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

Staff present:
Dr J Dewar—Committee Secretary
Ms L Pretty—Inquiry Secretary
Ms A Groth—Assistant Committee Secretary

PUBLIC HEARING—INQUIRY INTO THE VOLUNTARY ASSISTED DYING BILL 2021

TRANSCRIPT OF PROCEEDINGS

FRIDAY, 16 JULY 2021

Brisbane

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The committee met at 9.36 am.

CHAIR: Good morning, everybody. I now declare this public hearing of the Health and Environment Committee open. I respectfully acknowledge the traditional owners of the land on which we meet today and pay our respects to elders past and present. We are very fortunate to live in a country with two of the oldest continuing living cultures in Aboriginal and Torres Strait Islander people, whose lands, winds and waters we all now share. 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, member for Southport, is our deputy chair. The other committee members are: Mr Stephen Andrew, member for Mirani; Ms Ali King, member for Pumicestone; Ms Joan Pease, member for Lytton; and Dr Mark Robinson, member for Oodgeroo.

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 the submitters who provided submissions to the inquiry. The submissions will assist the committee with its consideration of the bill. This 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 electronic devices be turned off or switched to silent. Hansard will record the proceedings and you will be provided with a copy of the transcript.

Before I welcome witnesses, I want to correct the record. I believe it was at the Rockhampton hearing—it could have been Townsville; it has been a long week—where I said that costing of implementation was in a clause of the bill. In fact, it was related to a chapter of the QLRC report.

BROWN, Mr Andrew, Health Ombudsman

EDWARDS, Ms Heather, State Manager, Ahpra Queensland, Australian Health Practitioner Regulation Agency

GARNER, Ms Michelle, Chair, Queensland Board of the Nursing and Midwifery Board of Australia; Executive Director of Nursing and Midwifery Services, North West Hospital and Health Service, Australian Health Practitioner Regulation Agency

O'DWYER, Dr Susan, Practitioner Member, Medical Board of Australia; Executive Director of Medical Services, Metro South Hospital and Health Service, Australian Health Practitioner Regulation Agency

ORCHARD, Dr Jamie, General Counsel, Australian Health Practitioner Regulation Agency

CHAIR: Thank you all for being here today. We will start with opening statements.

Mr Brown: The OHO's written submissions in relation to the bill have been limited to the issue of the regulatory and complaints management framework which is to apply to the scheme and, specifically, whether that framework is clear. I consider there are three main types of actors who may have roles under the scheme: registered practitioners—predominantly doctors and nurses; unregistered persons; and organisations that may play some role.

In the case of registered practitioners, it is my view that the bill makes it clear that the national law will apply and, by virtue of that, the OHO will be able to receive complaints and notifications about registered practitioners involved in the scheme. Both the OHO and Ahpra will have jurisdiction to deal with complaints and notifications in this space. The picture is not so clear when it comes to unregistered persons or organisations. Whether the OHO would have jurisdiction to receive and manage a complaint in this space is I think a moot point. This is because under the Health Ombudsman Act the OHO has the power to deal with a health service complaint. In essence, the complaint must be about a health service. The ombudsman act states—

> A ***health service*** is a service that is, or purports to be, a service for maintaining, improving, restoring or managing people's health and wellbeing.

In my view, whether a service that ends a person's life under the voluntary assisted dying scheme amounts to a health service is open to some debate. If it is the government's intention that the OHO be able to receive complaints about unregistered persons and organisations who have roles under the scheme, I do not consider the current bill makes that necessarily clear enough. As I have previously submitted, in the Western Australian voluntary assisted dying legislative framework, an amendment to the definition of a health service in the equivalent act to the Health Ombudsman Act, the Health and Disability Services Complaints Act, was made to include voluntary assisted dying. Presumably, that was to deal with the uncertainty that I have just mentioned. A similar amendment is not currently provided for in this bill. I am happy to expand on these issues if the committee wishes.

Ms Edwards: Thank you for the opportunity to brief the committee as part of your consideration of the Voluntary Assisted Dying Bill in Queensland. As background, Ahpra works in partnership with 15 national health practitioner boards to ensure that the 168,000 health practitioners in Queensland and over 800,000 nationally across 16 professions are safe and qualified to practise. We do this by setting registration standards, registering and renewing practitioners, maintaining an online national register, managing complaints around registered practitioners—in Queensland they are referred to us by the Health Ombudsman—and accrediting programs of study that lead to qualifications in a registered profession. Our work is grounded in a national law that is enacted in each state and territory, with Queensland as the host jurisdiction. Together, health ministers from each state and territory and the Commonwealth oversee our work.

As Mr Brown mentioned, Queensland is a co-regulatory environment, with the Office of Health Ombudsman being the primary point of contact for all complaints about the health, conduct and performance of registered health practitioners. Ahpra and the national boards manage the complaints the Health Ombudsman refers to us. Our working relationship with Mr Brown and his office continues to be very positive.

All professions regulated in the national scheme have a code of conduct describing what is expected of them to practise in Australia. While individual practitioners have their own personal beliefs and values, there are certain professional values and standards on which all practitioners are expected to practise. Practitioners must be honest, ethical and trustworthy. Importantly, all codes of conduct condemn discrimination. It is these codes and standards that national boards use to evaluate practitioners' conduct. The standards also play an important role for the public as they can help the public understand what behaviour they can expect from a registered practitioner and whether their care meets professional standards.

Two examples were in our submission. The Medical Board of Australia's code of conduct provides that good medical practice involves registered medical practitioners being aware of their right not to provide treatment to which they conscientiously object but also not using this objection to impede access to treatments that are legal. The Nursing and Midwifery Board of Australia's code of conduct sets out the requirements of registered nurses in providing culturally appropriate end-of-life care, including to accept the rights of people to refuse treatment and to facilitate the provision of end-of-life care where relevant and in accordance with local policy and legislation.

With regard to registered health practitioners who may be involved in the scheme, the existing regulatory and complaints management system for registered health practitioners in Queensland would apply. The relevant provisions in the Health Practitioner Regulation National Law (Queensland) and the Health Ombudsman Act would have application to the conduct and performance of registered health practitioners participating in the voluntary assisted dying scheme.

We remain committed to playing our part to ensure that Queensland co-regulatory arrangements keep the public safe, treat practitioners in a fair and consistent way, and meet community expectations. We welcome any questions the committee has for us.

