



HEALTH AND ENVIRONMENT COMMITTEE

Members present:

Mr AD Harper MP—Chair
Mr SSJ Andrew MP
Ms AB King MP
Mr R Molhoek MP
Ms JE Pease MP
Dr MA Robinson MP

Visiting Member:

Mr MC Berkman MP

Staff present:

Dr J Dewar—Committee Secretary

PUBLIC HEARING—INQUIRY INTO THE VOLUNTARY ASSISTED DYING BILL 2021

TRANSCRIPT OF PROCEEDINGS

MONDAY, 12 JULY 2021

Townsville

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The committee met at 1.09 pm.

CHAIR: Good afternoon. Welcome to the Health and Environment Committee's public hearing on the Voluntary Assisted Dying Bill. One of our traditional owner elders is with us today, and I would ask Dr Gracelyn Smallwood to do the welcome to country.

Dr Smallwood then gave a welcome to country—

CHAIR: Thank you very much. I would like to introduce the members of the committee. I am Aaron Harper, chair of the committee and member for Thuringowa. Mr Rob Molhoek, the member for Southport, is now deputy chair. Other committee members are: Mr Stephen Andrew, the member for Mirani; Ms Ali King, the member for Pumicestone; Ms Joan Pease, the member for Lytton; and Dr Mark Robinson, the member for Oodgeroo. Joining us today is Mr Michael Berkman MP, the member for Maiwar, a former member of the health committee who did quite a bit of consultation with us on the former inquiry.

The purpose of today's hearing is to assist the committee with its inquiry into the Voluntary Assisted Dying Bill 2021. The committee would like to thank all of the submitters who provided submissions to the inquiry. Those submissions will assist the committee with its consideration of the bill.

The hearing today is a formal proceeding of the parliament and is subject to the Legislative Assembly's standing rules and orders. I ask that mobile phones and other electronic devices be turned off or switched to silent mode. Hansard is recording the proceedings and you will be provided with a copy of the transcript. Later in today's program, after the registered speakers have finished, we will hear three-minute statements from members of the public who wish to come up and speak on the record. To do that, please liaise with our secretariat, Jacqui, to register your name and we will call you up to the table after the registered speakers. I would like apologise because we are running a little late, but we will adjust times accordingly.

CHAIR: I would like to welcome Dr Gracelyn Smallwood and Dr Stephen Hagan. If you would like to begin with an opening statement, then we will move to questions.

HAGAN, Dr Stephen, Chief Executive Officer, Townsville Aboriginal Islanders Health Services

SMALLWOOD, Dr Gracelyn OAM, Adjunct Professor, Division of Tropical Health and Medicine, James Cook University

Dr Smallwood: There is an urgent need to recalibrate the nation's moral compass on voluntary assisted dying. My name is Dr Professor Gracelyn Smallwood, and I have lived almost 70 years in Townsville and travelled the world. As a proud Birri Gubba South Sea Islander woman with a distinguished work history of over 50 years as a registered nurse, including 45 years as a midwife, providing quality care for all patients, both First Nation and mainstream, I make the following comment about voluntary assisted dying.

Before doing so, I wish to preface my views on this contentious topic by removing those myriad health hats that are applauded internationally and speak from a sanguine place where I believe common sense must trump political ambivalence parading as health reality. I speak to you today about the imperatives of recalibrating our moral compass. We must show compassion for those families, friends and associates who are terminally ill so that they, through inconsistencies in state legislation, should not have to endure pain and suffering to appease the sensibilities of influential players actively engaged in this controversial debate.

One of the favourite pastimes of Australians is gambling. With gambling losses of \$1,288 per adult, we rank No. 1 in the world as the biggest gamblers ahead of Singapore, Ireland and Canada. It is not unfamiliar for Aussie gamblers to witness a horse fall during a race meeting and think nothing of an ambulance arriving swiftly to the scene of the accident and for attending officers to assist those impacted by the unfortunate but sadly too frequent occurrence. When the unmistakable and deafening sound of gunshot comes from behind quickly erected covers, the punters are unambiguous

in thought that once again a prized and well-loved thoroughbred has run its last race and breathed its last breath. Why then cannot we, as a mature and sophisticated society, apply the same empathy we show for a gravely incapacitated horse that has been treated humanely and swiftly after a horrific race fall to someone's father, mother, sister, brother, son or daughter who has been dealt an awful hand with poor health. I am not talking about recklessly intervening in someone's life but rather to do so under the clear guidance of the Victorian Voluntary Assisted Dying Act 2017.

Voluntary assisted dying is legal in Victoria if a person is over 18 years of age, is an Australian citizen or has been a resident in that state for at least 12 months. The affected person must have the decision-making capacity. They must be diagnosed with a disease, illness or medical condition that is incurable, advanced and progressive and is expected to cause death within six months and is causing suffering to the person that cannot be relieved in a manner that the person finds tolerable.

Let us move on from fear around safety and that vulnerable members of our communities around the nation may be subject to being coerced into ending their lives at the convenience of others. The Churchill Fellowship study on how voluntary assisted dying laws worked overseas by Dr Linda Sheahan, in 2012, concluded that 'the slippery slope in terms of risk to vulnerable groups has not been demonstrated by the data'.

When punters at a race meeting witness a tragic fall, they do not jump the fence to intervene with arguments around the horse's culture, breed, athleticism and aesthetically pleasing attributes. They forgo all vexed reasoning to prolong the inevitable and allow common sense to prevail. With recent surveys showing around 80 per cent of Australians and around 70 per cent of New Zealanders supporting legislation for some kind of voluntary assisted dying, I believe the time is right in 2021 to implement uniform national policy on this matter that has or will impact every one of us during our lifetime. I wish the committee well and thank you for listening. God bless you all.

CHAIR: Thank you, Aunty Grace. Of course, in its former inquiry the committee consulted broadly with Queenslanders. We held 40-odd public hearings and thousands of submissions were received. One of the things the committee heard, particularly in rural and remote locations, was that people did not want to leave their communities but wanted to have support and care provided there rather than being transferred to a medical institution on the coast. In terms of the bill, there has been some discussion around telehealth and providing advice via telehealth. With your many years in clinical nursing practice and having connections through country to remote communities, do you have a view on whether telehealth is of benefit? Should it be considered when delivering advice around voluntary assisted dying if you do not have a specialist in a rural community?

Dr Smallwood: We very rarely have specialists in community and telehealth is absolutely imperative but not just for voluntary assisted dying; it is for all health care because, whether you are First Nations or non-First Nations, telehealth is the key to connecting with all of the medical and health professionals within the city.

CHAIR: Dr Stephen Hagan, do you have any views or commentary around this?

Dr Hagan: No, I am right, thank you.

Mr MOLHOEK: Dr Grace, I add my acknowledgement of country to that of yours and others. I pay my respects to elders past and present. I was really excited to see that you were appearing today. I have to say that your credentials and your contribution to Queensland and to the communities that you serve are absolutely outstanding so I feel very honoured to meet you today. That said, I have no real understanding of Aboriginal and Torres Strait Islander culture in respect of the issues that this legislation addresses. We have certainly heard from Go Gentle and many other organisations, although I was not part of the previous round of hearings. Where does the concept of voluntary assisted dying sit within Aboriginal and Torres Strait Islander heritage or culture?

Dr Smallwood: As you all know, my religion and culture have been around for 60,000 years. Our people have a very strict lore. Voluntary assisted dying was dealt with very culturally appropriately. There was no fuss. There were people not saying no or yes, because we had a team of elders and traditional healers and what we call ngangkaris who always dealt with that. If twins were born—and I am talking as a midwife—if the weaker one was very sick then the weaker one was sent to the creator. In saying that, with the controversy around this bill, I have had a lot to do with Christianity and I know the Bible inside out as Christianity was introduced to my people under the colonial act. However, I do understand why Christians are saying that they do not want this, that it is God's will.

From my clinical experience and from seeing people suffering so much and hearing the arguments of some of the doctors and nurses—I contacted 100 on the weekend and they said if they have quality palliative care that is fine. I say unless you are there seeing patients suffering terribly no

matter how much morphine you are giving them, because there is a strict law around that—and you have experts following me. When my mother had cancer, my father, my daughter-in-law, so many close friends, I was pleading to double the morphine because they were crying for help and asking. It was not so much my mum but my father and many friends, relatives and patients I did not know were crying for help. Of course you can have quality palliative care, but people's tolerance to pain is not the same right across the board. I have a girlfriend who has been suffering for six years. She is totally brain dead but she never put it in her will that she wants to go to her spiritual place. She could go on for another five years. The family are so traumatised about even visiting because she is fading away.

I am not speaking on behalf of all medical professional people. I am speaking from my clinical experience, not only in this town but all around Australia and I am a former consultant to the World Health Organization. I travel mostly to rural and remote communities but I also visit hospitals all around the world. I use the example of a horse or an animal. I love animals. I had to have two of my dogs put down. I suffered terribly putting the dogs down through the vet, but the vet said, 'It's time to put your baby down.' The dog was my baby. That is why I am speaking for the legislation. I know it is not going to be easy because I respect all people's cultural and religious values.

I guess it is up to the majority. I am sure that people have had someone within their family die of MS, HIV, cancer. I am not saying go out there and go crazy with anyone who has a disability. I am talking about a person who is suffering and if that person has put it in their will and the next of kin have spoken about it. Of course they have to have some form of board; it is not just, 'We want little Tommy to go because he is worth \$5 million.'

It has been a very painful journey, my 50 years of nursing. I have seen so much death and dying. I say I have been quite involved in Christianity because on average every two weeks I am at the funeral of one of my people from around the country. Christianity plays a very big role and I am very connected to high-rating Christians in this country. However, I am also very conscious that my religion is 60,000 years old and there was never a debate; if something went wrong, the elders made that decision.

Mr MOLHOEK: Further to that, the legislation proposes that there be a certain process of consultation with a couple of medical experts. Is that going to be a challenge or difficult for people in remote and regional areas?

Dr Smallwood: I do not believe it will be a challenge with telehealth. If you look at all the funding that is now going into First Nations health, if it is a challenge then the funding has to be reviewed because there is literally millions and millions of dollars going in to Aboriginal and Islander health to close the gap. It is about where this funding is being spent. We have telehealth. We have Zoom. We can send a man to the moon and we are one of the wealthiest countries in the world. We should not even be having a problem with connection with community to the hospital staff and to the city and the doctors, nurses and health professionals and, of course, the family and the next of kin must play a major role.

Mr MOLHOEK: I will defer to others. I would love to sit and chat with you for a while about a range of Indigenous issues. There are so many things that we could be talking about. Thank you.

Ms KING: Dr Smallwood, I felt very lucky to have a chance to look over some of your published works, including your thesis. I felt very privileged to get to do that. Listening to you speak, I am struck by the nexus of your clinical experience and your cultural knowledge and wisdom that you bring. If these laws are passed, are there any steps that we could recommend to make sure that these laws are as sensitive as possible to the needs of First Nations people in community where these laws and voluntary assisted dying would become available?

Dr Smallwood: There is the Closing the Gap strategy, the reconciliation action plans and the employment of senior key Aboriginal and Islander people throughout the state, and cross-culture is now becoming mandatory across the board, but all of those things have taken a while to happen. Just to give a very quick example, when my mother was dying Dr Cairns was her doctor. We nursed her at home for quite some time. She had 24-hour palliative care. Not everyone else has that privilege. Of course, I was the key player. We have lore. We have totems. We have the positive totem and then we have the negative one. Twenty-four hours before she passed away, she called us all to the bed and said, 'The death totem visited me last night and I don't want my spirit floating around my house. Could you take me to the hospital?' We all went up. We all said our farewells in the house and she went up to palliative care. She crossed over within 24 hours. She had clearly told us what the death totem said. We have two death totems. She showed us. That is one of the many cultural norms that our people have practised for 60,000 years. Not all have practised because of the impact of Townsville

colonisation, but my family has been very privileged to have had both worlds—both the cultural and the western side. We are always talking, especially when you are close to death and dying, that we have to pass on to the next of kin and to the medical staff what we want. All the staff should now be competent. For all doctors and all nurses, compulsory cross-culture training should be made available for them because too many mistakes have been made in the last 100 or 200 years on their behalf and not our behalf.

We have to establish a state Indigenous advisory body on this topic because it is such a sensitive topic. Many of my people are born-again Christians. I even went to church yesterday and sang in church and spoke to them all and told them what I was doing tomorrow and they all laid hands on me, calling out to Jesus. That was not making a mockery, because my sister is the local pastor there. I spoke to Dr Rod Wall, I spoke to many Catholic priests and nuns—all people that I totally respect. But this death and dying—each and every one of us who look very healthy today, just picture yourself if you have cancer or MS or HIV or COVID, gasping for breath, and your beautiful children and grandchildren are sitting there holding your hand and watching you deteriorate and screaming in pain for help and going on for quite some time when they all know you as very active members not only in the family but in the community.

Ms KING: As you have looked at the legislation you will have seen that we have the care navigator service that is an important part of the legislation. Would you like to see a First Nations voice included in that care navigator service to make sure it has that sensitivity?

Dr Smallwood: Absolutely—without a doubt, as I talked about the Indigenous advisory committee. For any society—it does not matter what race—that has survived in such a harsh continent like Australia for 60,000 years, they had to be doing something correct, and our visitors of 230 years. We have a mess in the country. We have a mess everywhere and it is everyone's business. We need to work together. I am very pleased with reconciliation action plans. I am very pleased with mandatory true history in the education system. I am very pleased with the changes that have been made under this state Labor government. We have to start somewhere. From little things big things grow. I believe that there has to be a dominance of an Indigenous group of people that is advising the government. I was one of Wayne Goss's advisers many years ago and we had an Indigenous advisory committee for the whole state and we were kicking goals.

