntary assisted dying is going to reduce if we all have access to the sort of care we should be getting, seamless integration between the various elements of that care and an understanding of what death is actually like which for most people is not fearful; it is not nice, I am not going to sugar-coat it by any means, but it does not have to be something that causes enormous fear.

**Ms PEASE:** Thank you for coming in today and thank you for the work that you do. I have heard of your hospice in Ipswich. Jen Howard, the member for Ipswich, speaks very highly of it. You have spoken a lot about what is currently happening. In your submission you overview what you think needs to happen. Can you put that into words? What do we need to do to improve what is currently happening?

**Dr Mitchell:** The first thing to say is that what people do in hospitals is very high quality, but we are in a system that is incredibly strained and that is going to get worse as the population ages and we end up with multimorbidity. Within the hospitals I think there is a problem of who takes overall responsibility for complex patients, who makes the decision that it is the right time to call the cardiologist in and tell the cardiologist to stop. That service does not exist, as far as I am aware.

Across the boundary between hospitals and the community there are a number of models that have been tested and to me the integration between what happens in the community and what happens inside the health system is the key to making the system as efficient as it can be. That means that hospitals have to start trusting that GPs know what they are doing. They have to give responsibility back to them and work together so they get to know each other better. Having said that, I know there is a bell curve of quality. It happens in hospitals too.

**Ms PEASE:** On that point, we have had people make submissions yesterday and today around the fact that GPs are not really in a position to undertake palliative care on their patients because they are not financially supported to do that through Medicare.

**Dr Mitchell:** As we pointed out in the submission, palliative care is a very broad scope of work. What I think you are defining is the last bit, the last few weeks when things get difficult. There is another sort of care, which we have called anticipatory care or supportive care, where we anticipate what is likely to happen and we plan ahead for that so that when it happens everyone knows what to do, including the patient and the carer. At this stage if they do not know what to do, remembering most people do not have a health background, and something goes wrong in the middle of the night it is panic stations and the first thing you ring is 000 and they end up in hospital. If GPs are looking after older people, by definition they are providing supportive care and I include that as part of palliative care. Three quarters of GPs say they do palliative care and that would include patients who are towards the end of their life and most of them will do it for their own patients. The problem arises when you do not have a strong relationship with your GP and the GP is coming in cold.

There is also corporatisation of general practice and there are external pressures that make it difficult for some GPs to undertake palliative care, but the point is that for that final bit we are talking small numbers. The economic argument in my estimation is a furphy because the numbers are so small. We are talking quality and the way we deal with the most vulnerable in our society should reflect our society.

**Ms PEASE:** Yesterday one of the presenters, I cannot recall who it was, talked about the community needs to take some responsibility. You were talking there about the carers and making them aware of what is actually happening so that they can respond to their palliative or end-of-life patient.

**Dr Mitchell:** Yes.

**Ms PEASE:** Is that something that your Death Cafe and death literacy is for?

**Prof. Winch:** I want to talk about that because when we look at population statistics 24 per cent of Australian households are single person households. The single person household is one of the fastest growing households. I am one. I do have a dog, I am lucky, but he is old too so he is not an assistance dog and the two of us will continue on. When we are looking at healthcare system models and we often factor in the carer we are starting to look at a problem. As carers age they may experience dementia as well. What we are doing with the Death Cafe movement, and we have developed through my charity our own Queensland version which is Wine and Die, is we are really getting people to talk more about end of life, what their options are going to be. At one fantastic Death Cafe I did out at Warwick we actually got groups of people who had been tree changers. They had family but their family were nowhere near them to make decisions so they set up groups where they could say, 'This is my end of life plan. How can we help each other as a community?' There is some of that work that is useful, but I think we need to be really careful about looking at there will always be a carer because going forward we know that that is not going to be the case.

What I would like to see is a bigger expansion of the hospice movement. I know there have been some announcements in hospice funding, but I know hospices struggle to keep going. I commend Geoff on the work he did in setting up Ipswich and the other one that I am very aware of is, of course, Hummingbird House. We have had some amazing individuals who have stepped forward in groups to do this, but to me it should be part of the public system. In 2015 the Loewen Foundation in Singapore, which I do some consulting for, did a major review of all palliative care services throughout the country and we came in second. I thought, 'What? Second? Us?', and it was because of our lack of hospice care and hospice movements that that happened. I think that is something to look for going forward which will provide a place for people who have no carers or whose conditions are too complex to manage dying at home—which is not always easy, you need four or five able-bodied people for you to die at home well so it is not the straightforward thing that people make out—so that we can cater for all aspects of the population properly.

**Dr Mitchell:** Can I add to that that the idea that the process has failed if a person does not die at home is also something of a furphy. If you can manage 95 per cent of your time at home and the last few days get particularly difficult and you go to hospital I would like to think of that as a near-miss home death. You have done pretty well. People should not feel that they have done poorly because they did not make it right to the end. If the number of single person households goes up they will remain the minority for a long time but as we grow older the carers get more ill and one of the things we really have not addressed well at all is managing the carers. We have done work in this area and developed a way of encouraging carers to go to their GP to work out what the predominant problems for that person are so that there is a focus on keeping them as well as possible. They have their own health needs. They do not know what to expect. They fear the future on their own. They cannot plan because they don't know what is going to happen. There are financial costs. There are relational costs as the person gets ill. All of those things can be addressed if they are actually articulated but what we do not do is to say here is the ill person, here is the carer, now what are your needs. The GPs are in a position to do that and the tools are there to do it.