CHAIR: I understand that you submitted that if the bill was passed you would welcome some early consultation with the Voluntary Assisted Dying Review Board, in conjunction with the OHO, to assist in ensuring appropriate regulatory mechanisms are in place. Nationally, Ahpra would have had these same conversations in Victoria and Western Australia. Are there any learnings from those jurisdictions in relation to regulatory governance, if you like, that Queensland might learn from?

Ms Edwards: We have been involved in Victoria, similarly as we have been involved in this state. The program has been implemented for two years in Victoria and they have regular meetings with the oversight board. It is only in its infancy in Western Australia; we have similar contact there.

CHAIR: Mr Brown, I understand that you would have jurisdiction to deal with, on a case-by-case basis, the conduct of unregistered health providers who breach clause 7 of the bill by initiating discussions about voluntary assisted dying. I understand that your jurisdiction may not extend to some personal care providers, as defined in schedule 1, who are not providing a healthcare service. Can you talk to any detail of that?

Mr Brown: The definition of a health service is pretty broad and it does encompass a lot of different things that an unregistered provider might do in the health space. It always becomes a little bit tricky on individual cases as to whether or not a personal carer is actually providing a health service. You look to the sorts of tasks they are undertaking. If they are undertaking cleaning and shopping on behalf of someone that needs it, they are out; if they move into personal hygiene, dispensing medications and things like that, we tend to find that it falls within. There is potentially a grey area between those two positions. Certainly, if they are providing a health service as part of being an unregistered practitioner and they breach that clause then we would consider they would be within jurisdiction, but some personal carers, depending on their roles, potentially fall outside that.

CHAIR: I understand that the QLRC in its report talked about defining the procedure of voluntary assisted dying as a health service. I am not sure if I can find the exact page right now, but does that help guide the OHO? I know that you want a clear definition and it sounds like an amendment is needed to clarify that. Could you just unpack that a little bit more?

Mr Brown: Certainly. It is a debatable point. I am not saying that there is one clear argument one way or the other, and that is what concerns me at the end of the day. What you look for as a regulator is real clarity. It makes everyone's job a lot easier. It saves legal challenges and various things like that. I think there are arguments on both sides of the fence. When you look at the bill and you look at the background to it, it certainly puts a medical and health type framework over the whole system. That would be an argument that you would use to say that some of these other players who are not registered practitioners are part of that; they might be a health service. On the flipside, you have this definition that uses words like 'maintaining', 'improving', 'restoring' and 'managing' health and wellbeing, and there is an argument to say, potentially, that ending someone's life under the scheme is not consistent with that definition. It is grey, I guess is what concerns me, in that space.

When you look to what Western Australia did to provide some clarity, it suggests that that was potentially a concern for them. It is not a difficult amendment. In fact, I think it can be done even by regulation in our act if that is government's intention that we play a role in this space.

I speak about some of the roles that could become questionable. I notice under the bill there are roles for people like a contact person, an agent or a witness. That might be, in some cases, family or friends, although I think there are limitations in relation to, if you are a beneficiary, whether you can perform those roles. However, one could imagine that they could also be delivered as a service by a service provider for people who do not have that. Then that raises the question: if you have a complaint about that service and the way they did something or what they did or did not do, who will deal with that?

The bill, in clause 156, makes provision for a voluntary assisted dying care navigator service. Possibly some of these roles might be provided by that service. That service has to be approved by the chief executive, so that would provide some right of complaint about that service to the chief executive, who is the approving authority. The concern I have is: if we receive complaints about a service like this without that clarity, it makes our job a bit difficult to work out whether or not we have a role.

CHAIR: Thank you for that clarification.

Mr MOLHOEK: One of the earlier submitters we spoke to this week suggested on the issue of conscientious objection that a lot of medical practitioners would have some discomfort with saying, 'I am a conscientious objector,' and suggested that, rather, they should be allowed to simply say, 'We do not provide that service.' I would be interested in Ahpra's views on perhaps the terminology or the language that is being used and whether there have been any concerns raised through your membership about that.

Dr O'Dwyer: I have not heard any concerns that have come up like that, but if I reflect on the termination of pregnancy laws, when they came in we had several clinicians who were conscientious objectors and were very happy to say that they were conscientious objectors. Indeed, as a cohort I believe they made a submission to this committee and named themselves as conscientious objectors. In my experience, people who are in that frame of mind do not have an issue saying, 'I am a conscientious objector.' That has been my experience.

Ms Garner: I have the same experiences, particularly around termination of pregnancy. Nurses and midwives most certainly were clear that they were conscientious objectors, and the health service put roles in place for that. Working in remote Queensland, we most certainly do have a small workforce where we have to consider conscientious objectors and the ability to continue to provide that system, so we put things in place around that.

Mr MOLHOEK: Mr Brown, can you explain the sorts of complaints the Office of the Health Ombudsman might expect to deal with in respect of voluntary assisted dying? What jurisdiction does your office have in respect of some of the provisions of the act around penalties for talking someone out of the decision or talking them into it or someone proactively suggesting that someone consider voluntary assisted dying when the act basically says it has to be a voluntary request from the patient, that doctors cannot proactively say, 'This is an option'? Do any of those issues fall within your scope?

Mr Brown: If we are talking about registered practitioners who might breach a provision of the act or not comply with a provision of the act, that would be something that could be subject to a complaint or a notification. My general view is that most of those things—and I would be informed by my colleagues here at the table—would probably fall less in the professional misconduct space and more in the unprofessional conduct and unsatisfactory professional performance, so at the lower end of the spectrum of complaints. When they are at that lower end, the OHO's role is simply to refer those to Ahpra to manage. There are offences created in the act for which there are penalty units that apply. We would not have a role in prosecuting someone for breaching those provisions, but the breaching of those provisions may then become an issue about their conduct or their professional practice. That might cause a separate notification to have to be dealt with through the system.

Ms PEASE: Mr Brown, I want to go to the opposite side of that in terms of the provisions about conscientious objection. If a patient requests it and their prescribing doctor does not let them know that they are a conscientious objector and does not refer them, would that be referred to OHO? What sort of reporting capacity would you have, given that it is the end of someone's life and there is only a short term, a nine-day window? What sort of processes would you imagine would take place there?