Dr ROBINSON: Dr Smallwood, it is nice to meet you again, and Dr Hagan as well. With the indulgence of the committee, having lived in Townsville in the eighties I met some of the Smallwood family and was involved also in tutoring with Cecilia Stanley and some of the Aboriginal and Islander education work. I appreciate connecting with you again today. I commend you on all that you do in Aboriginal health and in health generally.

I have a couple of questions, and if we had more time lots of questions, and I will try to keep it very tight today. I want to agree with you absolutely, as a fellow Christian and as a pastor myself as well, that showing compassion is really important and caring for the suffering and those in intolerable pain. I want to agree with you on that. There is a view shared by Palliative Care Queensland and others in the AMA that the biggest issue is the underfunding of palliative care, and that goes along with all end-of-life treatment and care and issues identified in terms of servicing remote and rural areas of Queensland. Could a lot of the suffering be alleviated by a greater focus and investment in palliative care that, according to Palliative Care Queensland and the AMA, is underfunded in terms of Indigenous perspectives? I wonder if you could make some comment.

Dr Smallwood: Without a doubt, but everyone is underfunded. Let us not fool ourselves, First Nations health is the worst in the world per head of population. I believe that we must have respected cultural advisers, not just in palliative care but right across the board. I believe it is happening but, yes, palliative care does need a lot more funding. I have worked in that ward and am always very sad when I go home because, even though you are not to get attached to patients, I have got attached to complete strangers and the pain of seeing the family. I worked under Dr Will Cairns and the staff and we all learned from each other. I have always been very outspoken as a human rights activist, but when I walk into the hospital every patient is my patient. I never judge them, but I used to feel so sad if they took quite too long to cross over. As long as they prepared themselves for the spiritual world, and you as a Christian would know—before they go into that deep unconsciousness you talk to them about 'What do you want to do about your spiritual otherworld?' Some people say, 'I don't believe in a spiritual world. I'm an atheist,' but a large percentage that I know of who are dying either have their Aboriginal lore and culture, their own cultural lore, but Christians in particular believe they are going to go to heaven to Jesus, so that all needs to be sorted out before they go into their deep unconsciousness.

Dr ROBINSON: I appreciate that previously you mentioned trying to find a balance and concerns about areas like coercion and how in the wider community we approach this in a way so that it is their wishes at end of life. As a Christian, I do not support the legislation, I have to say, because of gaps that I believe are in there and I do have a view that life is sacred, but I am trying to work those things through in my community. My question goes to some of the latest research that has just come out in 2019 and I want to get your comment on it. In a recent data study that came out in Oregon, they found that 59 per cent of patients that access VAD treatment cited feeling like they were a burden on society and that what others felt was a factor in their decision to take their own life according to VAD or assisted suicide, depending what you call it. If we lift the lid on what some would call a Pandora's box, could that result in forms of elder abuse and coercion as has happened in other parts of the world?

Dr Smallwood: In Australia we have learned from other countries. We have also learned that people cannot afford to go over to Switzerland to take their life. That is for wealthy people. With the statistics of cancer, of course it can be abused, like any legislation. A lot of common sense has to prevail here, which is why they have to have a team of people—Christians, non-Christians, atheists or whatever—because we have to watch what happened overseas and we can learn from their mistakes. People are saying, 'If I get cancer or if I get MS, I am going to have a concoction ready and I am going to take my life.' If we have it that they understand—and if people cannot read and write you have to get interpreters in—that we are not asking them to take their life; we are asking what they want and then talk to their family and hopefully before they go into unconsciousness—

Dr ROBINSON: On that basis, do you think there should be specialists involved in the process? At this point the legislation proposes just two doctors, but there is no psychiatrist to deal with mental health, there is no palliative care specialist to ensure that proper palliation has occurred and there are no cultural specialists involved in the process. Do you think the legislation would be improved and protection strengthened with strengthening that medical area?

CHAIR: Dr Gracelyn might be aware that there are safeguards within the bill.

Dr Smallwood: There are safeguards. I suppose the more professionals the better with different views. It is probably one of the hardest challenges, euthanasia, and the data is very challenging. Sometimes we find that research is not really happening on the ground. I am sure that if this legislation does go through they will have a look at that and say, 'We will not just have two doctors.' They might increase it to make things look more transparent. I know doctors that are born-again Christians. I know doctors that are atheists. You just cannot have everyone running that same mile with the same views. Yes, it would be great if there were a few more professionals, but I am sure that is going to happen with the view of the community. This is the view of community and people who have had a bit of experience.

Mr BERKMAN: Thank you, Dr Smallwood. We appreciate you being here to share your perspectives. You have already touched on the importance of telehealth, in your view, in delivering a scheme like this. You might be aware, though, that there is a bit of a legal grey zone that exists around Commonwealth and state legislation around the so-called use of a carrier service to incite suicide. How important do you think it is that that is cleared up to make sure telehealth is available for a scheme like this to operate equitably across the whole state?

Dr Smallwood: I like what you said about a bit of a difference between the state and Commonwealth. This country is known for major differences between the Commonwealth and the states and they all have to come together because this is a very sensitive topic. The worry I have is that sometimes there is a project done with a political party that is working, and sometimes the opposition comes in—it does not matter what party it is—and takes away all of the hard labour that has been done. It is imperative, if this is going to go through, that the Commonwealth and state come together as one for the welfare of all of Australia.

Mr BERKMAN: On telehealth specifically? It is imperative that that is available to practitioners under a scheme like this?

Dr Smallwood: Telehealth is imperative. I was delivering babies in the early seventies with no technology in the Pinjarra lands—no telephone—and you were it so anything is an improvement. Telehealth must be a priority and for state and federal governments to come together. It is about human and monetary resources. They must be funded. We have to take money from the greedy and start giving to the needy.

Mr BERKMAN: Well said. Thank you.

Mr ANDREW: Great to see you, Dr Smallwood. We are kind of related through Aunty Joan Fatnowna and also Robyn Baggo and the Baggos. On the First Nations side of the bill, are there enough amendments in there to protect what you and the First Nations people throughout Queensland see as being enough protection in there? Will you look to run amendments to ensure that?

Dr Smallwood: Absolutely, which is why I have talked about the First Nations respected people on an advisory committee. The politicians know who is who in the zoo. My grandmother is a Baggo and we are connected. A lot of our people over the last 200 years have had not so much faith in bureaucracy. We have to change that by giving them hope and faith, because we have a long way to go in not only closing the gap but also race relations. There will be, no doubt, time for amendments, not just for First Nations people but for all the community.

CHAIR: We appreciate your contributions today.

CAIRNS, Dr Will OAM, Private capacity

CHAIR: Thank you for being here today. You did come before the former inquiry into this subject. I might start by asking if you would like to make a brief statement, particularly around your background and qualifications, and then we will move to questions.

Dr Cairns: Thank you, Mr Chairman. Thank you for inviting me along to speak today. I would first like to acknowledge the traditional owners of the land we are meeting on today. Gracelyn and I have known each other actually for 41 years, because we were both working on the same ward. She was a new nurse and I was a junior doctor. Our paths have crossed, as she mentioned, with her mother's care but over many years.

My wife and I came to Townsville in 1978 for 18 months—and we are still here. I worked as a GP from 1982 to 2000 and in the mid to late 1980s I really became interested in palliative care through the need to look after my patients as a GP, which I did very badly because there was no training or skills for us then. Over the next few years I helped established the palliative care service in Townsville and I was director of palliative care here from 1992 until 2016, and I moved full time to specialist palliative care from the year 2000. Over the years I have held a number of regional, state and national leadership roles in the creation of a specialty of palliative medicine and the development of palliative care in Australia. I will not go on with all the different jobs because there are probably about 15 or 20 of them.

There are a few key points that I think can help with the discussion and thought about the voluntary assisted dying legislation and the issue in general. For palliative care, voluntary assisted dying has been an issue which we have been addressing for many years, really since we first were created, because that coincided with the development of the legislation in the Northern Territory that allowed euthanasia for a short period of time. I think it is fair to say that our community of palliative care have the same diversity of views as the general population, from strong support to vehement opposition. I am not quite sure how the numbers fall, but I suspect that we are more, as a group, tending towards opposition, although I am not sure where the numbers lie.

Anyway, eventually, after much argument and discussion internally, we realised it was actually impeding our ability to develop palliative care, so we agreed not to talk about voluntary assisted dying and euthanasia because we had a large amount of work to do in the development of palliative care and it was distracting us. We felt that our organisation should take a neutral stance.

When I was president of the Society of Palliative Medicine, we created a position statement which said that VAD is not part of palliative care. Since that time, Palliative Care Australia has found more or less the same thing—that voluntary assisted dying is not a component of palliative care. While we may have views on it, they should not interfere with our ability to do what we do; nor should palliative care be construed as either promoting or opposing voluntary assisted dying, because we felt that that would distract from our ability to do what we do; and nor that palliative care should be a solution for avoiding request for voluntary assisted dying. In fact, in Oregon, 90 per cent-plus of patients who request VAD are registered with a hospice and palliative care service, so I think that is a fair indicator.

Our position now is that if we were to engage in voluntary assisted dying it would be outside the bounds of our specialty. Most people are familiar with Venn diagrams. The Venn diagram of palliative care is one circle and the Venn diagram of voluntary assisted dying is outside, so they do not intersect. That leaves the practitioners of palliative care feeling that they can do the full gamut of what we do and still remain separate from VAD. If we were to take it on—and some people may or may not, and have and have not in other states—then we would be stepping outside the bounds of palliative care. It is really important for patients to be able to say that palliative care does not include VAD: 'If I go to palliative care from the palliative care service, that is not something that I will be receiving.'

Our focus really—and from the conversation I had last week with one of the leaders of palliative care in Victoria—is that our goal is to offer palliative care to everyone irrespective of their beliefs and their plans. In the Northern Territory, when the terminally ill bill was active, the palliative care service there made the decision that they would continue to deliver palliative care for all patients until such time as they died, even if they had been planning to engage in voluntary assisted dying in the future. My own view is that, really, our main role is to help people to find peace about their dying through their own beliefs, and what I may or may not believe is not really relevant to their ability to find their peace. Palliative care is best defined as patient centred, whole-person care.

The second point I would like to discuss is that over the past 30 years as I have cared for perhaps 7,000 to 10,000 dying people, plus their families, commonly I found patients who appeared distressed. I often ask them, 'Are you fearful or worried about anything?' The answer might be, 'I am afraid of dying.' I would reply—and this may sound a bit flippant, but I do not think any patient took it as flippant—'Do you mean being there or getting there?', then follow that up with, 'Are you worried about the process of dying or what happens to us after we are dead?' The vast majority of people were not too concerned about being dead. Most of them said things like, 'There is not much you can do about being dead. You just have to live with it,' or, 'I have very strong faith and therefore I am not concerned about what happens to me after I die,' or, 'I have no faith, therefore I have no concern about what happens to me after I die.' People were finding their own solutions to those questions. However, they said, 'I am more worried about my symptoms.' Depending on their disease, that might be pain or breathlessness or general weakness. 'What is going to happen to my family? How will they cope when I am dying? What will happen after I have died?' It might be about loss of control or dignity and, 'Who will look after me? Where will I be? Will I have to go into hospital?' There was a whole range of things that gave people concern. In other words, far more people were concerned about issues of the here and now, and many of these can be addressed by good care and palliative care—that is what we do in our work—but not all, and that is pretty obvious from the data from Oregon.

The third thing I would like to talk about is the changing community perceptions of the locus of control. Locus of control is the extent to which we, as opposed to outside agents, make decisions on our behalf and control our thoughts. I noted a letter that was sent from Catholic Health Australia to the South Australian health minister regarding their legislation, and it was concerning the issue of access to voluntary assisted dying discussions in institutions that do not support voluntary assisted dying. That suggested that allowing that to happen—I am quoting here—'might override decisions of, or make decisions in lieu of, the medical practitioner who is directly responsible for a patient's care and wellbeing'.

Over my career I have noticed that the relationship between doctors and our patients has changed significantly. Patients now make their own decisions from the options they are offered by their doctors. Advance care planning and consent are now at the core of medical practice, even though, and appropriately, the default position is to engage in life-prolonging treatment without instruction from the patient. However, patients do have the right to refuse or to withdraw from treatment. Perhaps one of the best examples of that is people who have been having renal dialysis for a period of time, maybe even decades, and then decide that they have come to the point where they have had enough of the life they have been leading and their time has come to let go. They know they can stay on dialysis and it might draw out the end of their life but their quality would be severely diminished. They are in a position where they have an exit ticket, if you like. They can stop their dialysis and within about two weeks, on average, they will die from kidney failure, often very peacefully with sedation just from their disease. Many people accept that as a very reasonable behaviour. People who do not have renal failure do not have the same option to control the timing of their death. They may not have anything to withdraw from that is sustaining their life.

The other thing about the issue of control is that communities actually hold a range of beliefs at variance with the leaders who might believe that they have control, to have the power to determine belief about what we should believe—that is a convoluted sentence at the best of times.

Finally, most importantly, for those of us who work in palliative care, we have promoted the normalisation of death and the acceptance of dying so that our patients can find a place of peace. We encourage and support people to make the transition from pursuit of cure and avoidance of death that has characterised much of modern medical practice to the acceptance of the normality of death and dying. For me, it is not really surprising that, without fear and in an era where people have decided they have the right to control their own lives, some may decide that the time has come for them to end their life, that they would like to opt out of the unpleasant bit at the end, not just for themselves but also for the sake of their families who they feel responsibility for, to sometimes step aside.