**Mr O'ROURKE:** Thank you for being here this afternoon. My first question is to Professor Winch. Your submission outlines issues in regard to the disparity in access to palliative and aged care with access and equity changes according to location and disease. What can we do to actually improve that?

**Prof. Winch:** Thank you for your question. I think there are some real difficulties. We know that there are Queenslanders in residential aged care with dementia who should be receiving palliative care who are not receiving palliative care but clearly that is Commonwealth funding so that is a little bit more difficult. What I have been very much aware of, because of moral distress from doctors particularly, is that hospital and health service districts may restrict the funding of palliative care. It is low-hanging fruit. If we have to make some cost savings we will reduce the amount of time that people can get to palliative care. It is very much seen that palliative care and cancer are linked but if you look at the top causes of death the No. 1 cause of death is cardiac issues. The second, and it has actually become the first in Queensland for women, is dementia and then we have cerebrovascular issues, then we have emphysema and those issues and then at No. 5 we are really starting to look at a cancer coming forward.

**Prof. Winch:** Yes. I have not spoken to Andrew Denton personally, but when I have heard him say things like, 'I watched my father dying in agony,' which is a common statement, I think, 'Why didn't you pick up the phone, get an ambulance and get him to an emergency department?' because that is what I would have done. I know to do that and I talk about doing that in our death literacy messages because emergency departments are able to deal with pain that is acute at any age, and a big shout-out to our emergency departments because quite a few of them have particular specialist palliative care physicians working—dually qualified—in both areas. I am a bit surprised by that, so, yes, I think there is a drive around a fear of death. We quote in the submission Stephen Duckett's paper. It is really interesting to look at the sorts of submissions. He analysed all of the ones—and you would have got plenty here—where people said, 'I saw my mum or my child have a terrible death,' and truly they are heartbreaking because you think, 'Okay, I get that that happened,' but I want to know why that happened. I want to know was it a level of death literacy? Did no-one take them aside and tell them what they wanted to do or support them through this process and why not, because we have a whole bundle of great deaths—best deaths possible—and good dying which very rarely make the media because they are not good stories and then we have a bunch of stories which are just dreadful and I cannot get my head around why they are dreadful.

There was one case I did from pain medicine group college where they said to me, 'Sarah, we just want you to look at this particular case,' where they went all around the world to try to get pain relief for somebody who had a particular condition—all around the world. I am just struggling as to why people cannot connect. Clearly, it is a lack of access, it is a lack of information and then an incredible fear. A lot of that is around acceptance of diagnosis and an understanding of what palliative care is. People think, 'If we go to palliative care we will die. They will kill us.' That is sort of an understanding as well, so I think there is a lot of messaging that needs to change.

**Mr HUNT:** Yes, and we are getting those horrific stories. It is near on impossible for us to go through each one to try and investigate where things went wrong.

**Prof. Winch:** Exactly.

**Mr HUNT:** As a general statement, I note that you say 40 per cent of people have access to good-quality palliative care. Is that right?

**Prof. Winch:** That has come from one of the reports that we have looked at.

**Dr Mitchell:** Yes, that is 40 per cent of people who could benefit from specialist palliative care.

**Mr HUNT:** Right, so is that 60 per cent of people not getting it?

**Prof. Winch:** Yes, but there is a big remit I guess from people who are dying and do not require specialist palliative care. For example, in my husband's death he never had specialist palliative care. He had an excellent death, but there was no requirement to have the specialist palliative care. There is an extraordinary high end of palliative care that is the very high end that is run out of the big public hospitals, but a lot of death and dying is particularly uncomplicated. There is some support needed but you do not really need to be thinking about that, and then other end-of-life care happens in intensive care units when we withdraw life support. Do you know what I mean? We have this huge range of it. I think everybody can use information to help them make good choices, and that is completely lacking, and then there are those who might be fortunate enough to get referred through.

**Dr Mitchell:** The other issue there is the competence and the education and the confidence of the treating medical professionals and nursing professionals. Because of the opioid issue in particular, some people find it difficult to think that they are capable of managing this sort of thing. Education and realising that end-of-life care is everyone's business is incredibly important so that it becomes a central plank of standard medical care regardless of where you end up as a specialist or a GP. Really, there are only two specialties that do not do that sort of care, and that is radiologists and pathologists. One deals with shadows and the other deals with parts. The rest will inevitably find someone that they are looking after who dies. If they know the basics, then you are going to be able to manage the symptoms maybe 70 per cent or 80 per cent of the time appropriately without specialist help.