Mr Brown: To be honest, I have not thought that one through completely, but that would be a breach of the act. There is a duty to refer someone on in circumstances where you are a conscientious objector, so there is an issue there. That could form the basis of a complaint or a notification. That would be unlikely, potentially, particularly on a one-off, to amount to professional misconduct. That would require, I think, the prosecution of that practitioner through QCAT, so it would be a matter that we would urgently refer to Ahpra as a matter of professional performance. That would be my view.

Ms PEASE: Would Ahpra like to comment on that then?

Dr O'Dwyer: If it was referred to us that somebody was a conscientious objector and failed to refer, as was referred to in the opening statement by Ms Edwards, it is in our code of conduct that we must not impede access to health services. In addition to being in breach of the legislation, they would be in breach of our own code of conduct for the provision of health services. They may fall foul of that, so certainly it could be a performance issue.

Ms PEASE: May I just ask another question around conscientious objection but for entities. I know that you talked about that in your opening statements. In terms of access, Michelle, you spoke about being from the north-west region and that you are limited often by residential aged-care facilities' health providers because they are often faith based; people do not necessarily have access. Can you make any suggestions or give any commentary around the conscientious objection by entities?

Ms Garner: I do not think you would have conscientious objection through an entity that an entity would put in place, but most certainly if people employed within the organisation conscientiously object then the organisation would put things in place. Again, going back to the termination of pregnancy, it was very clear from the start who were conscientious objectors and so systems were put in place. Telemedicine is an extremely beneficial and viable method of being able to bring the south-east corner to rural and remote areas. There are ways to work within this and still stay within the regulatory space.

Ms PEASE: Further to that, with regard to access to voluntary assisted dying using a carriage service, the federal government has oversight of that legislation. I know that the chair probably wants to put some questions about that. You are probably familiar with the fact that currently they have made it quite clear that there is not an opportunity. We have a letter that the chair has provided to us.

It has been tabled and I think it might be circulated on your tables. It is from the Director of the Department of Prime Minister and Cabinet and stated that the Prime Minister, the Hon. Scott Morrison MP, had asked him to respond to this person's email. It states—

> Looking at the issues that you raise—

which was access to a carriage service—

> the Queensland State Government would be best placed to respond to you. To assist with that we have referred your letter to the Queensland Premier's Office for consideration. You can contact the Premier's Office ...

CHAIR: To put that in context, a constituent in regional Queensland wrote asking to get clarity and address the Criminal Code where it refers to a carriage service.

Ms PEASE: We know that it is a federal government matter yet it is being referred back to the state government. Who do you believe is best placed to resolve this issue, given that you talk about using telehealth and how important it is to regional and remote communities?

Ms Garner: I would have thought that, in first the instance, it is a Queensland issue that we need to resolve but acknowledging that it is a federal service so that clinicians can, in their practice, practise safely.

Ms PEASE: Again, as you said, being able to provide equity of access everywhere across Queensland.

Dr ROBINSON: Thank you for taking the time to appear before the committee today. I would like to follow on from my colleague Rob Molhoek's question around conscientious objection which falls to individuals, whether that is doctors or nurses who may have some concern on some ground about being involved in this, and institutionally—that is, organisations such as many that have come before us and said that they would like the opportunity to opt out of providing certain services because of their very strong convictions.

Yesterday Professor Jane Turner from the University of Queensland spoke about the individual case of doctors where they may be forced to refer because the legislation requires them to refer. Some with a religious background have said that that is not a problem to them; they do not see that as an ethical thing for them. For others with a religious background, Jane Turner—and I do not know her, but on my take of it—said that it would be inappropriate for the legislation—and this is my word—to 'force' people to refer when there is knowledge that you can access these services in other places. If there is no formal referral and you have not officially been involved in the process and, therefore, your own conscience—which is important when you think of Muslim doctors or Catholic doctors. I wonder what you will do in areas of complaint if somebody says, 'I am a conscientious objector,' or if an institution says, 'We opt out of that,' yet the legislation is either grey or problematic to them and they could end up being prosecuted. What are you going to do?

Dr Orchard: I think in any matter that is referred by way of complaint there are a number of factors to take into account. It would not necessarily just be an aspect of whether the legislation itself has been breached. In circumstances of a complaint finding its way back to Ahpra for Ahpra to consider and put before the Medical Board, we take into account all of the surrounding circumstances, including the code that applies to all medical practitioners. The obligation in the code is slightly different in relation to conscientious objection in that the obligation is not to impede a person's access to other services, as opposed to a positive obligation to refer the party on. If the complaint was put before us, we would take into account all of the actions of the practitioner—whether they had met the requirements of the code insofar as not impeding and whether they had or had not met the requirements of the legislation. That is the initial approach we would take.

Dr O'Dwyer: I would agree with that. We have to take into account all of the circumstances. In my experience, people can be conscientious objectors but very compassionate practitioners and understand that people have their own desires and their own ways of wanting to do things and not impede access but still not refer on. There are other ways in which they can be facilitative in that. You would look at what the circumstances were and what else the practitioner did in order to assist that patient. I do not think it would be cut and dry: 'You fell foul of the legislation here.' It would be an assessment against the code as well and what else they did to support that patient.

Dr ROBINSON: Others who have spoken to me are seeking assurances in this area that they are not drawn into something that goes very strongly against convictions. When you think of faith based agencies and people with a strong faith, in a tolerant postmodern society we are inclusive, but then this legislation does impose certain requirements on them. There are deep concerns that have been expressed to the committee and no doubt they will come up in your areas.

CHAIR: Member for Oodgeroo, we will move to a question from the member for Pumicestone.

Ms KING: I am also interested in the issue of conscientious objection, particularly in shifting the focus back to the person in the broader scheme who should ultimately be at the centre of all of the legislative frameworks that you are here to administer and ensure—that is, the dying and vulnerable patient who is at the end of their life. I was reflecting on the comments of Ms Edwards about not using conscientious objection to impede access to treatments that are legal. A number of people have come before the committee arguing for changes to the legislation that, it would seem, would certainly act to significantly impede access to people seeking voluntary assisted dying at the end of their lives. I want to hear from anybody before us whether these issues of conscientious objection have proven to be, to your knowledge, a significant issue in Victoria. Have they taken up a lot of the time of the equivalent body in Victoria? Have they been played out multiple times or have they been managed, as you have discussed termination of pregnancy issues have been managed? Can anybody inform the committee as to those matters?

Ms Edwards: In line with the commencement of voluntary assisted dying legislation in Victoria in June 2019, Ahpra set up a process so we could readily identify all notifications associated with their VAD scheme. Since that time we have received only one notification from the Victorian Voluntary Assisted Dying Review Board and that matter is currently being investigated.