There are a number of areas in the legislation—first of all, conscientious objection. As I said, I had a long conversation with one of my colleagues in Melbourne about how, in his religiously based institution, they have dealt with that. The question of coercion goes both ways. People might be coerced to participate in voluntary assisted dying, but then they may also be coerced to not do something they wish to do and that is legal. I think reporting requirements need to accommodate that.

I think the issue of communication is really important in our very large state. First of all, the Commonwealth law does seem to cause obstacles for using the technology which has become the norm, and particularly in mask-wearing COVID time, but also for people in remote areas to be assured that, if we do have legislation that allows voluntary assisted dying, people, wherever they live in the Townsville

state, can access it without having to travel vast distances to complete assessments. While I agree with the comments expressed a short time ago about the need to ensure appropriate assessment of patients for their suitability, I think that should not mean that we make the process of getting approval for voluntary assisted dying so challenging that people will not avail themselves of it. It is hugely disruptive. We have a friend who has a motor neurone disease-like illness, and him having to travel a few hundred kilometres or even 50 kilometres for an assessment would be beyond his ability. That is really the final observation of my remarks. Thank you.

CHAIR: Thank you very much, Dr Cairns. Firstly, can I just remark and say thank you for the work you have done in palliative care. For all of those people who work in palliative care, who are looking after people who are diagnosed with terrible terminal illnesses, I am sure I speak on behalf of the committee when I thank them for the work that they do. It is very much to be acknowledged.

You did come before the last inquiry, and I have struggled to always find through the reports some wording you use. I ask you the two-part question again. As you are someone who has treated 7,000 to 10,000 dying people in your career, can palliative care, despite the best modernisation in pain relief, relieve pain and suffering in everyone all of the time? Secondly, should people have choice, in your view, of accessing a voluntary assisted dying scheme if it was legislated?

Dr Cairns: To the first part of the question, I think there are very few palliative care professionals who believe we can resolve all of the issues from which people are suffering at the end of their life. We are pretty good at controlling pain but certainly not to 100 per cent. Some people have some pretty horrible things which we cannot fix. I will not go into graphic detail, but there are some dreadful scenarios that people find themselves in.

CHAIR: I would actually appreciate it if you could give an example.

Dr Cairns: With some pelvic cancers, people may have had an operation which allows their kidneys to keep functioning and they have a stoma inserted for their bowels, yet they have invasive disease invading the nerves to the bottom half of their body. None of their vital bodily functions are impaired in any way, so they have normal kidney function, the bowel still works and they can still eat, but they have locally invasive disease invading their spine, pelvis, legs and nerves and blocking their lymphatics so their legs are swollen up and they cannot walk. This localised bottom-half-of-the-body disease does not kill them, for example. There are many things you can do to ameliorate the pain, but some people find themselves in terrible physical distress, and I think that is borne out of the evidence from Oregon. That is the kind of thing I can think of. Head and neck cancers are the same kind of thing, where someone has an airway which is not obstructed. That is not to say that everybody who has those symptoms would choose to have voluntary assisted dying, but I think the key thing in the descriptions of the reasons that people might want voluntary assisted dying is that it is insufferable from their point of view, not from someone else's. It can also be about non-physical distress that people are experiencing at the end of their life.

I think there is also a cohort of people who accept the tide of the time has brought them to the end of their life and they would be willing to say, 'Okay, I think my time is up now. I have had a really good life. I have a life-limiting illness. My life expectancy is very short and I would much rather have a short end to my life than a long, drawn-out end to my life.' Does that address the first part of your question? I do not think we can guarantee that we can resolve those issues because sometimes they are deeply embedded in someone's psyche, and they are not in someone who is not depressed.

To answer the second part of your question, during my career in palliative care and palliative medicine I felt that my role was to promote palliative care and not be publicly too forward about discussing my views on voluntary assisted dying, because I thought that would distract from what I can do. One of the key things is not to conflate palliative care with voluntary assisted dying. If I as the director of palliative care were to have been talking about voluntary assisted dying in the same paragraph or chapter of my conversation, I might be implying that they were related. I think it is important that they be kept separate. Throughout my life I have always been supportive of people's right to engage in voluntary assisted dying, with appropriate safeguards obviously.

CHAIR: Are you of the view that people should have choice?

Dr Cairns: I am of the view that people should have choice to access voluntary assisted dying, obviously under suitable conditions and with the safety constraints.

Ms PEASE: I begin by thanking you for the great work that you and all palliative specialists do. I know that many GPs who started in GP practice have been with people from their birth, watched them raise their families and helped them at the end of their life. Thank you. It is a lovely road and a real privilege for you to be able to do that, and it is lovely for me to be able to thank you for that. You
Townsville

have spoken about the intolerable pain that some of your patients at the end of life might be suffering where sometimes the medication is not cutting through. Have any of your patients ever begged for their time to be ended?

Dr Cairns: Many people have requested, but I am not someone who would break the law. One of our duties as a palliative care doctor is to discuss these issues with patients, but we also have to say that this is not something we can do within the law. I have had many patients who have raised the issue of ending their life. I have said, 'Well, that is not something that I can do within the law but I can talk to you about what your reasons are.'

Ms PEASE: On the flipside of that, you mentioned in your opening statement that occasionally patients are given treatment, which might not necessarily work, to increase the length of time they have. Sometimes family members or loved ones seek that intervention. Have you come across that very often?

Dr Cairns: It is not uncommon for family members to wish that their relative not die, and sometimes patients wish something along that line. There are a couple of things. One is if someone becomes unable to swallow putting in a feeding tube. Say it is someone who has motor neurone disease, for example. It used to be that people would put in feeding tubes at the first signs they were having difficulty, sometimes without discussing it with the patient. It was just the norm of the things that were done. Now people realise that it actually did not prolong people's life particularly and just put them more at risk of side effects and complications. Sometimes family members are keen for people to have a tube put in for feeding when people stop eating. Part of the discussion with the family is about what the goals are but also reframing their perspective on what is happening. I would say to someone, 'Why do you think they are not eating?' 'Oh, they are not hungry.' There is a sense that if you gave them food they would actually get better or be better. I try to reframe it as, 'Actually, it is not the case that they are dying because they are not eating; they are not eating because they are dying.' If you think of it as the other way around, then people could come to a better acceptance of what is happening.

The other thing is to talk about the scope and nature of their disease or sometimes show them the scans they may not have seen that explain why—if for example they have a brain tumour—they are not interacting in the same way. If you see a great big lump somewhere, that helps to understand things as well. Part of it is the conversation and the communication about what the goals are and what is likely to be achieved for the person. I have had a few patients who have committed suicide. One in particular shot himself because he was not able to do the things that he always enjoyed doing. That is how he measured the quality of his life.

Ms PEASE: Can you perhaps elaborate on that a little bit more? How many numbers would you be able to indicate to me?

Dr Cairns: As with the number of patients I have seen over the years, I never kept score. I suppose I should have over the years. Not many have committed suicide by violent means, but I think there may be some people who have used more of their medications than prescribed. It is very hard to know when people are going to die. We make predictions. Even the experts in oncology find it very difficult to predict someone's life expectancy, and things happen suddenly. You can have patients in the ward who seem the same as they were for the last three weeks and suddenly, as with Gracelyn's mother, they call in the family and have a little talk to them and then they die that night. To look at them they are not any different, but they know they feel different.

Ms PEASE: Potentially, it is no different than the person on dialysis, as you discussed earlier, who makes a decision to go off dialysis and know that their time is limited. There is potential that when some of the patients you have dealt with—between 7,000 and 10,000 people—learn that they have a life-limiting disease they make a choice?

Dr Cairns: I think people can let go but sometimes nothing happens. I have known people who have decided that they did not want to go on anymore and they are sort of sitting there looking around waiting for something to happen. I remember one man who had some bone marrow disease—I think it was prostate cancer taking over his bone marrow—and was sustained by red blood cells and platelet transfusions. He decided that he was going to stop and that he would die the same day. When we explained to him that it does not mean it is going to happen that way, he was sitting there getting more and more distressed. I had a talk with him about what was going on and that sometimes things do not happen when you think they will and that the best thing to do, if he could manage, is relax about it, enjoy the company of family and then the clock will take care of itself.

Mr MOLHOEK: Thank you, Dr Cairns, for your incredible life's work and commitment to helping people. It is humbling to hear some of the stories and to be here with you today. The legislation as proposed is quite specific around the fact that a practitioner cannot encourage someone to consider Townsville

voluntary assisted dying as an option but, rather, it has to come as a voluntary request from the person with a terminal disease. How do you see that working practically? It sounds to me from some of the dialogue today—you have obviously had a very close relationship with many of your patients. How does that work in practice and how do you ensure that you do not end up being prosecuted for perhaps offering something that could have been misconstrued?

Dr Cairns: I guess it depends on how you define the question of who initiates things. If patients are talking about their future and they start talking about maybe not wanting to be here anymore or say, 'I've had enough,' and you say, 'What do you mean by that?,' I think it would be a reasonable thing to do. Otherwise, if you were just to ignore a statement that the patient makes, that would be an abrogation of your duty to inquire about something that is distressing someone. You could say that it depends on how it is done, and that would be hard to assess perhaps. I think all of medicine relies on honesty and candour, and that that applies to the way we record what we do in the way we interact with our patients. Our moral and professional duty is to be supportive and to help people explore their difficulties and to be honest and open about things we do and to act within the law.

Mr MOLHOEK: You may not be able to answer this question, but do you think the legislation is clear enough in protecting practitioners from those sorts of conversations in terms of any sort of legal recourse or prosecution down the track?

Dr Cairns: My understanding is that it is not as obstructive as the Victorian legislation, which I think is very problematic for doctors in terms of what they are able to say. As I said, if you are exploring with people the issues that are important for them and they have raised the topic in terms of their distress about how long they might be living, even a question, depending on their response, would be the way that I would address that professionally.

Mr MOLHOEK: One of the submitters—I think it was Cherish Life—said in their submission that they feel that by introducing these laws it will discourage a lot of people from wanting to practise medicine for fear of having to have these sorts of conversations.

Dr Cairns: I cannot see that many people withdraw, because they have a right to conscientiously object and not participate in the process. I think that is really important. There is always a tension between the right of people's conscientious objection and the rights of patients to have things which are legal. It would be interesting to see whether that has caused big problems in Victoria, for example, where the laws have been in place for a while—or in Oregon as well.

Ms KING: May I make a brief contribution, Chair? I just want to reflect very briefly—perhaps for you to make a response to—that the provisions of the legislation allow a healthcare provider to raise the issue of voluntary assisted dying where they are also raising issues of all of the full range of the person's treatment options, including palliative care and continuing treatment. That is just in case there was any confusion.

Mr MOLHOEK: Sorry, I was not seeking to confuse the issue; I was just wanting to get a response from someone who—

Dr Cairns: The description you gave seemed to me to be more like the Victorian legislation rather than what I read.

Mr MOLHOEK: My concern was more that it seems to me that there is a fine line between providing advice and being asked to provide the advice and how that could be interpreted in different settings, depending on how the family or others are after the fact. I guess that is something that doctors would generally deal with.

Dr Cairns: There is also a fine line between being facilitating and being obstructive, too. It works across the spectrum. Issues arise about how we react in ways that reflect our beliefs versus the patient's beliefs. There is a tension in the whole exercise that is almost unavoidable, but acting in good faith is the important thing.

CHAIR: Chapter 17 of the Queensland Law Reform Commission talks about compliance and protection from liability, health practitioners' duties and health practitioner regulation. That certainly goes to the detail of talking to patients and raising the issue.

Ms KING: Including that steps taken in good faith do not expose medical practitioners to liability. I have two fairly brief questions. One is about the large number of people in Victoria who go through the process of accessing voluntary assisted dying and then do not proceed to take the steps, in some cases presumably because they pass away before they get a chance. There is speculation that there may be an emotional or psychological value to those people in knowing that they have that option. I wonder if in your experience as a palliative care provider you can comment on that.

Dr Cairns: When I looked at the Oregon data from 2019, I think about 40 per cent of people who had prescriptions did not proceed to use the medication—or were given prescriptions. Whether they got them filled I am not sure. As I was saying in my introduction about locus of control, for many people the important thing is that they control their own life. I think that, for many of us, if we are told we cannot do something our first reaction is to think, ‘Yes, I can,’ but then the second question might be, ‘Do I really want to?’ People may make the request while not knowing exactly how the disease is going to progress or what issues will arise for them, so maybe the things they fear will not happen. If there is a reasonable chance that they will or circumstances change for some reason, they may not do it, but they have the option to refuse. I think that is where the issue of voluntary assisted dying, where you have to have capacity at the time, is really important so that the outcomes for people can reflect the fact that it has been about their control.

It might be very interesting to work out what the differences were between those who did not use the medication and those who did in terms of their disease, but that is a question that can only be answered when you have actually found out how many people do and looked at a retrospective analysis of the data. That is part of a case which perhaps needs to be made for more intensive reporting from the regulatory organisations, because I think if we are to look at the pluses and minuses of voluntary assisted dying then you have to collect the data, and that means the fairly comprehensive collection of information about the circumstances of individual patients. It may seem a bit intrusive, but that is the only way you are really going to find out.

Ms KING: Would you like the committee to recommend further and greater data collection in the implementation phase perhaps?

Dr Cairns: I think certainly there should be careful thought given to what data you want to collect from the outset, but really there will not be any data coming out of the analysis of the results until after it has been going for a year. Obviously the first year, like all new projects, might be a bit scant on data. I think in Victoria they had more patients than they had anticipated. From a conversation with my colleague in Melbourne last week, there were a whole number of issues that turned out to be more complex than they thought. Actually, the solutions they found worked out pretty well as far as he was concerned from his perspective.

Ms KING: The QLRC’s aims were to produce legislation that was safe, accessible and compassionate. Do you feel they have been successful with the draft Voluntary Assisted Dying Bill?