**Mr HUNT:** Thank you.

**ACTING CHAIR:** Thank you both for coming in today. Taking my colleague's point just a step further around the use of the word 'fear', is it like a wave at the football match—one starts and they all go up around the cauldron?

**Prof. Winch:** Yes.

**ACTING CHAIR:** I can accept that fear can certainly generate a desire for an outcome, even a desire for the outcome, but we do not live in a perfect world. We do not live in a world where in Cunnamulla, in Barcy, in Winton and other places north and west we have access to the perfect Brisbane



palliative care system. Telehealth might help to that extent, but we are talking here about an ideal scenario. My concern is that that ideal does not translate into reality for many people who go through that very painful time in their life before they pass on, and that is the argument that is going to come back to us. What comment do you have about that? Are you saying we should wait until we get a perfect system or what?

**Prof. Winch:** If we are saying that we need to have VAD as part of a suite of options for people who cannot get a particular service that is delivered in a particular place, morally that is difficult to defend—it really is—because it is saying, ‘Unfortunately, you live at Cunnamulla. There’s nothing we can do for you, but here’s some VAD.’ It becomes a humane choice that is not open to everybody. I think what we need to do very strongly is try and make sure that people have the access that they need so that VAD actually becomes a choice and not a humane option because it is a policy funding failure.

**ACTING CHAIR:** So you would say they should sit side by side?

**Prof. Winch:** I would say from my perspective—from an ethics perspective when you look at it, whichever way you look at it—VAD would only be able to be considered when it is actually a reasonable choice within a suite of choices, not because there is no other option.

**ACTING CHAIR:** Not the last choice?

**Prof. Winch:** Not the only choice because there is nothing else available. Do you see what I mean?

**ACTING CHAIR:** I do. Go back 10 years and where palliative care sat at that point in time to where we are now with palliative care. I would imagine that there have been major advances in palliative care treatment, drugs and the like in that time line.

**Dr Mitchell:** The answer is no. The answer is 10 years ago we were not that far behind where we are now. What we are doing is starting to look much more at refining what is there. The principles of palliative care have been known for decades. Basic palliative care—that is, how to control most forms of pain—has not changed. How do you improve someone’s nausea or breathlessness? There is more evidence there, but basically that evidence was there 10 years ago. Our willingness to use it is still a problem I think, as is the importance of knowing these basic tools amongst the doctors at Cunnamulla, for example, and the understanding of people that there can be things done and there is a vast array of resources available for people to find out what to do. I can name quite quickly a number of world-class online teaching resources, for example, that are available to pretty well every health professional in the country. Are they known? Maybe not.

We are talking about a very complex set of circumstances when we talk about rural and remote medicine—there is no doubt about that—and a lot of it is to do with the need to staff these hospitals with whomever is available. Some 50 per cent of the people who staff hospitals in regional areas are brought in from overseas and the nature of training in some parts where these people come from is fundamentally different to the type of training that we accept as normal in Australia. In developing countries it is all about acute medicine. It is about controlling someone’s malaria or TB. We are about chronic disease. We have a western view of how end of life should be managed. If there has been no exposure to it and they are out there with not much support, how are they going to provide it? In fact, go back a step: how do you provide it? What should you be providing as a fundamental part of training these people before they are put in that situation?

**Prof. Winch:** If the model is followed like the Victorian model, you need to have prognostic certainty that the patient is going to die within six months and that the patient has capacity to make that decision, and we heard previously that that is very difficult to do under an advance direction currently. Therefore, your three leading causes of death do not fall into that bucket. I am sorry, but prognostic certainty is really difficult. It is difficult in heart failure and it is difficult in stroke.

Even from that perspective of looking exactly what it is, it is a very small number of Victorians who will be able to use this. There is a lot more who think that they are going to be able to use it than those who, in actuality, are going to be able to use it.

In the case I did last night I said to the palliative care physician, ‘I’m going to put you on the spot. Can you please give me a time when you think this woman is going to die?’ He said, ‘Yes, I actually do think it will be short weeks’—tick. He said ‘Short weeks’, but then a few weeks ago we thought it was a day or so. Prognostic ability in this area is not easy, yet you have to be able to say within six months or within 12 months of death.

**ACTING CHAIR:** Am I right in assuming that Professor White’s and Professor Willmott’s draft bill has no time line in it? Are you aware of that?

**Prof. Winch:** No, I have not seen their draft bill. I am not surprised they have done one, but I have not seen it. That is probably why, because we have done some joint research together.

**ACTING CHAIR:** You would say that VAD is not needed at this point in time?

**Prof. Winch:** I would say that, if you are looking at it from an ethical perspective, on autonomy and choice you need to make sure that you are offering people a true choice—that you are not saying to someone, ‘Here’s a glass of water and here’s a glass of sump oil.’ Do you know what I mean? They are being corralled into a particular area. I would like to see a balance in terms of the choice and then, going on the Victorian legislation, the investment for what is such a very small group. I have not seen Ben and Lindy’s draft bill. I know that people have had concerns about the narrowness of the Victorian legislation. That is diverting resources to benefit a very small number of people.