Ms KING: Does anybody else have any matters to add to that? Mr Brown, are you aware of any notifications or similar complaints that have arisen in Victoria?

Mr Brown: No, I am not. We have not made those inquiries, but I am not aware of any.

Dr ROBINSON: I have a question supplementary to what I was asking about before. This is on a specific case in Victoria. I believe there is a case of a public hospital in Victoria that has refused VAD on its premises but the refusal is apparently based on employee conscientious objection. How do you work through something like that when you hear of that kind of situation?

Ms Edwards: For Ahpra that does not fall within our scope. We regulate individual practitioners. It would probably be another health complaint entity that would manage a complaint around a health service.

Mr Brown: Perhaps if I talk about the issue of facility. In Queensland it is the OHO who has jurisdiction to deal with public hospitals or other health service organisations. Provided the jurisdictional issue was clarified and there was clear jurisdiction to deal with a health service or a hospital that is refusing access or failing to comply with the legislation in some other way, the powers that the OHO has in that space are really limited to a resolution function. It could be possible that the OHO could seek to resolve the dispute between an organisation and an individual patient or to investigate it and simply report on it with recommendations. We could investigate, write a report that made findings that there was a potential breach of the act and recommend that the act be compiled with. That is the extent of our powers in that space.

Dr ROBINSON: I believe in one case it was the head of the palliative care unit in a public hospital, so we are already seeing this occur. What would happen in that kind of situation where the head of palliative care believes that a VAD service is not appropriate in that particular circumstance?

CHAIR: We have a different legislative framework to Victoria, so we have provisions in here that—

Mr Brown: That would be a complaint or notification about a registered practitioner in that case.

Dr ROBINSON: Are we going to see a palliative care specialist in this case hauled before an authority because they do not believe that the provision of that service is appropriate in a case, based on their professional opinion? Are these grey areas?

CHAIR: My observation is that that scenario cannot happen under the proposed legislation in front of us, but go ahead, please.

Dr O'Dwyer: There are many health services and many hospitals that cannot provide the full spectrum of services that are legally available to anybody in the community. Those services can therefore be coordinated through partnerships or collaborations or engagements or contracting with other service providers to do that. If the requirement under the legislation is for a public facility to provide access to voluntary assisted dying, then the obligation would be on the CEO of that health service to enable that to happen however that is, whether it is onsite, offsite, through contracted relationships with somebody else or through engagement of other service providers.

Mr MOLHOEK: Dr O'Dwyer, one of the concerns that has been raised through some of the hearings is the slippery slope. It is interesting that what is legal is not necessarily always considered moral or appropriate by different sectors of the community. It is a debate that has gone on in many other areas of medical science. Last night we heard from Dr Philip Nitschke. I asked him if, to some extent, the moral dilemma that we have about end-of-life choices has been accelerated because we have become so good at sustaining life and keeping people alive longer, and should we not be having the same ethical debate in reverse. My question is: at what point do different institutions that run services have a say about what they are prepared to do? Outside of whether or not it is legal, should institutions be allowed to exercise some sort of moral or religious conscience or view?

Dr O'Dwyer: I can only speak as a medical practitioner and not as a regulatory representative or as a representative of Metro South. Medicine and health are continually evolving and ever moving forward. We frequently do things that are not usual, that have not been done anywhere else before, like growing a tibia from a frame for someone who does not have a tibia. We do things like that. We have processes and structures in place—such as human research ethics committees, clinical ethics committees and governance structures—to put a framework around that to say, 'Is this the right thing for this patient in these circumstances? What are the safeguards for the patients? What are the safeguards for the practitioners and for the institutions?' In health we frequently do things that have not been thought about, are not documented and are cutting edge. Our systems and structures have developed in a way that we are used to doing, particularly in research and in experimental things. We often have new drugs on trial and all sorts of things like that.

I think that is separate from the issue of conscience and morals. I think offending somebody's conscience is significant, and I take that on board for practitioners. Practitioners are individuals with a conscience and it is important that everybody, in my opinion, does not offend their conscience. Harm can occur to a person from offending their conscience. In weighing up these things, which is the greater harm? I think that is what you are saying. Is it the harm to the patient who is unable to access something versus the harm to the practitioner who would feel offended in their conscience by having to provide the service? They are tricky issues and they are personal issues. They are very tricky when they come before a regulator as well. We end up having to consider the entirety of the matter, including the frameworks in which people work, the regulatory system and then the personal manner in which people practise and what patients want.

Mr MOLHOEK: They are tricky issues and personal issues, to use your words. Should government be legislating rules or requirements over people that would actually force them to act against their conscience?

Dr O'Dwyer: That is outside my scope, really. The government represents the people.

Mr MOLHOEK: Perhaps to Heather, Dr Orchard or even Andrew?

CHAIR: I think that is asking for an opinion, Deputy Chair. We have a draft bill before us—

Mr MOLHOEK: These are professional people and—

CHAIR: I will make a ruling. Let us at least keep it to the draft bill. Do you want to rephrase the question?

Mr MOLHOEK: In your professional opinion, should medical practitioners be allowed to exercise conscience without fear of penalty or prosecution?

Ms Edwards: I think all practitioners do that. Every day when they are practising I think they work within their own conscience. I am a practitioner and when I was practising I would not do things that I did not agree with, but I would always make sure the patient was cared for to the best that the service could provide.

Dr O'Dwyer: I think practitioners deal with this a lot every day in their clinical practice. It is not a singular issue in relation to voluntary assisted dying at all.

Mr MOLHOEK: Are there any other areas that practitioners work in where they are at risk of prosecution because they failed to refer someone or had discomfort about referring people to a particular course of treatment?

Dr O'Dwyer: I believe the termination of pregnancy laws include that as well.

Ms PEASE: I wanted to talk about terminal sedation and end-of-life care and palliative sedation—whatever you want to call it. We have heard a lot about it. We know it takes place currently in palliative and end-of-life care and to a certain degree is largely unregulated. It is about the patient and their end-of-life wishes. Something like the voluntary assisted dying legislation puts protections around the patient for that. Would you be able to comment on that position? Do you think it provides greater safeguards for a patient in terms of how they choose to end their life?

Dr O'Dwyer: Again, I think it is a very personal position. This is not a representative position of any of the bodies from which I come. The legislation as drafted seems to put in place good safeguards to ensure that only appropriate people are involved in the conduct of the scheme.