Dr Cairns: I think so, yes. I think the fact that there are differing opinions on whether people can opt out suggests that it is. Neither side is entirely happy, which usually means you are probably in the right place. I think it is compassionate. What were the other ones?

Ms KING: Safe, accessible and compassionate.

Dr Cairns: I think it is safe, accessible and compassionate. I think the accessibility issue will be determined as much by how we roll it out in rural areas. I am involved in a project in Cape York which is looking at how to establish more effective palliative care services in communities where there are no specialist staff within existing resources, so how that kind of thing goes will have a big impact on the palliative care side of things.

Dr ROBINSON: In terms of the legislation dealing with voluntary assisted dying there are a couple of disconnects. One is a right to palliative care. There is a stated right to palliative care in the bill. I am trying to understand what that looks like on the ground. We know through Palliative Care Queensland and Palliative Care Australia that there is substantial underfunding of palliative care. We know that many people are not receiving the care they should. We know that in many cases they are receiving it only weeks before they pass away. The bill seeks to enable people, if they are diagnosed with a terminal condition, access to voluntary assisted dying up to 12 months out or with a 12-month determination of their condition. Do you think that is the wrong way around? If they are not getting access to palliative care, should the guarantee for palliative care mean that someone like a palliative care specialist ensures they are getting that proper treatment, and then if people believe it is necessary to take their life—shouldn’t it be the other way around?

Dr Cairns: I think there is a presumption that the reason people ask to end their life could be addressed by palliative care because there are other than physical symptoms as a cause and palliative care may not have answers for those things. I think certainly in Oregon, for example, and I think Canada as well, resources for palliative care were increased significantly after the legislation regarding voluntary assisted dying was put into place. I think it is an issue—

Dr ROBINSON: But my question is that you would assume you would put palliative care first.

Dr Cairns: I think palliative care has been developing quite rapidly. A couple of years ago I was the statewide clinical lead for palliative care, and even during that time we went around to all of the HHSs and promoted the development of palliative care. Since that time there have been regional palliative care consultants whose role has been to develop palliative care in rural areas. I think there are four across the state. The resources for palliative care have been increased over the last two years or so. Palliative Care Australia itself supports a neutral line on voluntary assisted dying, but it is using—and appropriately—the rolling out of voluntary assisted dying across Australia as a strong argument for improving palliative care. I think that, without a clear definition of what we would set as being the requirements for palliative care across the country, it will be a long time before voluntary assisted dying would be approved. I am not sure that those who oppose voluntary assisted dying would accept voluntary assisted dying even if palliative care was available everywhere.

Dr ROBINSON: In terms of the issue of the guarantee, is the guarantee worth anything in the legislation? We are talking about safeguards and protections. We can bandy the term around, which it has been, but in real terms are you saying that the palliative care guarantee is worth something or is it worth nothing?

Dr Cairns: Do you mean a guarantee that it will be provided or the necessity that it be provided?

Dr ROBINSON: Because it is not now in many cases.

Dr Cairns: I think it is very hard to roll out specialist palliative care services in small communities. I think it is a worldwide problem. It is not always easy to arrange that. It is a question of how you network, how you use technology like telehealth and so on. There is a lot to be done in the development of palliative care and the rollout to small communities. There will never be specialists in the smaller towns around the place. They require networking, and that is being developed at the present time. I do not think we will achieve the standard we would like to have in palliative care in Australia before voluntary assisted dying legislation is passed, assuming that the legislation is passed, but I think it might be also a bit more of an incentive to get it done more quickly. I think it is really important to remember that often the reasons that people request voluntary assisted dying are not things that are ameliorated by palliative care. As I said, 90 per cent of the people in Oregon who request voluntary assisted dying have been registered with a palliative care service—or more than 90 per cent. It remains an issue even where people are connected to palliative care.

CHAIR: Thank you, Dr Will Cairns, for your significant contribution today. We do appreciate your time and expertise in advising the committee.

McNAMEE, Dr Heather, Queensland State Convenor Group, Doctors for Assisted Dying Choice

Dr McNamee: I would like to acknowledge the traditional owners of the land on which we meet and pay my respects to their elders past, present and emerging. My introduction was timed perfectly to three minutes, but because there have been some points raised it may go a little over.

I am a GP; I have been for 25 years. I currently work in Cairns. I have also experienced working in Cape York and the Torres Strait, both for Queensland Health and for the Royal Flying Doctor Service. I have a special interest in adolescent health. I particularly want to address the VAD legislation in relation to rural and remote patients, which is a passionate area for me.

We cannot restrict health professionals involved in this to doctors. As you all know, there is a chronic shortage of doctors in rural areas, and our nursing colleagues carry a lot of the responsibility that in other countries would be carried by doctors. To limit it to nurse practitioners would be equally restricting because there are a minimum of nurse practitioners present again in remote areas, so it is very important that the legislation also says that registered nurses can take part in this process.

I was interested to hear Dr Robertson suggest that psychiatrists should be the people assessing people who request VAD. In my area there is a six- to 12-month wait to get in to a psychiatrist, and that is completely unworkable. As a GP with a special interest in mental health, I feel it slightly insulting to suggest that GPs are not qualified to assess people's mental health and capacity to decide.

As Dr Cairns clearly stated, palliative care specialists in the main are opposed to voluntary assisted dying. I think there are a number of reasons for that, both self-serving and otherwise; therefore, to expect that palliative care specialists would be the main providers of VAD is completely unrealistic, particularly in our dispersed population.

The initiation of the discussion about VAD in the Victorian bill is completely unworkable and would really be against the principles of modern medical practice, where all decisions should be shared between the doctor and the patient. If you cannot inform a patient of all of the options then you are not doing your job properly. Were Queensland to amend their bill in line with Victoria, then the most vulnerable groups—such as those with limited English, low literacy or limited education—are the people who will not be able to access VAD, as they will not have the background knowledge.

The issue of telehealth again is one close to my heart. I have been providing telehealth services since 2013 across Queensland and in other states. We have to be able to use telehealth for this and we have to be able to do that confidently, without being concerned that we are going to be prosecuted under Commonwealth law. I am not common amongst my profession: I believe that my oath to do the best by my patients is more important than laws I may not agree with. Most of my colleagues would not subscribe to that. They are absolutely terrified of any sort of prosecution or legal redress, so the fact that the QLRC suggested that the Commonwealth DPP brings in prosecutorial guidelines whilst they address the Criminal Code on the use of carriage services is really to be highly commended and needs to be addressed with urgency before implementation.

Conscientious objection is well covered in the proposed bill, as it was in the abortion bill. We need to have that in a society where we have differing views; however, in the Victorian experience there has been obstruction to access to VAD by doctors who did not support the patient's request. I know of one case where there was a seven-day delay in the doctor even telling the patient they did not agree with VAD, let alone referring them to someone else. I would suggest that if a doctor does not agree with VAD and receives a request from a patient they should be required to immediately tell the patient their views and that within 24 hours the details of a care navigation service should be provided to the patient.

The question of institutions and blanket bans on VAD is extremely controversial and difficult to address in a country where many of the aged-care services are religious based, which I personally think is unfortunate. For the residents of these institutions, that is their home. If you are in an aged-care facility, that is your home. That is where your furniture is. That is where you live. That is where all of your clothes are. That is where all of your possessions are. You should not be forced to leave your home in your dying days or weeks. Access to these institutions by other professionals who support VAD must be allowed. It is not realistic to transfer someone in their dying days or weeks. In fact, it is completely inhumane.

There are two things I will end on, both of which are equally controversial. One is the issue of dementia. I understand that the committee and the QLRC last decided to sort of park that issue for now, and I totally understand why. We need to get this legislation in place, up and operating and see

what the exact issues are in Queensland before we take on such a difficult issue to legislate. However, the loss of dignity and autonomy that dementia inevitably brings is one of the biggest causes of distress to people diagnosed with it. The use of a possible advance health directive with VAD built into I think would give people immense comfort. Even the AMAQ, who have not been overly supportive of the legislation until recently because I think they have seen the writing on the wall, have stated their support for the use of advance health directives for someone to say that 'in the event of my becoming completely incapacitated I wish to access VAD'.

Finally, another issue close to my heart is the under-18s. I work in Headspace in Cairns with young people with mental health issues between the ages of 12 and 25 and, trust me, people under 18 are perfectly capable of understanding complex decisions and having autonomy around their own health. I realise that that is a stretch too far for most people in Australia and in Queensland, but I would suggest that there should be a provision for exceptional circumstances to avoid 16-year-olds having protracted and painful deaths. If this is not included in the initial bill, which I suspect it will not be, I would encourage the committee to consider that at the first review.

I will give just a little factual point. I think the member for Lytton was asking. There are seven suicides a month in Queensland of terminally ill individuals. Those figures come from the National Coronial Information System from 2016 and 2017. Let us please remember: those are only the people who have the access or the courage to do it and there may be many others who would have done it had they had means. Thank you for your attention.

Mr BERKMAN: I appreciate your time, Dr McNamee. You have already gone some way to answering the question I was going to ask, which was around institutional conscientious objection. A lot of suggestions have been made in various submissions about how this should be tightened, and a lot of that revolves around the transferring of patients, which you have already mentioned. Can you give the committee a sense of what in practice it means to be trying to transfer patients who might be eligible for the VAD scheme and, as a bit of an addendum, in the context of remote and regional communities, what that looks like?

Dr McNamee: Incredibly messy, incredibly difficult and probably impossible, to be honest. If you look at any medical ward in a hospital, people are queuing for aged-care beds, and they do not often get a choice of where they are going to go. When the first available beds come free, they are put into that institution. I am not sure where we think these beds are going to even be, that there is going to be some magical empty aged-care facility specifically for VAD, considering the limited number of hospice beds there are in Queensland let alone bringing a whole new institution. I think really in the aged-care setting that is practically impossible.

I suspect private Catholic hospitals will do their utmost to obstruct any access to VAD. I guess there always is the possibility of being transferred to the public hospital, but you could argue: if you have paid your private health insurance, why should you have to end your days in a public facility at the public purse? In my own mind, I think it is completely impractical. I think we need to legislate that these institutions have to state clearly their position on VAD in their protocols and policies prior to people being admitted there so that families and individuals can factor that into their planning, and if these institutions wish to conscientiously object—that is their right—they need to give access to other professionals from outside if a patient requests VAD.

Mr ANDREW: Thank you for coming in today. Earlier you mentioned that there was a six-month wait on psychiatry. Is it not delivered through telehealth, or is telehealth not a medium that you would consider to be a way of being able to deliver that for this bill?

Dr McNamee: Telehealth is being used for psychiatry due to the waiting times in the public system, but there are a few issues with it. One is that there is generally only one consultation because the Medicare rebate for a subsequent consultation is extremely low. For instance, at Headspace we have access to a telehealth adolescent psychiatrist because it is not easy to access them in Cairns, and Cairns is a reasonably sized town, so there are issues around that. Getting psychiatrists who are prepared to telehealth—and with these particular issues, because it is a subspecialty area, you are going to have an even more limited pool of psychiatrists that you would draw on. As an experienced GP, if I see a patient who I feel does not have capacity to decide or I am worried somebody is psychotic or deluded, obviously I will consult with a psychiatric colleague, but the majority of people who are terminally ill are not psychiatrically unwell. They are making a rational decision that they do not wish to have a protracted death in front of their family or, as Dr Cairns alluded to, their symptoms are intolerable and they no longer wish to continue to suffer them.

There was a letter in the *Cairns Post* yesterday from my arch nemesis talking about how there are all these doctor murderers out there who just want to go around killing people. There have been some famous doctor murderers in the media, but this idea that somehow by bringing in legislation

this will be less regulated—it is completely unregulated at the moment. I would say to any doctor in Australia that they have all offered terminal sedation to someone at some time. What that really looks like is the patient is half conscious, semi-conscious, may be crying out in pain, the relatives are sitting by the bedside crying and you come in and go ‘They’re clearly distressed. We need to increase the dose. If I do that, there is a chance they are going to stop breathing. Is that okay with you?’ That is what happens. That is as much of a discussion that goes on. The morphine is put up; the person passes away. You effectively have VAD with no regulation. That is what is going on in every Australian hospital every day at the moment.

For people who are scared of VAD or worried about safeguards, remember that this is bringing in real legislation, real review—two-doctor reviews—and a board that is going to watch every case that is decided. It will be a massive increase in safeguard and legislation and will avoid doctor murderers who go around euthanising people without consent.

Dr ROBINSON: There is a lot in what you have said, Dr McNamee, and I would suggest there is a lot of different opinion to what you have shared amongst your colleagues. Just to clarify something I think you misunderstood in what I said in me calling for specialists to be involved, that was in no way denigrating our GPs and I would reject your comment entirely. In fact, I would add that Dr Smallwood talked about the role of specialist cultural advisers in the process of VAD that might happen in the case of First Nations people. I am not dismissing GPs and I am not dismissing the role of specialists. Your statements about specialists I found interesting.

Coming to my question, why would we not try to fund and train more psychiatrists, more palliative care specialists, more Indigenous advisers? When it comes to those who have an intolerable level of pain that this bill deals with and, as we see around the world where VAD is rolled out, people who suffer with dementia who have lack of capacity and are having VAD treatment, why would we not, to ensure there is not the levels of elder abuse, to ensure people do have capacity—specialists are there for a reason—have more of them and use them?

Dr McNamee: Absolutely, but I am not in charge of the funding of the health system. My point is that you do not require a psychiatrist in the majority of cases because the ability to assess capacity is done by every GP in every consult with every important decision. Patients decline treatment all the time.

Dr ROBINSON: Are you saying that you do not need specialist psychiatrists?

Dr McNamee: In the majority of people, you do not need a psychiatrist to decide if somebody has the capacity to make a decision or not.