**ACTING CHAIR:** Which should come first? Palliative care or VAD for an individual?

**Prof. Winch:** I think it should be palliative care first and I would like to see an improvement in death literacy. I would not be surprised if anybody who has no association with people in the end-of-life field thinks, ‘Please, I’m going to have to move to Victoria and become a Victorian because death and dying is so terrible and I need to be there, because palliative care is a failure.’ I would not be surprised if many people are thinking that, and that is a real shame.

**ACTING CHAIR:** That comes down to education.

**Prof. Winch:** It comes down to education.

**Dr Mitchell:** And performance.

**Prof. Winch:** And performance.

**ACTING CHAIR:** You mentioned the HHSs. They can be used to pluck money out of palliative care. This week, we were in a town and staff from the HHS appeared before us. The HHS had budgeted \$17,000 for the year on palliative care, leaving aside the wages. I think that is an example of what you are getting at.

**Prof. Winch:** Yes. I will not name them, but there are some repeat offenders. One thing that this government can do through the HHSs is to say, ‘The palliative care money is protected and must be used for palliative care,’ and define the range of palliative care services across all the different areas. I think that is something that this government could do going forward. Geoff might want to comment more.

**Dr Mitchell:** We have objective A, which is about aged care, which is the big thing in terms of burden on the health system. I think it is going to become an intolerable problem by the time it is your turn and my turn. We have to look at the way the system works and get the system working in a way that maximises the potential of all parts of the service and makes them work together. That is not cheap and it requires a fundamental reshape of how state health works. If we do not, we are going to run out of money. We will be starting to get into the territory where VAD is seen as a humane option when it really is a symptom of a problem rather than a cure of a problem.

**ACTING CHAIR:** Do you think that in Queensland we need a statewide palliative care plan?

**Dr Mitchell:** I think we need a statewide integration plan.

**ACTING CHAIR:** Covering what?

**Dr Mitchell:** Everything—chronic disease, complex problems, multimorbidity and palliative care as part of it, remembering that I was talking about supportive care as being the start of the whole journey. There are a lot of very unwell people who are going to remain unwell and dependent on help from all parts of the system for years before they die but, if they do not get that help, they end up in crisis—they break their hip, they cannot move because they have not been able to move because their pain relief has not been applied properly. They are a burden on everyone when it is preventable.

If we look at the way the system works, there is this big wall between what happens inside the system and what happens outside. That unnecessarily complicates the whole thing. Breaking that wall down in the current state-Commonwealth divide is difficult, but it is not impossible. For example, if you think of the wall as a membrane, you can push state health out into the community—you still have the membrane there but provide integration, which is pretty much what we did in Ipswich with the case conference work that we did. It is doable. We just have to see the benefit.

**ACTING CHAIR:** Dr Mitchell and Professor Winch, thank you so kindly for being here today and taking our questions. We enjoyed your papers.

**Proceedings suspended from 3.06 pm to 3.19 pm.**

**DILLON, Dr Lisette Helen, Private capacity**

**GERDSEN, Ms Erika, Private capacity**

**McNEILL, Mr Dennis, Private capacity**

**ACTING CHAIR:** On behalf of the committee, I want to extend our full appreciation for you coming here today to give us your personal background and experience in relation to the issues that the committee is looking at. Bearing in mind that we have the submissions, I would like each of you to make an opening statement and then we will pose questions to you at the conclusion.

**Ms Gerdson:** Thank you very much. I would like to thank you for inviting me to be a witness at the public hearing. I am very honoured to have this opportunity. My journey into aged care, end of life, palliative care and death began on 9 August last year when we found my then 84-year-old father-in-law lying on his bedroom floor at around 11 o'clock in the morning. Later that day, we were told that he had suffered a severe stroke in his right occipital lobe and was going to be completely blind and paralysed down his left side for the rest of his life. He would require 24-hour care and it was recommended that he go into a nursing home. What none of us could have known was that just seven months later he would end up having another severe stroke, which hastened his end of life. In hindsight, this was a good thing, as his quality of life had changed rather dramatically and he did not want to live like that. Prior to his stroke, he was living alone in a house and was more or less independent.

What I would like to convey today is that, over those seven months, with the support of my partner and sister-in-law, I navigated an extremely confusing and imperfect system. I learned that you do not get what is on the box, that the packaging displays the ideal, but that is not the reality. All the brochures and websites with smiling, happy people and the high-level promises most of the time do not stack up. Instead, I encountered a clunky system that requires a client or their carer to jump through an awful lot of hoops and go around in circles. I came to learn that even those working within the system did not fully understand how things operate. I have a document that I would like to table today.

**ACTING CHAIR:** You are seeking leave to table it?

**Ms Gerdson:** Thank you.

**ACTING CHAIR:** Leave is granted.

**Ms Gerdson:** For those who cannot see it up close, it is a table spanning eight pages. This table is a summary of all the various entities I dealt with over those seven months. I sorted them into eight categories: hospital and rehabilitation, five; medical, 10; financial, two; government at a state level, four; government at a federal level, eight; service provider, nine; supplier, 13, and other, four. That is a total of 55. I interacted with 55 different entities over seven months, or 28 weeks. Some of the interactions were brief. I would make a phone call. They did not have what I was asking for, so I moved on. With others, once my father-in-law was fully engaged with that service, or whatever, there might have been daily interactions.