Obviously it has not run out, so there are always things that you do not think of when you are putting something together. The scheme as constructed does seem to provide safeguards for the patients in respect of accessing voluntary assisted dying. That would be my answer.

CHAIR: I thank both Ahpra and the OHO for being here today. You are regular contributors to the committee and we thank you very much for your considerations.

Proceedings suspended from 10.19 am to 10.30 am.

KIRCHHOFFER, Dr David, Director, Queensland Bioethics Centre, Australian Catholic University

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

Dr Kirchhoffer: I would, thank you. Thank you for the invitation to appear before you today. I am an ethicist. That is my professional capacity. Much of my work and research is focused on the role of the concept of dignity in contemporary ethical discourse and, more recently, on respectful autonomy, particularly as that is worked out in the notion of informed consent.

Today I would like to propose several improvements to the bill. These improvements do two very important things: first, they help us to ensure this bill really respects individual autonomy by ensuring that people are adequately informed and that those who want nothing to do with VAD can steer clear of it; second, they help us to better protect those whose autonomy may be compromised for any number of reasons by increasing transparency and accountability such that the treating doctors or institutions, the review board and QCAT are better empowered to act on behalf of people in their care to ensure eligibility and protect against coercion.

As I have only three minutes, I will present these improvements in the briefest possible way. There are seven of them. First, the bill should require a consultation with a palliative care specialist. Only then can we say that a person is adequately informed about their palliative care options. Second, a consultation should be required with a specialist in the disease that the person is claiming makes them eligible. Only then can we ensure the person is adequately informed about their disease, their prognosis and especially treatment options. Third, the person and the coordinating practitioner should be required to inform the person’s treating practitioner to improve transparency and accountability regarding diagnosis and capacity. Four, the bill should require evidence of eligibility to be submitted to the review board to ensure proper oversight and increased accountability. At the moment it does not require any evidence. It says you may submit evidence.

Fifth, those with conscientious objections to VAD should not be required to provide information to a person about how they access VAD. If I could just comment on what I heard in the previous session, it does not require, in the current form, a referral. It requires that you provide information. It is important to have clear distinctions around what the actual bill says. I would argue that it should not even require the provision of information. We can talk about why I would suggest that, but I will just tell you what they are for now.

Six, in order to adequately exercise their duty of care to all patients and staff, institutions that object to VAD on whatever grounds and provide care to non-permanent residents—so we are talking here primarily about patients in hospitals and hospice care—should not have to allow access to external practitioners for the purpose of requests, assessments and administration of VAD. Such institutions should be allowed to transfer such patients elsewhere if reasonable to do so, which the bill does talk about, but the reasonability of transfer should be decided by the facility management and their clinical staff in conjunction with the patient and not with the coordinating practitioner, which is the default decision-maker in the current bill.

Seven, in the case of permanent residents—so now we are talking about residential aged-care facilities—the bill should require the resident and coordinating practitioner to inform the entity’s management so that the facility can exercise its duty of care to all staff and residents in that facility as well as to the person who is requesting VAD. If they do not know about it they cannot help in any way. A facility that objects to VAD should then be able to discuss transfer, if reasonable, as part of the informed decision-making process and care of that resident. The reasonableness of any transfer should be decided by the facility and its clinical staff with the resident and should not be decided by the coordinating practitioner alone, which is what the current version of the bill allows.

If respectful autonomy is indeed a foundational principle shaping this bill, as is stated by the Queensland Law Reform Commission and in the bill itself, then it is crucial not only that people have access to VAD but also that those who want no part in it can work, live and be treated in health and aged-care facilities where they know the risk of exposure to VAD will be minimised, so it is creating that correct balance, if you like, in the liberal pluralist democracy in which we find ourselves. Thank you.

CHAIR: The draft bill as proposed already says that all information in regard to someone accessing VAD information should also include palliative care options. Your first point was that there needs to be more consultation around palliative care.

Dr Kirchhoffer: It should be consultation with a palliative care specialist.

CHAIR: You do not think the bill goes far enough? I would have to find the exact clause.

Dr Kirchhoffer: The bill requires that as part of the information process a person should be informed about palliative care and treatment options. The problem with the bill is that the coordinating practitioner and the consulting practitioner require no specialism in either of those facilities. They do not need to be palliative care experts; they do not need to be experts in the disease that they are saying makes the person eligible for VAD.

CHAIR: We had GPs comment on this particular point. They are often the first ones who see the person who is given a provisional or differential diagnosis of what is going on. They are often referred to oncologists or palliative care people as their disease progresses to manage that. Would they not already be in care? What we heard with the Oregon report was that 70 per cent of people who access VAD were already under specialty palliative care. Can you talk to that point?

Dr Kirchhoffer: In a way you have given me the answer: 70 per cent are under palliative care. There is another 30 per cent who are not. The question is around: if this is about adequately making sure that people are making informed choices then they have to really know what is going to be really good for them, potentially. Whether that is around palliative care or treatment options, both of which require specialist knowledge, they need to be part of that process. The bill does not require that. That is the point. It is true that in many cases, and probably most cases, people would already be in that kind of care pathway. One would hope that the person is dealing with an oncologist if they have cancer, for example. One would hope that they already have access. There is no guarantee of that, of course, but one would hope that that is the case.

What I am proposing is that we put in amendments that require it to be the case. Let us say it comes to the GP. Let us say the GP is the person that the person is asking the question to. From the GP’s own perspective in terms of being able to act with integrity, they can then ensure they have referred that person to an appropriate specialist and that person has explored the appropriate avenues around diagnosis, prognosis and treatment but also around palliative care options. This is why we have specialists, because both of those spaces are spaces that are advancing, that have new knowledge all the time, and, whilst GPs are experts in the broad sense of the word of all sorts of things and are great at being able to manage a patient through their disease, they refer to experts for that reason. The bill says that you can refer if you are unsure, and the Ahpra guidelines say that you ought to refer if you are unsure, but there is nothing that says you have to refer. I am suggesting that it is important in this case, on the premise of respectful autonomy, that evidence of that expertise being part of the process is in part of the process. Does that make sense?

CHAIR: I want to continue that line of questioning for one moment. For every study there is always a counter study, but going back to that 70 per cent and you said 30 per cent would not. Isn’t that about patient choice, because some people do not want to pursue palliative care?