Dr ROBINSON: On what evidence, what research, do you base that comment?

Dr McNamee: On the fact that that is normal practice in Australia, that GPs have the training and the experience to assess somebody’s capacity and to pick up those who do not have capacity or are immensely unwell or whose dementia has reached the level where they do not have the capacity anymore. That is an intrinsic part of being a GP and seeing hundreds of patients a week. Are you suggesting we send every patient who declines chemotherapy to a psychiatrist to assess that decision when they are making that decision as an informed adult?

Dr ROBINSON: I do not think you should put words in my mouth. I think you have a strong view and you are entitled to your view, but it is not my view.

CHAIR: Please do not argue with the witness. Let us move on to questions. Do you have another question, member for Oodgeroo?

Dr ROBINSON: No.

Ms KING: Lovely to see you, Dr McNamee. I want to go back to something you said in your introduction. You reflected on your concerns that some in the health profession would be held back from participating in voluntary assisted dying, despite perhaps being otherwise inclined to, because of the current status of the Commonwealth carriage laws. Specifically you touched on the prosecutorial directions situation. I wonder if you could please elaborate a bit more on the impacts that you see would come from that general situation and how you know that. What other situations have you seen play out maybe in this region that leads you to have these views about your medical colleagues and their capacity for taking risks in this space?

Dr McNamee: The medical profession in general is a conservative, risk-averse profession. I think we see that when issues like this come up. There is a reason I have flown the whole way from Cairns to be here when you can just phone up your average Townsville GP and ask them if they would like to come and talk here—particularly in Australia, because it is the second most litigious nation in the world when you come to medical things. Doctors are particularly paranoid about legality.

We pay high indemnity fees to protect ourselves from litigation. The issue with this is because it would be a criminal case that we would not be protected from, even by our medical indemnifiers. Because the Commonwealth carriage laws have not been reviewed for a very long time and because opponents to VAD try to align VAD to suicide, there is that grey area. I am no lawyer, but I have listened to people like Professor Ben White address this issue that there is a greyness there and that we cannot proceed with this with greyness in the law as far as those of us who may be offering it are concerned.

I am a rebellious and courageous individual and believe that sometimes you just have to stick your neck out and hope it does not get chopped off if you feel that what you are going to do is the right thing to do, and I have other colleagues who feel the same as me about our responsibilities as doctors to do the best for the person in front of us, but most of the profession are not like that at all and would run scared with even a hint of the fact that there could be a criminal case brought against them. Remember, in every single episode of VAD the doctors involved are going to be dotting their i's and crossing their t's and nervously hoping that they have not slipped up and that they have stuck to all the right paperwork and done everything at the right time.

It is an awesome responsibility to be involved in the death of another human being and I just think we cannot have uncertainty and greyness there. From what I understand from Professor White, it can be fairly easily fixed in the short term with just a single sentence saying that VAD is not considered suicide when performed within the state laws and that that would be sufficient to protect any VAD cases from being prosecuted.

If we cannot use telehealth for VAD, anyone north of Cairns is not going to be able to access it. A lot of the communities do not even have a doctor; they have a fly-in flying doctor service. You are not going to get two doctors who have the time to travel up there to the cape. I do not know if any of you have been to Thursday Island, but it is a whole day journey just to get there. It is really essential for this to be equitable across metropolitan and rural areas that the telehealth issue is cleared up.

CHAIR: Thank you very much. I believe the member for Lytton is going to make some closing comments.

Ms PEASE: Thank you, Chair. Dr McNamee, thank you for being a rebellious and courageous doctor. It is really important. I value, and no doubt your community values, the great work that you do for your community. Thank you for coming and sharing your expertise over 25 years of general practice. It is an amazing job to undertake and we value your commitment in coming down today. I know that you attended our other hearings previously. It is very much appreciated. I was particularly interested to hear your comments that VAD is currently happening but it is unregulated. I appreciate your commitment. Keep on being courageous and rebellious.

LARKINS, Prof. Sarah, Dean, College of Medicine and Dentistry, James Cook University

CHAIR: Good afternoon and welcome. Would you like to start with an opening statement and then we will move to some questions?

Prof. Larkins: I come to you today with a couple of hats on. Firstly, I am the dean of the College of Medicine and Dentistry at James Cook University. Today is my first day in that job. I have my 'teaching medical students' hat on. I am also an experienced general practitioner. I just recently ceased clinical practice and have lots of clinical experience in rural and regional areas with both Aboriginal and Torres Strait Islander and non-Indigenous patients. I would also like to start by paying my respects to the Wulgurukaba and Bindal peoples as the traditional owners of this land and pay my respects to their elders past and present. I am also, of course, a member of the public and that is the other hat. I think everyone shares personal and professional experiences with people with terminal illnesses.

Firstly, I will speak with the dean hat or the medical education hat on. We spend a lot of time talking to our students, and at James Cook University we are particularly trying to educate a health and medical workforce for rural and regional areas—a fit-for-practice workforce. We spend an awful lot of time talking to our students, educating our students and role-modelling to them about providing person centred care. We do this with the help of our fantastic volunteers. I note there are a couple of our volunteers in the room today. We talk to them about patient centred care and person centred care, about listening to and understanding patient perspectives, values and views, and combining their perspective of their illness with our bio-psycho-social view of what is going on. We talk to them a lot about the importance of recognising and respecting an individual's autonomy and providing information about the condition and the range of possible treatment options and outcomes available to them. We talk to them about beneficence and non-maleficence: how can we best do good, how we can avoid doing harm. Patient centred care, person centred care and respecting individual autonomy is an absolutely critical part of all of these discussions.

As a doctor myself, I have had the privilege of being involved in palliative and end-of-life care for a wide variety of my patients. In my experience, faced with a terminal life-shortening illness there are many causes of suffering. One of them is fear of unbearable suffering and uncontrollable symptoms, as Dr Cairns was talking about. Another very common cause of distress—existential distress, if you like—in my experience, is a feeling of loss of control, loss of autonomy and having that sense of the disease or the illness happening to you with no control over the situation. People in that situation are really fearful of not being able to control in any way the time, place or means of their death.

In my opinion, a voluntary assisted dying bill, as in the proposed legislation, has sufficient safeguards to ensure that a person with a life-limiting condition has the opportunity to have access to some sense of control and autonomy about their own end-of-life care. In my experience, having this sense of control often means that people are able to then avail themselves of the best available palliative care, end-of-life care. In fact, in many cases they do not need to use it; it is just knowing that that option is there and available to them should it become necessary and their suffering becomes unsustainable.

I would also like to really echo the comments made by Dr McNamee about the importance of access to voluntary assisted dying for people wherever they live and whatever their circumstances. It is really critical in areas of poor access to health services that people are still able to access those services. That does mean consideration to a broader range of health professionals who might be able to provide advice and consideration of telemedicine or telehealth as a way of delivering those services.

CHAIR: Thank you very much, Professor Larkins. With your experience as a rural GP, can you talk about some of the practicalities of dealing with someone in a rural, remote or Indigenous community who has been diagnosed with a terminal illness in terms of providing care? I am not sure if you were in the room, but our former inquiry heard from people who did not want to leave their communities to be provided with care there. If this bill is passed, should there be the ability to access voluntary assisted dying information and/or directions by telehealth and how important might that be?

Prof. Larkins: I think it is critically important. I have certainly had considerable experience caring for people with exactly the same illness and the same condition. One may live in a rural or remote area and make the decision that they are not willing to leave home to access treatment and as a result they die quite rapidly. The other person may live in another location and is able to travel

and access more care and has a much longer life and more access to treatment and is able to access that. I think information about voluntary assisted dying and, in fact, access to that for people wherever they live is critically important and we need to think about how we do that.

CHAIR: This is a bit of a pointed question before I move to others: should people be given choice at end of life?

Prof. Larkins: Absolutely. I believe 100 per cent that people should be given choice, with reasonable safeguards. I echo the comments of Dr McNamee that a good GP who has a relationship with a family over the long term is actually in an excellent position to assess both competence to make decisions and also whether undue coercion might be being brought to bear by other family members.

Mr MOLHOEK: Professor Larkins, one of the issues that really weighs heavily on all our hearts is around equitable access to palliative care. I guess that flows on to equitable access to qualified medical professionals who can provide support and advice to people who want to choose voluntary assisted dying as a path. That is a very broad issue right across Northern Queensland, Western Queensland and many parts of central and regional Queensland. If we cannot even deliver well basic health services in some parts of the state—and I have heard some interesting stories about Western Queensland—how do we ensure we have safeguards by way of alternative pathways available to people who are suffering from terminal diseases in the north and the west?

Prof. Larkins: You are right: it is a difficult problem. It is an intractable problem that has been taking some time to sort out. JCU graduates are doing a great job at getting out there and filling gaps and delivering services. It is one of those questions. In a perfect world, we would have access to top quality palliative care in every corner of this country and this state. I heard Dr Cairns talking about some of the limitations in terms of access. What we do have is very friendly and accessible specialist positions in the regional centres and very skilled generalists of a number of persuasions in the rural and remote areas and they are linked by phone and video. There are various ways of getting that expertise to the people where they are. I think exactly the same applies to education and support and access to voluntary assisted dying. Just because we are not 100 per cent confident that we have it all absolutely solved is not a reason to stop trying. We just have to try and do the best we can and make sure that we write it into the legislation—as it is, I note. We have to keep trying to execute that as well as possible. It would be a travesty to say that because we cannot do it perfectly the first time then we have to not do it at all. That would be a shame.

Mr MOLHOEK: Given that we already have significant challenges in attracting good quality medical practitioners to a lot of the remote and rural parts of the state—at all levels, whether they be nurse practitioners, registered nurses, specialists, GPs or rural health specialists—do you think there is any basis in some of the views that have been put forward that the imposition of VAD legislation onto doctors and practitioners in the rural areas might become a further deterrent to people wanting to work in the regions if they are conscientious objectors?

Prof. Larkins: I think that is a bit of a furphy of an argument.

Mr MOLHOEK: It has been raised in some of the submissions, which is why I am asking.

Prof. Larkins: There is no doubt that practitioners who choose to work in rural and remote areas certainly need to have a wide skill set and are constantly tested in their range of scope of practice.

Mr MOLHOEK: This makes it even wider, doesn't it?

Prof. Larkins: Absolutely, but that is the attraction as well as one of the demands. In fact, increasingly we are finding health professionals who are willing and able to do that. One of the attractions for them is being able to find that full range of health services for people and meeting people's needs in whatever way they can, with advice and support from specialist colleagues in the larger centres.

Mr MOLHOEK: I think the Commonwealth response has been that they will not permit the carriage service to be used for voluntary assisted dying purposes. How do we work around that? Does it mean people have to drive and meet face to face? How do we make VAD workable in rural and western and remote Queensland?

Prof. Larkins: I think it is kind of out of line in terms of all the other advice that we are able to provide using carriage services. In fact, if we were not able to do that, much of the health service would be in serious trouble so to me it is an inconsistent piece of legislation.

Mr MOLHOEK: It needs to be nussed out, doesn't it? I should declare an interest: my son is a rural health specialist in Central Queensland. He has shared with me and I have visited quite a lot of remote services. It is a challenge just finding GPs and specialist nurses and other specialists in some of those areas. Trying to find people who have been trained or have done the training for VAD could be quite an interesting challenge as well. Now I am getting into opinion and that is not my role at this point.

CHAIR: We will move on, thank you, Deputy Chair.

Ms KING: Professor, I would like to draw on your experience over so many years as a GP and providing palliative care services and services across the scope of all kinds of care in regional and rural settings. In your view, when people make the decision to enter an institution for care, do they often have a lot of ability to weigh up between one institution and the other in a regional setting?

Prof. Larkins: No. Those options are generally not there. Many people, if they are lucky enough to have support around them, are able to stay in their homes and do not need to go into an institution. However, if they do the options in regional and rural areas are extremely limited.

Ms KING: We are seeing some pressure to change these draft laws to allow faith based institutions in particular to provide a blanket refusal to provide any information or even access to a person's own GP for the purposes of providing information or voluntary assisted dying services. What do you think the impact of that would be in practice for a person at the end of their life?

Prof. Larkins: My personal view is that everybody should be entitled to a full range of information and should be able to access a wide range of information in terms of making their own choices. That is a philosophy I abide by. I am aware that not everyone shares those views. There are circumstances where people might only have the option of a faith based organisation. In most places there are other options as well, but I believe everyone should have access to the full range of options and the full range of choices to make their own decision.

Ms KING: Do you consider that this draft legislation provides a safe, accessible and compassionate option for voluntary assisted dying in Queensland?

Prof. Larkins: Yes, I believe it covers the required safeguards and is well drafted.

Dr ROBINSON: In terms of ensuring that if the legislation does pass there are built in the maximum safeguards and protections that we can, I note in the bill there are no specialists. We have commented on that. I am also led to believe that the bill does not require that the two doctors or even one of the doctors has a relationship with the patient. You could have cases where two doctors do not know the patient. We are talking about the potential of mistakes being made, of not knowing all of the circumstances. In your view, should the bill be amended to increase those safeguards and protections? Should there be at least a relationship between the patient and the doctor, not just two people they do not know, and even specialists involved?

Prof. Larkins: I think that is a little restrictive. There are plenty of people living in communities where there is no doctor, so they may not have a doctor and their care is provided by a remote area nurse, so they may not have a pre-existing relationship with a doctor. Whilst it would be ideal in many circumstances to have a known and trusted GP or another doctor who has an ongoing relationship, in some circumstances in remote Queensland that is just not possible.