Let me expand things a little further. For each hospital or rehabilitation place, there was always a team consisting of a case manager, or team leader, a social worker, an OT, a physiotherapist, a dietitian, a speech therapist, plus various nursing staff providing the day-to-day care. Each time my father-in-law moved to another hospital, or rehabilitation place, we needed to meet a new team. Over the seven months, he met five OTs, five physiotherapists, five speech therapists and so on.

It does not stop there. One service changed OTs part-way through because someone returned from maternity leave and then the new service provider at home, after the rehabilitation program had finished, also had an OT who needed to meet my father-in-law to make sure that all the equipment issues were finally sorted. That is seven different OTs in seven months. Where is the consistency? Unfortunately, the discharge summaries do not entirely bridge that gap and each OT or whomever brings with them a different set of knowledge, skills and experience.

What we all found really disappointing was how quickly my father-in-law was moved from intensive rehabilitation to slow-stream rehabilitation. There was no private facility option for slow-stream rehabilitation and, disappointingly, the public facility was a huge backwards leap in terms of the individual attention that he had been receiving.

Once he was home, the community rehabilitation service was much better, but still not ideal, and the majority of the support needed had to come from the family. In the early stages, my father-in-law asked, 'How, am I supposed to go on like this?' My response was, 'We just have to make

the best of a bad situation. Anything else would be illegal.' Fortunately, he had sufficient wealth to pay for his own home modifications in a time frame of his choosing. He was also able to privately employ a few overnight carers so that the family did not have to do it all themselves. Fortunately, he had two children who lived locally and did not work full time, so they were able to play their part in ensuring that he could return home after rehabilitation.

What was even more fortunate was that 2½ years earlier his son had met me, an experienced disability support worker and coordinator. I gave up my three-day-a-week job, my weekly personal training and yoga sessions as well as my social life, including Facebook. I focused on providing my father-in-law with the best in-home experience any average person could hope for. Without these elements—the money and the family support—he would have most definitely experienced seven miserable months in a nursing home. At home he got the food he wanted, he got the attention he needed and he was consulted on all matters. We even brought in farm animals to his bed, because he was no longer keen to go outside—small farm animals, I should add.

When he had his final stroke and entered into a vegetative state just before lunch one day, we entered another unknown area around palliative care at home. This was also quite a shemozzle and a very distressing and upsetting time.

If you are feeling dizzy looking at that table that I have provided, just imagine you are in your 70s, you do not use email or internet very well—if at all—you have health problems of your own, you do not have any children nearby and you are receiving only a basic pension. How do you think you would manage as a carer or partner for someone after they have had a debilitating stroke?

In closing, I would like to thank Centrelink for the \$225 per fortnight I received for the 70-plus hours per week of high-quality care that I provided to just one disabled and elderly man. No wonder it is so much cheaper for the government if people are cared for at home.

**ACTING CHAIR:** Thank you very kindly. Can I say that your father-in-law was indeed a man blessed with a loving family who could help him during a very hard time. I think the effort that you put into caring for him, as did the rest of his family, shines through in what you have said here today. Congratulations in a very sad set of circumstances.

**ACTING CHAIR:** Dr Dillon, could we please have an opening statement from you?

**Dr Dillon:** First of all, I really appreciate the opportunity as a regular member of the community to contribute today. I am a community based JP and I do a regular roster at a local Magistrates Court. My role is to witness a wide range of documents that enable people to take the next step in life, whatever that might be. It might be anything from a house purchase, an arrest warrant, to a simple certified copy of qualifications for job application purposes.

In the full spectrum of witnessing, it is the important end-of-life documents, most notably being enduring powers of attorney, that arouse the most discussion, concern and, at times, anxiety among my regular active cohort of JPs. Simply put, we see too many things go wrong with end-of-life documents that leave elders vulnerable and exposed despite the intended goal of acting as a safeguard. Families can be left without recourse. They are fractured by the fallout and too humiliated to share a story among their own social network that exposes the behaviours of some of their family members.

As my submission partly relates to the role of a community JP, I feel it is also important for me to clarify that the role of a JP does not involve being an advice giver or change maker. That is not what it is about. People are typically grateful for our volunteer services, sometimes stressed and tend to trust the unpaid neutral space we operate in, we hear a lot of their stories. I hasten to say that private discussions of concern amongst JPs are 100 per cent deidentified, and there are no exceptions to that.