Dr Kirchhoffer: That is true. The point is: at the moment many people do not have access to high-quality palliative care in the first place. Let’s assume we were to put in the bill a requirement that you get a palliative care consult. The problem is: that is the bill that is going to be the law, but it also assumes that that is actually available. You need to also be able to make sure that people can access palliative expertise, can access treatment expertise. There are potential shortfalls in that space too, which is a separate question from the bill itself.

In order for the bill to meet the requirements around being informed, it seems to me that the bill requires to be more explicit, I suppose, around what are the things you want people to be informed about. You want them to be informed about their treatment pathways and you want them to be informed about their palliative care options. If you would want to go and be informed about something else, say Rugby League, you would want to go and speak to someone who is a real expert in Rugby League rather than the guy at the pub down the road. I am not suggesting GPs are guys at pubs down the road; I am using the analogy to illustrate that if I am making an important decision, which is a life-and-death decision, which this is, then I would want to make that on the best possible information available. It will never be perfect information because that is an ideal, but it needs to be based on the best possible information available. The best possible information available will come from experts in that field, recognised as such.

At the moment in the bill neither the coordinating practitioner nor the consulting practitioner need to be experts. The bill says they can refer if they are unsure about anything, but it does not require referral. The kind of amendment I would be suggesting is that either one of those people has to be experts in those fields, so that one of them has to be a treatment specialist, one of them has to be a palliative care specialist, and if they are not themselves then the law should say they must refer to someone else to get the relevant information.

The flipside of that, to finish the point you were making about many of them already being in treatment, is that the law does not require the person or the coordinating practitioner to actually consult with any of the people the person is being treated by. Let's say a person is currently being treated by an oncologist at X hospital. There is nothing in the law that requires the person who is approached as the coordinating practitioner to consult with that practitioner about whether this person actually has the disease that would make them eligible and the prognosis is accurate. It seems to me that would be an important piece of this puzzle, also in terms of professional practice, which again is in line with the Ahpra code of conduct that professionals should confer on these matters. It would enable the coordinating practitioners and consulting practitioners in their reports to the review board to actually provide evidence that those channels have been adequately explored. At the moment they just say they have done it, but this means they can actually provide the paperwork by law as opposed to if they feel like it. That empowers the review board to do more than simply administer a procedural process and actually evaluate those assessments and those judgements around the evidence that is provided. It gives them a bit of teeth: if they are going to refer to the ombudsman or QCAT or anything, they actually have something on which to refer.

Mr MOLHOEK: Thank you for your submission. I think you make some great points. We have certainly heard from many other organisations on this issue this week.

Mr ANDREW: It is interesting. I have heard some stories. You are saying that 70 per cent are already in palliative care. Are they in care or registered for palliative care? Figures can be mismatched or not actually add up. Those checks and balances that you are proposing are a good idea. Is there anything else that you think needs to be looked at in that fashion? Are there more checks and balances that could be evidence for the review board—for instance, the Health Ombudsman, Ahpra et cetera?

Dr Kirchhoffer: I think it is a package deal, if you like. One is the requirement for a palliative consult and a treating consult or expertise in the disease consult combined with the requirement of the coordinating practitioner to consult with the existing treatment expertise, whether that is the oncologist, the GP or whomever, and the requirement to provide evidence to the review board reporting. That is one piece of it. That is all about the doctor and the patient relationship.

The other side to that package is around transparency in relation to the organisations that the people find themselves in. If the person is in care, say, with an oncologist or an existing palliative care expert or in residential aged care or in a hospital or whatever, requiring those organisations and other treating experts or health practitioners to be informed about the process means that the requirements in the bill, for example about QCAT, actually mean something. The provisions that say you can refer to QCAT if there are questions of eligibility et cetera are meaningless if no-one would ever know.

Under the current model, it is possible that a person can go and find a doctor and the whole process could be done just between that person, the two doctors who might be working together and a couple of other people who are involved. However, the organisations who have a duty of care to that person—their treating practitioners, their GPs, the hospital they are in or the residential aged-care facility they are in—might never know. In order for QCAT to have any capacity, this expands the possibility for people to actually raise concerns about eligibility in terms of whether they have a terminal disease that will lead to their death within 12 months or whether there are questions about their capacity to consent to VAD in the first place.

Ms KING: I do have some concerns about the amendments you propose. They seem to me to load up all of the autonomy, all of the power and all of the dignity on to institutions and doctors, who are the more powerful players in these relationships, at the expense of dying people who are vulnerable and at the end of life. More specifically, in the case of a conscientious objection decision about the reasonableness of transfer, does your proposal that the question of the reasonableness of transfer be decided by the facility in conjunction with the person not present a profound conflict of interest, especially given the power imbalance between the institution, who is very powerful and also constitutes the place of residence of the person at that time who is vulnerable, potentially in a great deal of pain and at the end of their life? Does that not present a very profound power imbalance and potentially a very serious conflict of interest in that scenario?

Dr Kirchhoffer: No, and I am going to say no because of those reasonableness criteria. By expanding the circle of concern that we are talking about, getting more people involved in the information that is happening here, those reasonableness criteria have to be evaluated as criteria in the way that they are. If the facility, for example, were deemed to be acting unreasonably by the patient or by the coordinating practitioner, they should be able to then appeal to QCAT and have that challenged.

Ms KING: My concern is the ability of a dying person in the last days or weeks of life to do something as profound as appeal to QCAT. To me, it seems like the person's own coordinating or consulting practitioner's decision is the one that is more independent in this scenario. Along with a number of the proposals you have made, I am concerned that your proposals weigh up that power very much on the side of the institution. I will defer to other members who may have questions.

Dr Kirchhoffer: If I may respond to that, you make the point that the coordinating practitioner is the most independent person in this and therefore should be the decision-maker. The problem is that it is precisely because of their independence that they are probably not the best decision-maker. The facility in relation to the person has a substantial duty of care to a whole bunch of people in that facility: the people who work there, the other people who are resident in those facilities as well as the patient. They have multiple obligations. In that sense they are the better person to be involved in the decision-making because the coordinating practitioner themselves has no actual vested interest in any of it. For example, the premise of the bill at the moment is that it only has an obligation to transfer the patient if it is inconvenient for the coordinating practitioner or the coordinating practitioner is unavailable to come to the facility to consult the patient. Then it is up to the facility to move the person to go for the consult and bring them back. That strikes me as saying, 'Surely, if someone is going to be agreeing to be a coordinating practitioner they should make themselves available accordingly.'