Mr BERKMAN: I am very interested in the question of capacity and how a framework like this could deal with dementia sufferers. You would have heard Dr McNamee's response before. I am interested in your view on whether an approach that can accommodate dementia sufferers is something that we as legislators should look to in the future, even if not under this iteration of legislation. Beyond that, what do you as a clinician, a practitioner, see are the most effective ways to deal with the real quandary that throws up?

Prof. Larkins: Again, I think this is a slightly divisive question. Personally, I am a supporter of looking at that for future legislation. I think it has to be done very carefully. For this legislation, I think how it is is probably optimal to get VAD on the table. As someone who has witnessed family members dying of dementia and so on who have very clearly expressed their views while they still are competent and in the early stages, I think that is something we need to tackle as a society. It needs a lot more debate, but it is worth considering.

Ms PEASE: Thank you very much for coming in today, and congratulations. I hope your first day at work is going well for you. In your dealings, have you come across patients who are at end of life and suffering intolerable pain?

Prof. Larkins: Yes.

Ms PEASE: So the medication that you have had access to is not easing pain and it is making it very uncomfortable and terrible for the patient?

Prof. Larkins: In many cases it is possible to ameliorate pain. It depends how you define pain, too. There is physical pain; there is also existential pain. There are many kinds of pain that we are not capable of adequately dealing with with medicine.

Ms PEASE: Would having a regulated voluntary assisted dying program that allows people choice be a good option?

Prof. Larkins: Yes.

CHAIR: Thank you very much for your contribution today.

I recognise the member for Mundingburra, Les Walker. Thank you for being here today. I also recognise Bishop Tim Harris from the Anglican Church of North Queensland.

JOSEPH, Right Reverend Dr Keith, Bishop, Anglican Church of North Queensland

CHAIR: Reverend Joseph, thank you very much for being here today. If you would like to begin by making an opening statement, we will then move to questions.

Bishop Joseph: Thank you, Chair. I think, like most of the others, I ought to introduce myself. I have not always worn a clerical collar. My background has largely been in the military and academia. I spent 25 years in the Medical Corps, full-time and part-time, and two years in a peacekeeping force overseas. My PhD was from the University of Newcastle on the philosophy of science and medical ethics. I did a PhD on chaos theory and the ethics of human genetic engineering, which I will not bore you with.

I have had a lot of time to think about death and dying, ponder on it and see it. It should also be said that my family background is important here. On my father's side of the family, most of them were lost to state sanctioned violence: the Holocaust. Whilst this is nothing like those circumstances, it does engender reservations about the way in which death and dying is handled by the state.

Ms PEASE: I am sorry, can you please repeat that? We did not understand what you said.

Bishop Joseph: I am sorry. I am Jewish on my father's side. Whilst this is nothing like the circumstances that obtained in Europe in the 1930s, it informs one's consciousness and gives you a certain sense of reservation about how death and dying is handled by the state. It should also be said that I have written 'Courage is a Multifaceted Virtue'. As a major in the Army I wrote in the *Australian Defence Force Journal* in support of selective conscientious objection to the Iraq war, which possibly did not endear me to the hierarchy. I have long taken an interest in the issue of conscientious objection. That is probably where I will concentrate most of my comments.

The move towards VAD has been very interesting. It has been going for about 30 years now, give or take. It reflects, I think, two significant changes in society: first, that we have far better medical technology. Thirty years ago a person suffering their first multi-organ failure would have died. Nowadays they will usually survive, thanks to good medical intervention, and go on. In the case of my mother, I think she survived three organ failures before she finally succumbed to lung cancer. That is one factor.

The other factor is that we are increasingly libertarian. Our basis for ethics and decision-making is based on the autonomy of the individual rather than the community, whereas our society even 30 years ago was far more community oriented. Since that time we have seen the rise of neoliberalism and the rise of even consumerism. It did distress me that some of the submissions you received talk about the right to death as a consumer right, which seems to me to be casting it in entirely the wrong structure.

I accept it is likely that this legislation will go ahead. I have to say that, when my diocese met in April at its annual meeting, they wanted me to stress their strong opposition to euthanasia or VAD. I put it to them that it is most likely the parliament will move to legislate for VAD and therefore my comments would encourage a more conservative approach. There are a number of tensions you have to face. If you make it too conservative it becomes very bureaucratic, but if you make it too liberal—a good example would be if you said that you could avail yourself of VAD for chronic conditions rather than for terminal illness—how do you define chronic conditions? Where does that take you? How do you define the severity of a chronic condition?

The comparison would be made, for example, between the Oregon legislation and the Netherlands legislation. In the Netherlands, the use of serious illness as a mechanism for availing oneself of VAD now results in 6,000 cases a year in a population of about 14 million or 15 million people. Oregon, which is far more conservative and is very similar to the Victorian legislation, certainly results in a far lower number of people availing themselves of VAD but also, arguably, prevents forms of abuse of VAD.

CHAIR: You mentioned Victoria and fewer people accessing VAD, but I just wanted to get some clarification. Are you supportive of the Victorian model?

Bishop Joseph: I am inclined to the Victorian model if you are going to go down the road of VAD, which I disagree with. But if you are, then the Victorian model is less likely to be abused than other models available.

CHAIR: Thank you. Please continue.

Bishop Joseph: That then brings me to the issue of conscientious objection. There are two issues here. The first is the issue of individual conscientious objection. At the moment, it is limited to health practitioners and speech pathologists. I would suspect there will be more people directly

involved in enabling VAD than just health professionals and speech pathologists; for example, translators, linguists, chaplains and so on. Clearly, you cannot extend conscientious objection to those indirectly involved—the person driving the truck with the pharmaceuticals, for example—but those who are directly involved or who would need to be directly involved ought to have the option to opt out without fear of losing their job. That would include people such as translators, contractors, clearly nursing staff, and so on.

The second is institutional objection. I think you need to allow institutions to be removed from the process of VAD. Dr McNamee was fairly strong on the idea that institutions should be up-front about their view, and I think that is entirely appropriate. My two aged-care facilities in the Anglican diocese both indicated to me at the start that they did not want to have VAD. They would certainly be willing to have as part of the contract of admission that ‘VAD is not available in this institution’ so that people can make a choice up-front.

The other area I wanted to touch on is that of VAD in Indigenous communities. My diocese includes the Torres Strait, where I spend a lot of my time, and I have spent some five years living in Indigenous communities in the Solomon Islands, which is a fairly similar culture to the Torres Strait—Melanesian coastal. As our first speaker Aunty Gracelyn said, in those communities, dying is communal, not individual. Aunty Gracelyn talked about the elders deciding on death under lore, and certainly in Melanesia my experience is similar—dying takes place communally. A person would not be seen as being able to determine, in that sense, whether or not they should avail themselves of VAD; it will be a communal decision. That does not sit easily with any legislative model that will work in the rest of Queensland. My suggestion for this would be that Indigenous communities ought to be able to choose whether or not VAD takes place in those communities—that the communities decide whether or not their healthcare facility will support VAD.

The other option you have is to essentially allow VAD to happen if an individual requests, but then you would need to face the tensions and disruption that will bring to the entire community. You have here, I think, a collision of cultures which is not going to be easily resolved. I note, as we sit here on the land of Wulgurukaba and Bindal peoples, that we acknowledge also their deep spirituality and community, and that means that we acknowledge that decisions are not made by autonomous individuals on the Western model. My Aboriginal and Torres Strait Islander people—and I have five Aboriginal communities and eight Torres Strait Islander communities under my care—have all indicated that they do not understand what is going on, they have not been consulted, there has been nobody there, and they are fearful. This process is not helping. It is Western and remote. Had you met on Thursday Island or in Yarrabah, it might have helped deal with some of those issues.

In the end—and I think I support Aunty Gracelyn on this—having Indigenous folk involved in this at all stages and all places as consultants and being listened to is essential. At the moment, my people at least are saying they have been ignored. I think they need to be brought into the conversation, particularly if it is intended to do VAD in remote communities. That finishes my basic statement, thank you.

CHAIR: Thank you, Reverend Joseph. I will start some of this discussion around the institutional objection. This might be a moral or ethical conversation to have, but should the institution’s right override the person’s right? If you have a person who is in a Catholic run hospice, which one sits above the other? Should it be the person or should it be the institution? I ask you to comment.

Bishop Joseph: It is a good moral question. If you are coming into this with a basis based on individual autonomy, very much a Western cultural approach to ethics, then obviously you are going to go for individual autonomy. Indeed, much of the health aged-care legislation is about charters of rights for patients and so on. I think the way to remedy this would be for the institutions to be up-front and say, ‘We are opposed to VAD. If you wish to have VAD we will assist you elsewhere, but this institution does not want VAD to take place on its grounds.’ I realise that this is an unpopular view to make, but certainly our people at Good Shepherd Home in Townsville and the Good Shepherd Lodge in Mackay have indicated they would be extremely uncomfortable—that would be the politest way of saying it—to have VAD occur there. The best way around that, I think, as Dr McNamee suggested, is for the institutions to be up-front and the people going there know it, as with their families.

CHAIR: I wanted to put some context around that, and I appreciate the view is very much so. In Victoria between June 2019 and December 2020, 405 people applied for voluntary assisted dying. Some 224 passed away after taking what was prescribed, and there are some numbers around some people who passed away before they made that choice or lost capacity. On Victoria’s figures, just 3.4 per cent of those given access to the VAD scheme were in a health service like a hospice or hospital. Based on that figure, of the 224 who used the substance, approximately seven people in Townsville

that state over the 18 months were in health entities. Do you consider that a heavy burden? Victoria has a similar population to Queensland of five million people. It is a very small percentage of people, it would appear on the data provided and reported, who have actually accessed that within a hospice. How does that settle in your views?

Bishop Joseph: Quite well. This indicates that this is a minor problem and therefore granting selective conscientious objection to institutions should in fact not be a significant issue.

CHAIR: There are provisions within the bill that if someone is at the end of life and has made the decision with capacity in a hospice—and I have seen the issue in my clinical career where when you move people at end of life they pass away, because it is just too much to move them. Do you have views on that part of the bill that says in the case where it is going to cause significant suffering and pain access to VAD should be provided?

Bishop Joseph: One of the problems with all of this is that we are dealing with the grey areas of ethics and we are trying to use black-and-white law to determine what ought and what ought not to be done. Whatever you decide as a parliament will have ethical grey areas and wrongs will occur whichever way you go. That is why you are elected to those positions, and I pray for you.

Dr ROBINSON: Thank you, Reverend Joseph. You rightly from a Christian perspective and rights and freedoms of belief draw out, I think, very important ethical issues that I agree with. One of the areas in terms of institutional conscientious objection is in terms of the requirement within the legislation for private aged-care facilities and hospitals at this point, unless the bill is amended, to my understanding, to allow VAD treatment or VAD in some shape or form to take place on their premises in certain circumstances. Is that compatible with the broader right to freedom of religion and freedom of belief in our Constitution?

Bishop Joseph: It is in significant tension. The religious institutions have been set up for good reasons in the past, like the Catholic healthcare system, which has a remarkable record of excellence, and we Anglicans have been more involved in aged care. If it is clear at the start what those institutions are doing and that the religion obviously underlies it, then you do have a significant clash of freedoms here. The idea that when you go into a hospital you are a consumer, and that is what you are and you purchase that health care, I think is an insufficient mechanism of what hospitals do, including religious hospitals. There is a far broader discussion here about religious freedom which is far more nuanced, but I take your point, and I think there are tensions.

Dr ROBINSON: We have seen it in our history as a nation at times: if government have pressed faith communities, whether Christian, Muslim or otherwise, beyond what they feel is acceptable in their values, the risk is, as it has been in the past in education, that they withdraw from that sector. I am not saying that is likely probable; I think people are trying to go with this with a very level head, but if the time came where religious institutions felt that they could no longer offer those services in good conscience and faith, what impact might that have on providing those services and then other secular or non-faith groups, governments and taxpayers having to fund that? What are your thoughts along those lines?

Bishop Joseph: It is a real possibility. One of my CEOs at one of the aged-care facilities said that if they had to do VAD he would actually prefer to close the place down. That would be a decision for the board, and the boards are independent of my direction, but it is a possibility. I think it would depend on how heavy-handed the imposition.

CHAIR: I might just clarify, Reverend: you were with the archbishop when I asked this question at our last inquiry. Victoria passed their law in 2017. Did they pull out of aged care after the VAD law was introduced?

Bishop Joseph: No, as far as I know they have not. I am not in close contact with the Archbishop of Melbourne. I suspect that the burden is heavy for the Catholics with their extensive hospice system. As I said, we mainly run aged-care facilities and I suspect issues of VAD were dealt with locally.

CHAIR: I did make the comment further to the archbishop in this discussion around pulling out of aged care in Queensland that it did not occur in Victoria. My observation at the time was: are you not the Catholic Church of the nation; why would one state be requested to pull out of aged care? Do you have any comment on that?

Bishop Joseph: The Anglican Church is a strange beast and I have very little in common with the Diocese of Sydney, for example. We have very different views on a whole range of issues. The dioceses are certainly independent and they can decide what they will or will not do. I suspect that in Townsville

practice there are a number of pressures on aged-care facilities including, shall we say, federal government underfunding and insurance issues. I suspect that VAD would be the straw that broke the camel's back in some cases.

CHAIR: We saw that in some media today, Reverend. You would be aware we made many recommendations in our aged-care inquiry, but I digress. It is a broader discussion, that is for sure.

Ms KING: Thank you for being with us today and thank you for the thought that you have applied to these issues. Clearly, you have given it a lot of thought over a long period of time. What do you think the community's attitude would be if the Anglican Church pulled out of aged care because the church was uncomfortable with voluntary assisted dying?

Bishop Joseph: I would suspect that the community would be upset. It would depend on how it was done. I doubt that we would just pull up stumps and send 250 people away and just let it collapse. My guess would be that if we decided to pull out it would be an ordered transition, probably into a commercial provider. I am not sure that would be of tremendous interest to most of the community.