As an example of a typical EPA story—and this is in some ways a too common type of occurrence—you might have a mother with apparent good judgement, obviously full capacity, in her sixties. She appoints two responsible, caring daughters and not her wastrel son as her EPA. By her early eighties the mother's loss of capacity prompts serious health and safety concerns with her daughters. After careful consultation with a long-term family GP over a period of time and a visit to a specialist physician, who confirmed her dementia and provided a detailed report, the mother was subsequently placed in an aged-care facility. The daughters were caring, regular visitors. During a gap in shifts and a rare visit from the son the mother became very vocal and asked, 'Why am I here?' When she was told that it was a decision made by her names—her attorneys—on her EPA, she demanded to have it changed and asked for a solicitor. In the absence of a full geriatric assessment, the home and the son assisted. The solicitor complied and a new GP was appointed, who asked her

10 questions and determined that she had capacity. In the interim, the mother's car, items of home contents and her jewellery disappeared and were never traced. A complaint was lodged against the solicitor with the Law Society. The GP verified that she had asked 10 questions. Nothing could be done. The family is permanently disaffected.

I think that is typical of how individuals who pass a tipping point can mask their capacity for a 10-minute period. Some even learn the answers to ACAT questions, believe it or not, and they also are quite commanding and insistent for a short period of time. Paranoia causes them to then turn on trusted family members, and it is their condition that is speaking. They are not speaking to their original intent. We find with principals that documents are confusing and often poorly understood. Many principals do not understand that an EPA is a living document and a will is a death document—the most fundamental distinction between those documents. It may be signed off by a solicitor who has just received a four-figure amount for his service without that actually being properly pointed out to the principal, which I think is extraordinary. Attorneys can be ill-prepared and may manage elder decisions, finances and so on with any knowledge of systems or understanding of needs. Some will sign first before the principal, or they may not even know they have been nominated until suddenly it lands in front of them. They may be left to deal with complex issues without an obvious avenue for affordable advice.

From my perspective, end-of-life matters are about as real as life gets, but somehow or other some of the documents that are associated with that period of life do not match that level of seriousness, scrutiny and regulation. These matters do not just fit neatly into either a medical, legal or bureaucratic model. They need to be framed with the individual person at the centre where respect, compassion and person-focused care are paramount.

**ACTING CHAIR:** You have raised questions of elder abuse, documents being very complicated and people not quite understanding what they are signing going forward.

**Dr Dillon:** Correct.

**ACTING CHAIR:** We appreciate that as a committee.

**Mr McNeill:** Firstly, I would like to say that I am appreciative of the opportunity to speak here today. I provided an individual response to the committee. I am a Christian, and this is reflected in my response. In summary, I believe that greater emphasis should be placed on family, friends and community care and how government can support same without the community becoming reliant on funding. An example I gave was a concept called multigenerational living, which is something that the Japanese are familiar with. Improved awareness should be placed on a person's health during the years 40 to 65, thus reinforcing a concept that I raised called value in old age.

On the concept of dying, dying should allow the person and the family, friends and community of that person dignity. The time leading to passing should be supported with appropriate medications such as morphine where pain is significant. VAD does not provide an holistic approach to dying; rather, an approach where the wants of an individual are separated from the people who have provided them with care in the past. It is these people who are left to carry their story. A proactive, value rich approach to aged care will lessen the economic burden on government and build strength and resilience in ageing communities. I also put some effort into addressing the issues for consideration, which you all have a copy of. I will leave it at that. If anyone would like clarification or emphasis on anything, I am quite happy to answer your questions.

**ACTING CHAIR:** Thank you very kindly. Dignity is important in relation to the journey we are all on, and a dignified death is very important with family and friends around you.

**Mr McNeill:** Also the dignity of those who are left after the death. The family, friends and community that person was integral to, their story and their carrying of the dead person's story is an important concept as well, to have dignity in that.

**ACTING CHAIR:** Are there any questions from the committee?

**Mr O'ROURKE:** Dr Dillon, thank you for the information that you have provided. It is something that we have come across a few times over the years and in recent times. Do you have any suggestions on how we can do it better?

**Dr Dillon:** The first obvious thing is that documents are ambiguous and confusing and they are not accompanied by a very effective public education presence. There are pages and pages and pages of instructions at the front of an EPA before the signing block; however, those instructions are, I would say, read 0.5 per cent of the time or not at all. There has to be more accessible, better packaged and understandable explanations of the importance of the documents.

I think quality control around JPs is another issue. These documents are too important to be handled by people who maybe are not under any scrutiny in terms of their training or refresher courses dealing with end-of-life documents. I know that that applies to all documents, but in particular end-of-life documents or any document that leads to fraud or elder abuse clearly are heavily weighted in terms of a skill that is needed. If you have an EPA that someone believes they have responsibly prepared and signed sitting in their drawer for 10 years and it has not been properly executed, unknown to them it is a ticking time bomb. When the tipping point is reached where there is loss of capacity, then anybody involved with significant amounts of money such as the bank or superannuation company can then refuse. Family members then desperately go JP shopping for a weak link somewhere who does not feel the need to do a capacity check, which involves a very good number out of 15 important questions which all JPs are meant to understand and ask when they are witnessing an enduring power of attorney. Those are two areas: definitely improving the clarity and understandability of documents and the scrutiny of JP training, which I think it is quite ad hoc.