I do not think it is as easy as saying that the coordinating practitioner is necessarily going to be super independent and have no other interests and that there is no conflict of interest between them as a doctor where there is also a power imbalance between those two things. That is my response to your question.

Dr ROBINSON: In terms of your role as a bioethicist—this is a broader societal question in terms of where we are going with providing health services, and I will quickly cite a Canadian study and then throw a question to you. The Canadian study that is called the *Second annual report of medical assistance in dying*—similar to VAD—found that 7,595 Canadians in 2020 accessed that MAID service and, as a result, their lives were ended; over 4,000 of them—I will quickly rattle off a couple of stats—received that service because they had cancer but there was no discussion with an oncologist about the course of action that they may or may not take; 1,253 took up the service but did not have a life-threatening or terminal condition; and 126 could not access palliative care at all before their life was ended. These are directions that have been taken in Canada, and there has been a similar direction in parts of Europe. It is not just the slippery slope argument; these are trajectories we see in the data. Could this be something we see as we lift the lid on this in Queensland?

CHAIR: That is a bit hypothetical, isn't it?

Dr ROBINSON: No, it is not. It is based on data. It is not a hypothetical.

CHAIR: You are talking about another jurisdiction.

Dr ROBINSON: They are very similar laws.

Dr Kirchhoffer: Let me focus on the bill as it stands in terms of that relationship and that question. For eligibility, the bill requires that a person is diagnosed with a terminal illness with a prognosis of 12 months and that they are suffering. The suffering can be physical or mental—it does not say it has to be both; it can be physical or mental, according to the bill—and the suffering is in the perspective of the person. That goes to Ms King's point around the idea that it is the person's own experience of suffering that is what counts. That means that the actual eligibility criteria is around a prognosis of 12 months. That is the real eligibility criteria here. The other is around capacity.

Let's just deal with that eligibility around 12 months. It means that a person who is adequately informed could, once they have reached that 12-month prognosis, say, 'That's very good. I can now start that process.' They can set that process long before we get to the nine-day deadline provision. The kinds of people we should be thinking about in one sense are the people who are well ahead of the game: they are well, they know that this is what they want to do, they reach a prognosis of 12 months and they go and start the process.

At the other end of the spectrum are the people who are not thinking about that up-front. They are going through the process, they are getting their oncology reports, they are in the system, they are not in private care, they are in public health care and they reach a stage where they are starting to experience the suffering. The problem is: if you do not have a system in place where you are providing adequate palliative care in the first place, where you are providing adequate access to treatment and treatment options in the first place, those are the people for whom the choice that is presented in the bill is not necessarily a real choice, because they are not actually choosing between palliative care treatment and VAD. What they are being told they are choosing between is VAD and 'grin and bear it', because 'we actually can't provide you with palliative care and we actually can't provide you with the treatment options you're looking at'. That is the real danger in a society where you start to create a potential expectation around these things.

It is not so much the slippery slope; it is that you start to change the way we think about what happens that is the best way to end life. That can be explicit. We can actually say to people, 'The best thing you can do is access VAD.' The bill goes to great lengths to try to prevent that. However, it can be much more implicit, where the real options that the bill says you are supposed to have you do not actually have. That is the real danger when you start to look at it.

The other thing that is interesting to note about the Canadian context, because it applies to this bill too, is that, unlike Victoria, this bill allows for both self-administration and practitioner administration. That is something they did in Canada as well—unlike say, for example, Ontario, which is only about self-administration. The interesting phenomenon in Canada has been that people have largely, by a very vast majority, opted for practitioner administration. That is where the practitioner is actually providing and administering the lethal substance. I think that is a really interesting thing. The language in Australia has been very much about trying to not be like other countries. However, in allowing for that process we end up with a practical reality where it is much more like the Belgium, the Netherlands and the Canada scenario than it is like an Ontario scenario.

Dr ROBINSON: In terms of the eligibility criteria—and I think you hit the nail on the head there—and coming out of Canada and looking particularly, say, at the Swiss model—and Dr Nitschke yesterday referred to that as his favoured model. In that model, basically the person just needs to be an adult and wants to access the service—and I am roughly paraphrasing him—with not much else. They do not have to be terminally ill or incurable, and Dr Chris Perry from the AMA wants the term 'incurable' added to this legislation to tighten it up. I make that point. Is it possible, as has happened in Canada and Europe, that eligibility requirements in the initial bill come in fairly tightly or everyone is trying to make it tight but they seem to be subsequently amended and it ends up heading towards the Swiss model? Is that a bioethical concern?

Dr Kirchhoffer: It is certainly possible. There is certainly evidence of that happening. There are interesting debates—it depends what you mean by the opening up or otherwise. There is certainly evidence that shows that the people who were originally eligible—those eligibility criteria have expanded over time in other contexts; that is true.

CHAIR: I will probably finish this session with a question around the individual's choice. This is ultimately what it comes down to. For the thousands of people who wrote to us in our broader inquiry including aged care, palliative care, end-of-life care and voluntary assisted dying, and the many who came before us and shared their stories, like Peter in Rockhampton with motor neurone disease, does this not ultimately land on the person who has the incurable terminal illness to make a choice? You have talked a lot about institutional objection. Ultimately, in relation to human rights and choice, should it be the institution that determines that or should it be the person? That will be the final question. It is a bit deep.

Dr Kirchhoffer: I will give you my dissertation later! This is one of those things where the communal good, the public interest or the common good, as you might call it—and in Australia we talk about a Commonwealth; that is why our nation is called the Commonwealth—is one element of what we are trying to be worried about and the other thing is the individual and the autonomy. Those things always have to balance.

Of course, we do not allow people choice in every respect. That is simply not the case. If people come to our country and rent a car, we do not say to them, 'Well, I know that in France you drive on the right-hand side of the road, so you can drive on whatever side you like in Australia.' The point of law is to balance legitimate choices with the public interest. That is why I focus here on the language of autonomy or personhood—I have not expanded on personhood—which is more fundamental than simple choice. Simple choice is a very thin concept around freedom. It is based on an inadequate understanding of what we mean by a human person. For those choices to be powerful—I think this something that everybody should want—people need to be adequately informed about the choice they are making. Therein lies the challenge in this bill.