Ms KING: Certainly these kinds of statements have been made in other states and it has never happened anywhere else. What I intended to ask you, though, was to the issue of community support for voluntary assisted dying. Very thorough surveying and polling has been done on a number of occasions and it shows consistent community support, between 75 and 77 per cent, but more recently some more thorough work was done that showed that within not only people who identify as having a certain faith but also active, church-attending faith communities, 71 per cent of Catholics, 68 per cent of Protestants and 77 per cent of Uniting Church identified active participants said that they supported voluntary assisted dying. Would you like to provide a response to that?

Bishop Joseph: I am sure those figures are accurate. All I can report is what my people tell me. Certainly those in the synod voted heavily against that, including Indigenous folk who were there from the Torres Strait Islands and Cape York Peninsula. Whether or not there is a city-country divide in this, I am not sure.

Ms KING: That was consistent right across the state, regional and metropolitan.

Bishop Joseph: I am not surprised. It has shifted tremendously over the last 30 years. It should be said that this is not the issue that keeps me up at night. The views I represent are the views that my synod asked me to present and reflect my own history which, as I said, tends me to be conservative on matters of death and dying rather than encouraging of state intervention in such matters.

Ms KING: I wonder what value your reflection is that it brings to a person's life. Say, hypothetically, their life ends two days earlier because they access voluntary assisted dying and they and their family as a result are saved enormous physical pain and emotional torment. How do you see that that impacts their life? What is the detriment that you feel that that brings?

Bishop Joseph: First, it is not my job to judge others. The church's involvement in that type of stuff fortunately ended long ago. It is not my job to judge others. On this issue, it would be a job that I would leave to the individual's conscience. In the end, I can only speak for what my diocese said and asked me to say and for what I personally believe. It is certainly not my job to make rules for anybody else, Christian or non-Christian.

Ms PEASE: Whilst we were travelling here today I sat beside former mayor Beth Honeycombe from Burdekin. She spoke very highly of you and said that you were a deep thinker and gave a lot of thought and insight into all of the conversations, which you obviously have. I really appreciate that. It was an interesting moment in time.

We talked about institutional objections. You felt that a resolution might be that you say, 'Well, as a stopgap at the beginning we are not going to take anyone. That is our rule. We do not take anyone; we do not assist with voluntary assisted dying.' One of the things that has been raised is that there are concerns that people might change their mind. What about if you have a resident for whom, for all intents and purposes, it is their home—they have moved in, they have memorabilia around the room, their families come and visit them, their grandkids see them there—and their circumstances change and they are confronted with an illness, an incurable disease, that is life limiting and they are in intolerable pain? Because of a decision of the organisation that they have gone into, they are not going to be allowed their final wish, which is a choice. How do we address that to that person? How would you as an organisation be able to say, 'Too bad, so sad. You signed up to it. Cop it sweet'?

Bishop Joseph: I think that is probably an unfair way of characterising what would actually happen. My knowledge in working as I visit our aged-care communities is that people there are incredibly compassionate and are hardly going to throw somebody under a bus in that sense. My

discussions have mainly been with the nursing staff in the aged-care facilities. They are going to be more likely to be with a person. They are not going to say, 'No, you cannot have VAD.' They are going to probably recommend transfer to another facility. Now your point would be that that is taking them out of their home. The problem you are going to have is that, if most of the staff there conscientiously object, you will have to bring a series of staff into that place to do the VAD. At the very least, I would have thought, if that is going to be the solution, it ought to be done in a way which has the least impact on the other residents and the least impact on their sense of security, safety and being in a place which they believe was one where that was not going to occur.

Ms PEASE: I understand that: do no harm; place of compassion, care and love. The preachings of Jesus are love, compassion and kindness. My concern about something like that is—and having experienced it myself with both of my parents and loved ones—if they are at the end of life, moving them would be the cruellest thing to do to another person.

Bishop Joseph: Perhaps I can do a short theological reflection here. Yes, indeed, the great commandments are love God and love your neighbour. My view as a priest has been that, if what you do is in the context of love then, whatever happens, God understands. I am not a black-letter law man when it comes to religious matters. I know from my own life, the places I have been and the people I have been with who are dying, there is no one template that fits all and that, in the end, the law is an ass when it comes to dealing with these minute areas.

It would be an incredibly difficult situation for staff, the person and the family and there is going to be no easy answer. If the staff decided that they were going to permit the death to occur there, I would not at all second-guess them on that. If they decided that it was going to cause an absolute ruction and distress the other people there, I would support them in that. It would be a decision they would have to make based on what they thought was the most loving solution for all concerned.

Mr BERKMAN: You bring a very interesting perspective to this, so thank you for being here. I think it has been broadly accepted by church leaders in previous inquiries that you, sitting here, by no means represent the diversity of views held by your congregants and that there would certainly be plenty of people in the Anglican Church who support VAD. To bring that fact into the question of conscientious objection, matters of conscience are deeply personal. Isn't the idea that an institution can conscientiously object to a scheme like this somewhat problematic, given that you will have employees and clinicians who work in an institution who themselves hold diametrically opposed positions of conscience?

Bishop Joseph: Once again, it is this tension between individual autonomy and community. An aged-care home, for example, is not just a legal institution; it is a community. The question is: do the rights of an individual override the rights of a community as a whole? That is one of the key issues in the Indigenous communities—this conflict between what an individual determines ought to happen, or an autonomous agent, as opposed to community. I would argue that the institutions are communities and that as communities they have a right to have some say on what goes on within those walls, including things which that community would find damaging.

Mr BERKMAN: Taking that notion a step further, if we are looking at a theoretical institution—say it is an aged-care service provider, be it Anglican, Catholic or any number of the different—

Bishop Joseph: Buddhist, Muslim, whatever.

Mr BERKMAN: Indeed. Let's assume that we treat that institution as a community. The overarching theological opposition to VAD may not be shared by the vast majority of people who work and provide care in that facility. In terms of those practitioners whose conscience demands of them that they provide this kind of care under a regime like this VAD one we are looking at, how do you see that the idea of community resolves that tension in that circumstance?

Bishop Joseph: The question you are asking is if you have employees who would be strongly in favour of VAD?

Mr BERKMAN: Employees or people of faith themselves.

Bishop Joseph: The Anglican Church has a wonderful diversity. We have people with all sorts of views on VAD. I have had intense discussions with some of my congregation who are in favour of VAD. As I said to them, if you are strong in your conscience and you believe it is an act of love, then that is your conscience and I respect you for it. In terms of a community, if the community's overall view is that VAD ought not to occur here, then one would expect that those who are employees would comply with that.

Mr BERKMAN: But what if the community's view is that it should apply? That is what I am trying to tease out here.

Bishop Joseph: So you are saying that it is the other way around?

Mr BERKMAN: Exactly. That is exactly what I am asking you.

Bishop Joseph: If the community was the other way around, if they conscientiously believed that VAD should apply, then that would be a matter for the board. I do not control the boards of Anglican homes and I certainly would not be sacking a board because they had a view differing from mine on this. It would be up to that institution to opt in or out according to what it saw as its community value. I am not going to tell them.

Mr BERKMAN: We can imagine that there is some degree of decision-making separation between the board and the folks who work in a facility.

Bishop Joseph: As will be the case in most places, yes.

Mr BERKMAN: Indeed, that is right. Again, there is very real scope for a different position of conscience and different views between those making decisions for the operations in a facility like that and those who are actually working on the ground, who are that care community for the residents of a facility like that.

Bishop Joseph: I would think that would be the same on any issue.

Mr BERKMAN: Indeed.

Bishop Joseph: I had this in the military with conscientious objection during the Iraq War. There are going to be differences of opinion between hierarchy or boards and employees. It is up to the board to sort it out. That is what the board is there for. Public servants are a good example. They may disagree significantly with what the ministers direct them, but they will comply. If they think it is illegal, presumably they would blow the whistle but, assuming legality of purpose, those public servants would comply with a minister's directions.

Mr BERKMAN: In a circumstance where a board at a facility has made a decision that they will institutionally object to VAD and yet the conscientious objection within the facility is in the other direction, that they believe it should be available, would you support that as a mode of conscientious objection within the institution?

Bishop Joseph: I would certainly support the right of employees to have that view and I would certainly support their right not to be sacked or to be acted against because they had that view, but I would not support their right to conduct VAD in opposition to the board's decision on behalf of the entire community.

Mr ANDREW: Thank you very much for attending today. Thank you for your ongoing prayers for the parliamentary colleagues here. I appreciate that. You have made a fairly comparative look at what we are presenting here as a VAD bill and the Netherlands. You quoted some figures in that regard earlier. My question is around the bill in the Netherlands. Where did it originate and has it morphed over time and changed to obviously present those figures? I am sorry that I have not looked at that bill. You quote as though you understand it much more. Has that bill remained as it was first introduced or has it morphed into a certain other way of being able to be presented?

Bishop Joseph: It has morphed, though I believe the starting point was chronic illness, not terminal illness. It certainly has morphed, and certainly the number of people availing themselves of VAD in the Netherlands has increased considerably per capita over the years. I do not have the exact figures with me, but that is my understanding. I do not believe it was ever as conservative as the Victorian or Oregon bill in the starting point.

CHAIR: I will make some closing remarks before we go to statements from the floor. The former health committee during its inquiry wrote to the former health minister to commend the important work that our churches do in spiritual care of people at end of life. We do thank you and applaud you for that. I have seen it in my clinical career where people have passed away or are passing away at home where they have no family and we have quite often, from an ambulance perspective, reached out to the church and the connection is made. Thank you very much for the work that you do. I know this has created some divergent views, but I want to keep it as respectful as possible so thank you very much for your contribution today, Bishop Joseph.

Bishop Joseph: Thank you, Chair; thank you, members.

WARD, Father Dr Rod, Private capacity

Father Dr Ward: I come here as a medical practitioner but also a Catholic priest. I am trained to share my experience and journey with people at the end of life and with their families. My experience, I find, differs from that which I hear regularly in the media and from many who support voluntary assisted dying, the VAD legislation, which is proposed for Queensland. In relation to my two areas of my experience, the first as a medical practitioner, following graduation I worked for the Queensland Department of Health for a number of years as medical superintendent in country hospitals, two years as a medical registrar at the Townsville General Hospital, and then went into general practice where I have been practising for some decades. During that period of general practice I was also Queensland government medical officer for Townsville and part of my duties there was dealing with the coronial matters in these areas. I believe that I have extensive experience surrounding those issues of death and dying. As part of my experience I have journeyed with families as a doctor through times when they are confronted with being told that they have an incurable disease, have a limited time of life, in the final times of life or at the moment of death. I have also journeyed with those with a whole range of disabilities and restrictions on life.

As a Catholic priest I find myself journeying particularly with families as I am preparing them for funerals and having those conversations which they share with me around that time and the circumstances of their loved one's death. My experience is that those people are at peace and I have not experienced the stories that I hear of people being in great pain and agony or in distress due to their condition. I have not experienced a case where these situations exist. Effective palliative care is able to ensure that the person does not experience this. Stories given by families who tell me about the time of their loved one's death also do not include the experience of the patients dying in great pain.

Research in jurisdictions overseas where VAD has been legislated indicate the top five reasons given by persons who request VAD do not include pain or fear of it. The argument used sometimes in support of that, that it should be supported to relieve pain in the person, does not appear to have validity. Some 107 of the 109 world medical associations, including the Australian Medical Association, oppose euthanasia and assisted suicide.

Archbishop Fisher, the Catholic Archbishop of Sydney, in a statement last Friday, 9 July, reminds us that the Catholic Church is the oldest and largest provider of health and aged care in the world. He reminds us that the Catholic Church has long operated to uphold the dignity of the elderly and the dying and compassionately to relieve their suffering, never entertaining killing them or collaborating in bringing about their early death. He is urging that in any legislation there should be clear guarantees that no institution, no professional, no sick person and no family member would be required to participate in or refer for euthanasia. This is a view that I strongly support and recommend to this committee for inclusion in any proposed legislation.

Finally, the Catholic Church's teachings on decisions at the end of life are often misunderstood. Guidelines are given in the document *Evangelium Vitae*. The person or those responsible can in conscience decide, and it is morally acceptable when death is clearly inevitable, that forms of treatment that are determined to be extraordinary or disproportionate can be forgone or discontinued. End of statement.

CHAIR: Dr Ward, with respect, you have said that you have plenty of years of being a GP but you have never experienced anyone in severe pain or complaining of suffering in severe pain at end of life, and I think you made the comment that it does not appear—something that you are referring to—to have validity around pain and suffering. With the greatest of respect, a couple of members of this committee travelled the state extensively, we had 5,000 people write to us and we had people come before us and share their experiences of loved ones suffering for days and weeks at the end of life. I struggle with the words that you used around that after we had people breaking down talking about their deeply personal stories of watching loved ones suffer, in great pain and suffering. We have had Dr Will Cairns here talking about people today, before you walked in, suffering at end of life and he believed in giving people choice. I think it is a difference of views, but what do you say to those people who came before us who shared those stories?

Father Dr Ward: I do hear the individual stories of individuals giving that indication that one of their loved ones was in pain. I know Will and I have worked with him in some circumstances with patients. My experience of those that I have been involved in with Will and those who are dealing with palliative care is that they are able to give effective management of pain. I am not sure what examples Will might have given of those where he has not been able to effectively control their pain. My experience is of those that I am with that they are at peace and that the pain has been controlled.

CHAIR: I will refer you to *Hansard*. I asked Dr Will Cairns to speak to some graphic detail of people suffering at end of life and he did that.