I also think we need some form of public education. Regular members of the public do not readily go and approach the Office of the Public Guardian or the Public Trustee all that easily. People do not know what the pathways are. There is no one simple, easy, accessible, affordable one-stop shop. I think that solicitors are notoriously happy to take money. I am not saying that that is across the board, but sometimes they are busy and do not always pay attention to the details of these documents and prompt to find out how much understanding the principal in front of them has. Those are some areas. I could go on, but those are the main ones.

**Mr O'ROURKE:** I have not reviewed those documents for a long time. The number of people who can witness signatures was quite broad. Is that still the case, or does it say that it has to be a qualified JP or solicitor? Are there a range of people who can witness signatures, particularly in relation to powers of attorney?

**Dr Dillon:** Solicitors and people with JP qualifications really should be the only people who sign them, yes.

**Mr O'ROURKE:** That is not the case at the moment, is it?

**Dr Dillon:** That is certainly my understanding. On a wheel, of course, you can have any two members of the community, so it is different again.

**Ms PEASE:** I would like to comment on Erika's story. My family and I have experienced circumstances but in probably a much better way. Both of my parents were sick and we had to take care of them. Fortunately, I have two sisters, so there were three tenacious women. My dad was the first one. We had to go nowhere near the same sorts of processes that you had did, but my sisters and I always said that it is difficult to navigate that process. If you are from a linguistically diverse background, if you are on your own or if you are elderly, it is difficult. I acknowledge that. I understand that some work is being done around the paperwork that goes with that. In terms of discussions around training, we have been talking to palliative care people, trainers and aged-care staff. I do not know whether there is some capacity in that space to provide coaching and direction to staff. Would it have helped your experience if the people you were dealing with were more compassionate and had more time to deal with you?

**Ms Gerdson:** Yes, and I think a lot of issues were about the clunkiness of the process. Once my father-in-law was home most of the community rehab team were mostly excellent. They still had limited time for their tasks, but I think he got better rehabilitation at home than in the residential place.

I cannot remember whether I put this in my original submission, but, in terms of the continence aids issue, I think in September I was told that it can take about eight weeks to process that form so 'Make sure you get that in early.' I was contacted by Ozcare community nurse, but she could not do it because he was still in a hospital environment. They were responsible. They just kept kicking that can down the road and I had to keep badgering people, 'I want that form done. I want that form done. Can you please get it done because I know it is going to take at least eight weeks to process it?' When it finally got done in January, there was then an unusual backlog. It was going to take three months to process the form. While he was still in the rehab program, they were providing all the continence aids he needed. As soon as they stopped, it was all up to him. I thought that for the next three months we have to go out and get this stuff.

**Ms PEASE:** That is what we need to look at—the streamlining.

**Ms Gerdson:** That is when I contacted the state member of parliament and, within a few days, someone from the minister's office rang and said, 'Oh, we are going to be making sure that is delivered to the home in the next few days.' Then we had this mass delivery and one of the pads was

the wrong size so we had to return them. Later on, one of the urine drainage bags leaked and then that had to be dealt with. There are all those other little hiccups which cannot be helped. That was one battle in among many others when we are trying just to care for somebody. That is just one little micro example of how things could be done a lot better.

**Ms PEASE:** It is lovely. From my experience, it is a real privilege to be there with loved ones.

**Ms Gerdson:** I still have both my parents to go through, so this was a bit of a dress rehearsal for me. Now that I have learnt a lot, I hope it is going to make it a bit easier.

**Ms PEASE:** Dr Dillon, thank you for your work in the community and for raising this important issue. You spoke about one particular instance concerning a resident in an aged-care facility, a solicitor was brought in and the EPA was changed. Do you think that an aged-care facility should facilitate those sorts of arrangements?

**Dr Dillon:** No, I do not. I am also aware that not everybody in an aged-care facility has the benefit of regular family members and support from family members who can take care of any requests on the part of the person who has a need of some sort. I do not think it should routinely without other checks be the role of a home to make contact on behalf of an elder regarding something as important as having a document changed. I think that there should be other safeguards. It simply is not right to have a document changed by somebody who does not have capacity when, in sound mind, their wishes were made very plain. What occurs when that is turned around by a home that may not have very much personal knowledge of that person's family context, their history or any of the important details that would prompt that kind of decision?

**Mr HUNT:** I thank all three of you for taking the time to make a submission to this committee inquiry and for coming along today to give a statement as well as answer some questions. Erika, I am frustrated just looking at this.

**Ms Gerdson:** Yes. These are all my notebooks. I brought them in just so you had an idea. I wrote down every single phone call that I made and face-to-face meetings. This does not capture everything. I do not know how many emails were sent over that time.

**Mr HUNT:** To take the time to diarise it and present it like this, I want to thank you very much. We do get submissions saying, 'You wouldn't believe what I went through.' To document it like this really illustrates the frustration of the navigation of this health system. This is for a man who I understand from the paperwork had private health insurance, too.