Ms KING: You talked about your years as a GP. We heard evidence earlier about the use of terminal sedation and how in many ways that does not necessarily differ in some respects from voluntary assisted dying, except that it is unregulated. Do you support the use of terminal sedation for terminally ill patients at the end of their life?

Father Dr Ward: Not terminal sedation, per se.

Ms KING: Perhaps I should specify. Do you support the provision of morphine type drugs to relieve symptoms even though that may lead to the end of somebody's life?

Father Dr Ward: Yes, I do. The provision allows the use of that form of management for pain, for relief of pain or relief of the stresses that might be occurring. In other words, the intention should not be to end life when one is giving those sorts of medication. The intention always is to provide relief for whatever the patient's condition is. If in giving that medication it somehow may shorten life, it does not prevent us giving that for the purpose of relieving symptoms.

Ms KING: Even though the patient may themselves not have fully consented to death as a possible side effect of the provision of that drug?

Father Dr Ward: Death is not the intended side effect of giving medication to relieve symptoms. If the sense is that the possible side effect of that medication does shorten life, it is still acceptable to give the medication to give that person relief.

WALTERS, Ms Royalie, Private capacity

Ms Walters: I have come along today to represent the 80 per cent of Australians who support voluntary assisted dying and to balance out some of the institutional coercion that I have seen today and that we all know goes on politically. In fact, I am currently the executor of a will of someone who died recently who had intolerable pain. We voted for VAD for him, but it did not work and he did not die at home as he wished. He had to go into hospital, which is not what he wanted. I also witnessed my brother's death and do not wish that sort of thing for myself or other loved ones.

I think Australians are sick of religious institutions dictating what we should do morally when I think we all know what has been exposed in the last few years and what they should be putting more of their efforts into, as someone who used to work with children. I am just saying I am really pleased to see that some people have done a really good job in putting forward our views and supporting us to try to balance out the power and the exertion and the coercion that is coming from religious bodies who are, quite frankly, out of step, out of date and need to stop pushing their beliefs onto everybody else. I am not asking anyone who does not want to have voluntary assisted dying to do it and I do not want them to tell me that I cannot do it. Thank you.

CHAIR: Thank you very much, Ms Walters. Thank you for sharing that deeply personal story. It is never easy coming before these committees.

COLLINS, Ms Lindy, Private capacity

Ms Collins: I came here to listen and to find out. My parents have been involved with Dying with Dignity. My first reaction 10 years ago when I found out about it was feeling quite horrified that they, as elderly people, should have a plan in place when their life became untenable to think about ending it. They have had very rich and very wonderful lives, but now my father is an amputee with heart failure and my mother has a serious disease as well. I like the thought that both my parents have got the right, and might have the right under VAD laws, to end it when the time is right for them to end it without recrimination, without the family feeling that they are going to die a miserable death, because the illnesses that both my parents have could eventually lead to that.

I personally have sat next to three very close family members and friends who have died really disgusting deaths from cancer. One was prostate cancer and no man should die like that. He should have been given an option of a clean, healthy exit rather than the sort of death he died, which was undignified and quite revolting. I will not go into the horrible details. I was with him at his death.

The other was my grandmother, who was a terribly alert, intellectually active person. She died of throat cancer. She had a PEG to extend her life. She had a tracheotomy. She was fully cognisant and she needed the relief of a death, a choice to die, but she was kept alive and every treatment just prolonged the agony she was in. She was fully cognisant right up to the end. She was given the option of choking to death or having an overdose of morphine. She chose the overdose of morphine. She had to make that conscious decision. With her little tracheotomy in her neck, she wrote to me and asked, 'Am I dying now?' I said, 'Gran, you have to make that decision of whether you have an overdose of morphine or you choke to death.' How much kinder could it have been? For 12 hours we sat with her and we sang to her. We were not allowed to stimulate her in any way so that it would interfere with her morphine death. We had to sit with her. We could sing to her but that is all we could do. To me that was totally inhumane. It was disgustingly inhumane.

Another very close friend had a brain tumour. He was 38 years old and he had a malignant brain tumour. He died and his body was kept alive because he had donated his body for medical transplants. We sat with his family because my husband had known him since he was three years old. We sat with them until the transplant people came from all over Australia to pick up his body parts. That was very traumatic but he had made a conscious decision to donate his body so he was kept alive, kept nice and fresh. He looked like he was just sleeping gently until they came and harvested his organs. Bearing witness to that, I think personally that VAD laws are the most humane way we can deal with end-of-life choice.

One of the first comments made was that 59 per cent of people in Oregon thought they were a burden to society. I think that is very ironic given the state of the American health system and the cost of health care to the individual and families. In Queensland, in Australia, we have free and wonderful medical care right from birth to death, whereas in America you die on the streets if you do not have medical insurance. With that 59 per cent, was it that they were worried about their families being in debt? People cannot afford cancer treatment in America and they will die because they cannot afford it. Is that the comparison you are making? If you are using that study to say that they thought they were a burden, I think I would be a burden if I was living in Oregon and it was going to cost my family to put me through VAD care. That was quite an irrelevant argument.

As a teacher and a former Catholic, something that has brought me great joy in Queensland is the new child protection laws that say that people making confessions of paedophilia cannot be protected now. In the same way, I believe that religious institutions cannot say, 'It goes against our teaching to allow VAD laws.' It does not equate. It is an individual choice. I note Reverend Joseph spoke about the Holocaust and made allusions to the Holocaust. I share the same family name. My maternal family are Jewish and my husband is Jewish. Alluding to the Holocaust as VAD and using the VAD analogy is really quite wrong because it is about individual choice. The people who were loaded onto the trains had no individual choice. It was not their choice to be born Jewish, to be recognised as culturally Jewish, so there is absolutely no correlation or analogy between what happened in Nazi Germany and VAD laws which give individuals the choice at the time of their choice to end their lives.

I think those religious hospitals that rely on their funding from the federal government should have their funding removed. Religious institutions get most of their funding from the federal and state governments, and if they cannot allow VAD within their institutions then cut their funding—nationalise them. There is no point in having them if they do not apply the majority rules of this country.

That is basically what I was going to say. I believe that telehealth is a really good way of dealing with it. My husband is a doctor and he worked for the flying doctors. My daughter is a doctor and my daughter-in-law is a doctor. In relation to the idea of having to have psychiatric assessment before Townsville

you decide, the fact is that when you are dying you are not mentally ill; you are just dying and you are facing the existential truth of your non-existence. You are not mad; you do not need to see a psychiatrist. You just need to have somebody caring and loving at your side who is going to bat for you, and a doctor or a nurse practitioner who you might or might not know who is caring enough to be there with you.

It is basically a human right. It is a human right of your choice to end your life as you choose when you choose—and if we can do it so that people do not have to suicide when they are faced with the idea of vomiting up shit, I think it is a really good idea that we give people options. It is not a problem. There has not been a mass of lemmings in Victoria of people dying, running off and doing VAD. There has not been. There was such an uproar from all the religious institutions about what would happen in Victoria, what has happened in Holland, what has happened in Belgium and what has happened in the states in America where it is legal. There has been no great lemming rush to go and commit suicide. Especially now with COVID-19 happening and when we are going to have people in very serious situations with long COVID and people perhaps having really bad symptoms—when the choice has to be made by intensive care doctors of whether they turn off their life support systems—this is becoming more real and it is an issue right now. It should be happening faster. Thank you.

CHAIR: Thank you for your contribution.

LAWRENCE, Mrs Marj, Private capacity

CHAIR: Thank you very much for being here for quite a number of hours. We appreciate it.

Mrs Lawrence: I have been a very strong advocate for dying with dignity for 21 years. At the moment I am in remission with pancreatic cancer and I hope I will live long enough to take advantage of this law. If the law is not in when my time is up, I am going to have to end my own life. I do not want to die the same way that six members of my family have died. They lost all their dignity and self-respect, and I do not want my family and friends to remember me in that way with the loss of all of that.

With this law that is coming in, I want to concentrate this afternoon on the reasons people are against voluntary assisted dying. Even though polls consistently say that 80 per cent of the population want to have a say in how they end their own lives, there are still people who argue against it. These arguments are generally unfounded and scaremongering, and let us just have a look at them.

The first one is that families will want to encourage the patient to die so they can claim their inheritance. On the contrary, evidence shows that families try to discourage their loved ones from wanting to end their lives. They want them to go on living with no quality of life and in severe pain. They just do not want to lose them, so that claim is false. In the 12-month review of the Victorian law which happened recently, there was no evidence of any coercion by another party. Also, before any laws were introduced into any states, Andrew Denton travelled to the Netherlands and spent eight months looking at the Netherlands, Belgium and Switzerland and investigated the laws that had been in place for up to 20 years. He could not find any evidence of corruption of any kind in any of those countries.

The next one we look at is the slippery slope. Very few, if any, changes have been made to laws around the world and there are many countries that have these laws. Those that have changed them have done so because the public wanted them.

Another reason is that we cannot be sure that the patient wants to die. The doctor would have to be sure of the patient's persistence and rational intention and have no doubt of duress coming from any other person. I know that my doctor would have no doubt whatsoever how I feel about this. Others may say that there might be a cure. The doctor would discuss with the patient as to whether this was possible or not. They just would not go ahead and issue the required medication unless that was totally discussed.

Others say that palliative care is better. We will always need palliative care. It helps a lot of people. But it is acknowledged that all pain cannot be controlled and pancreatic cancer is one of them. The treatment for patients is to increase the appropriate drug, which would render the patient unconscious until death supervenes. This process is not controlled. The patient has no say in the matter. They can go on living for days or weeks, gasping and moaning all that time, and their family has to look on in desperation, not being able to do a thing about it.

Religious traditions regard life as a gift from God and people should not reject God's will. People who hold this belief will not be affected by VAD so why are they complaining? The law is all about having a choice. No-one is forced to participate. Four states in Australia now have a VAD law and it is to be hoped that Queensland will be the fifth state.

There is one other thing that I need to mention. I could not hear a lot of what has been going on today and it has probably been brought up: it is the Commonwealth carriage law. It totally puts people in rural communities at a disadvantage, which is just not fair to those people. We need to convince the Commonwealth that they have to overturn that law. Thank you very much.

CHAIR: Marj, thank you very much. I note that you wrote a letter to the editor on Saturday on the issue of the carriage laws. I saw that in the *Bulletin*.

Mrs Lawrence: Yes, I did.

CHAIR: You have a personal story. I understand that you have lost a loved one to pancreatic cancer as well.

Mrs Lawrence: I have lost six members of my family to one sort of cancer or another and all have suffered very badly. One of my brothers died from pancreatic cancer. He had an horrendous death. I feel so sad every time I think about it. My older brother and mother died from metastatic melanoma. My father-in-law died from lung cancer that got into his throat and he could not swallow. I helped my sister-in-law nurse him. Every time he tried to swallow, his eyes would nearly pop out of his head. When I was there with him of a night, he ordered me to ring the doctor up and tell him to come down and give him a needle to end his life. I just could not do that, of course. That was horrendous. I also helped nurse my mother-in-law. She had Parkinson's. She curled up into a foetal
Townsville

position. If you have ever been to a nursing home you would probably have seen people curled up like that in their beds. It is not a nice way to end a life. She was like that for three years. My cousin also died from lung cancer. He had a terrible death. There were six of them.

I actually nursed my husband at home until his last breath. He had myelodysplasia and anaemia, very similar to Peter Gleeson's brother. You may have read that article in today's paper. He had the same condition. He was bedridden for 18 months. He faded away to a skeleton. He was just like a ragdoll in the end. He had no energy to lift his hand up to feed himself or do anything. He had to wear napkins. He had to be bathed and fed and everything else. It was horrendous. It scarred me for life.

It was after his death that I decided that I needed to do something about my death. That was 21 years ago. I made myself familiar with how I could end my life quickly and easily. I just put that aside for 21 years. Now that I am in remission with this cancer, it is just amazing the comfort I have from knowing that I will not suffer at the end. So many people have said to me, 'You're so calm with what you are going to have to face.' Doctors as well as friends and acquaintances have all said that to me. It is because I know I will not suffer. If we get this law in, everybody will have that comfort and they should have it.

Ms PEASE: Marj, thank you. I am very sorry for the troubles that you have had. You have had some terrible experiences. They have certainly made you another courageous woman. It is great to have met you. Thank you so much for sharing your story.

Mrs Lawrence: Thank you for listening to me.

Ms PEASE: Thank you for being so strong.

CHAIR: Well said, member for Lytton. Thank you very much, Mrs Lawrence. Our final speaker is May Glaney.

GLANEY, Miss May, Private capacity

Miss Glaney: I want to speak in support of voluntary assisted dying and also to say I am a bit disgusted that it has not happened already. I came two years ago to the inquiry into VAD. Now I am back two years later saying I still support it but nothing has happened. I am not happy with the Labor government and how they have dillydallied and done nothing about it. I wish I had a choice at the end of my life. That is all I have to say.

There is something else. Everyone should have a choice and I am not against people who want to die whichever way they want. For me, I want to die peacefully and quickly. I do not want to linger and that is my choice, not theirs. Nobody should have a say over what I am allowed to do.

CHAIR: May, thanks very much for your contribution. If there are no other speakers from the floor, I would like to thank everyone for their contributions and for being here today. Certainly it has helped inform the committee as we deal with the bill. May, I remember you coming before us at the inquiry. We held 40 public hearings. That was a broad-ranging inquiry into aged care, palliative care and end-of-life care. For the first time we asked Queenslanders for their views on voluntary assisted dying. Indeed, our former committee made recommendations and this is the result of that—that is, the bill before us. In eight weeks time we will table our report and the Premier has already said publicly that September will be the month to debate that. Thanks very much, May, for your contribution. To everyone here today, we appreciate your time. I now declare this public hearing closed.

The committee adjourned at 4.18 pm.