**Ms Gerdson:** Yes, that helped him in the first instance. He was able to go to intensive rehab in a private facility, but they could only allow him to stay so long. I think the standard was 28-30 days; they pushed it out to 45 or something. I have all the dates there and the days. He then had to go to a public place for the slow stream, and that was while we were still doing our renovation. We would have liked to have him home sooner. The in-home rehab was much better, but it takes a bit of time to do a whole new bathroom and get flooring changed in an older house, because he became a wheelchair user. There was not a private option after that intensive. The private health did not really help much after that.

**Mr HUNT:** That was an interesting observation too, because a lot of us assume that we are looking after ourselves by paying private health insurance, that everything will be looked after and that we will not have to go through all this. You mentioned getting in a form. The other day we visited a wonderful hospital, but I did notice a wall full of forms still in the emergency department that reminded me of the old police stations I used to work in. A couple of weeks ago a constituent had an issue with a fax being lost. I thought, 'Who is still using faxes?' There is no record of those sort of things. Thank you for bringing this to our attention. As I said, I am frustrated just reading it but it is good for to us get a good picture of the difficulties of someone as experienced as yourself to navigate.

**Ms Gerdson:** I am an experienced coordinator. How does somebody who has not had my background deal with it?

**Mr HUNT:** It paints a good picture for to us consider moving forward.

**Ms Gerdson:** I also thought whether it was state or federal was interesting. For example, coming back to the continence aids, for those who are eligible the state government provides them, but then there is a federal fund where they pop money into your bank account every six months. Why? That is two lots of forms to be completed. It is very confusing and it still is to do with continence. Why is there that differentiation?

**Mr HUNT:** As I look through the list of people you had to contact for various things, I am thinking of a way to make this better. Could it be a navigator or an advocate?

**Ms Gerdson:** One idea I had was that, when it was identified in hospital how severe his situation was, I would have loved to have had someone like me appointed to be on that journey all the way—a social worker or a case manager. They can then do all of that navigation, they would get to understand the systems better. Having the same rehab team would also be nice, but I can see how that could be complex when moving from a facility; but why can they not stay longer in the intensive rehab? I really thought it was a bit backwards too, because after you have a big stroke you are very fatigued. Having lots of things to do was hard, so just having a shower tired him out. They should ramp up the rehab once he is less fatigued, but it went from intensive to virtually nothing. In the public facility he had weekly sessions, but if he was asleep when they turned up they just left, did not come back and he missed out. Sometimes his rehab almost ground right down to a halt. That did not make any sense. I do not know whether people should have the same rehab team, physio and OT all the way through rather than people handing over the baton to the next one. That would be great, I think.

**ACTING CHAIR:** Mr McNeill, I refer to your conversation to the committee about dignity. You have a concern about VAD being an outcome that would benefit our community. Can you explain why that would be the case? Why would voluntary assisted dying not be of benefit?

**Mr McNeill:** First, I mentioned in my preamble that I was a Christian and that my understanding of VAD is that it closely resembles suicide, a state approved suicide. Therefore, my Christian belief is that—and I wrote in my response—there is a concept of God being the sole component of a person. I know that all people are not Christians. In a pluralistic democracy, there are other belief systems. People do not believe in God. However, from a Christian point of view, there is a system that is currently in place. I am not a medical practitioner. When a person has a terminal illness, they have been around for a long time. There are systems in place to deal with people who have terminal illnesses and for their end of life. My point is twofold. One is from a Christian perspective. God gives life and God is there when life goes away.

In families where a suicide has occurred, it is not an accepted concept that is spoken about. It is probably what might be referred to as 'taboo'. What if I have someone special in my life who has been part of my journey and the journey of other people? What if we have cared for that person for a considerable time and they are part of a community and part of a network? When a person dies through a system of palliative care where their pain is managed and their major organs cease to function, it is a part of a narrative that more likely would be picked up by their support network—that is, ultimately the people left on earth. The person who invokes VAD is not with those people any longer. I would prefer that family narrative is one where that person has a dignified end to life.

**ACTING CHAIR:** Thank you very much. Again, I thank all three of you for your time today. What you have told us will inform us and inform our report to the parliament in November. I do thank you for your time, effort and integrity as well. Clearly, you have a strong belief in what you have told the committee, and that came through very clearly. Before I formally close today's session, I want to thank a number of people. First, all those who appeared today and yesterday to give evidence. It has been very frank, open, honest and informative for committee members. I thank those who listened and heard what was said yesterday and today. There are a few faces I recognise from both days as well. Thank you for the interest.

I sincerely thank Melissa, Erin, Hansard, Zachary upstairs, Sue upstairs and also all parliamentary staff. One person in particular I want to thank is Rob Hansen. Rob is the secretary of the committee. Without Rob we would not be functioning whatsoever. Ladies and gentlemen and Rob Hansen, well done and congratulations. I also thank the committee members, because this is an emotive area. Believe it or not, we still are all human beings. We might be politicians, but we still have a sense of right and wrong and it is very emotional for us. To my colleagues, congratulations, including the member for Thuringowa, the chair, who could not be here this afternoon. I now formally close this hearing. We will meet again in due course. Thank you very much indeed, have a lovely weekend and travel safely.

**The committee adjourned at 3.58 pm.**