For most people who will access it, you are probably right: it is fine. They will have private insurance, they will have been in an oncology program and they will have access to palliative care. They may come from a position of influence because they are a retired judge, for example, and be able to tell people, 'This is what I want. I want this information,' et cetera. What is more tricky in this space, in terms of the public interest or the common good, is the huge number of people who will be accessing treatment services or palliative care within the public health system, for whom choices around palliative care or treatment may be substantially limited because they do not have the financial, societal or social resources to access VAD or to get the treatment they want.

It is certainly not about weakening choice. These amendments do not stop a person from choosing; they improve the quality of the choice the person is able to make. In other words, the person who is seeking assistance with dying, the doctors involved in that process, the institutions involved in the process and especially the lawmakers who put the law into place can say that this is a bill that adequately respects autonomy rather than simple choice.

CHAIR: Thank you very much, Dr Kirchhoffer, for your time this morning.

Dr Kirchhoffer: Thank you.

BURDICK DAVIES, Ms Rebecca, Director, Strategy and Mission, Catholic Health Australia (via teleconference)

GOOD, Professor Phillip, Director of Palliative Care, St Vincent's Private Hospital Brisbane

CHAIR: Welcome. Would you like to make an opening statement? Then there will be questions from the committee.

Ms Burdick Davies: Thank you for the opportunity to give evidence about the Voluntary Assisted Dying Bill today. Catholic Health Australia represents the largest grouping of non-government health and aged-care services in Australia. What that means is that we provide more than 15 per cent of all hospital and aged-care beds in Queensland. Our members include household names that you would all know such as Mater, St Vincent Care Services, Southern Cross Care and many other organisations that provide cradle-to-grave compassionate care to Queenslanders.

I will say that, first of all, the Catholic health and aged-care sector will not take part in VAD. Our opposition to this bill is well known. It is an opposition that I do not think we need to go through in detail today. Today my focus is to propose constructive changes to the bill so that, if it is passed, it is fairer, safer and better protects vulnerable Queenslanders. I know that is a key concern for all of you on the committee.

The first problem with the bill is that we have two VAD doctors, coordinating and consulting practitioners, who decide all. They verify a patient's diagnosis and prognosis, even if they do not specialise in their disease. They decide if someone is choosing VAD freely and without coercion, without having to make any inquiries into their personal situation. They decide whether a patient has capacity, but they do not have to obtain advice from a relevant specialist, even when that patient has a condition such as dementia. That is why we are proposing stronger safeguards and obligations on VAD doctors including: compulsory referral and assessment of palliative care options; the holding of specialist expertise in the person's underlying condition or referring them to a relevant specialist; imposing a positive duty on the doctors to examine whether the person may have been coerced; providing reasonable support for people with issues that may affect capacity—for example, for a culturally and linguistically diverse person, translation support; and, lastly, where a person has a condition that affects their capacity, referring for an independent assessment—for example, a neurologist for a patient with dementia.

Secondly, our members have provided cradle-to-grave care for Queenslanders, as I said earlier, in many cases for more than a century. We can be trusted. That is something I would like to repeat a few times today: we can be trusted to provide compassionate care for every person in every circumstance. What I think is extraordinary about this bill is that it dismantles our members' ability to pursue that mission of compassionate care. It requires our hospitals and aged-care facilities to allow access to VAD doctors, most of whom or all of whom they would not have any existing relationship with, from the first assessment right up to administration of the lethal substance. While a patient may be transferred at any stage, the decision rests with the VAD doctor and not with the institution or their doctors. We find this an extraordinary requirement. It has not been included in any other VAD legislation elsewhere in Australia. I would like to respectfully ask the committee to recommend amending the bill so that our hospital and aged-care facilities are informed if a person they care for is seeking VAD; that they are not obliged to provide access to VAD practitioners, clinicians who do not have a relationship with them; and that they are able to make decisions concerning patient transfer at each stage of the VAD process.

Lastly, the bill presents a problem no amendment will address, and that is a promise that every person requesting VAD will have the choice of palliative care. It is a promise that cannot be delivered on due to the inadequate funding and access to quality palliative care in Queensland. I am joined today by Professor Phillip Good, who is an eminent palliative care expert who can speak on these issues. Our commitment to caring for the vulnerable, including the terminally ill, will of course never waver. We ask the committee to offer Queenslanders a better choice. I am open to any questions.

CHAIR: Thank you, Ms Burdick Davies. We have just had a discussion with a bioethicist with regard to institutional conscientious objection versus the human right to choose. Do you have a view on that? The issue of the hierarchical dilemma has come up several times before the committee. Who has the ultimate say when people are in a residential aged-care facility run by Catholic Health Australia? Can I say: you do fantastic work and it is very compassionate. We thank everyone involved in delivering that care. Ultimately, what we found in the Victorian model was that moving people outside for an assessment in order to access VAD caused significant problems. You mentioned a specialist neurologist. There is not too many specialist neurologists in regional Queensland, where I come from. What do you say to concerns about moving terminally ill, unwell people?

Ms Burdick Davies: There are a few issues there. You made reference to a hierarchy of needs. This whole problem—the needs of a person for autonomy and to make decisions about their health and the interests of everybody else in the facility—I do not think should be regarded as a hierarchy. The way that we consider that issue of striking a balance between the rights of the person to choose VAD and the rights of all the people who live and work in our facilities is about striking a balance. That is why you need some kind of an arbiter in this. We would say that a VAD doctor is not the best person to be making those decisions.

The VAD doctor is not somebody who is best placed to make a decision about what a person's health and clinical journey has looked like to date, what their pastoral needs are or what their journey has been like from a spiritual perspective. They also have no understanding of the interests of the other people around that person—for example, other residents in an aged-care home or the clinicians who are working with that person on a day-to-day basis. That is why we think the decision should rest with us. We have a holistic understanding of that person's health and spiritual journey and we have a real understanding of what their best interests would be. Of course we would always involve a patient in any conversation about their care. Of course we would speak with a VAD doctor if we were informed that a person in our care was intending to undertake VAD, but we believe the ultimate decision does need to rest with us for those reasons that I talked about a moment ago.

You referred to Victoria. I found that an odd reference, because we know that our members in Victoria have been operating in a jurisdiction where VAD has been lawful for about three years. The case study you have mentioned is an isolated example. We have had many people go through every stage of the VAD process within our member organisations in Victoria, and I can confidently say that those people have experienced compassionate care at each stage of that process. We have had that advice from members that have large operations in Victoria. They have established protocols about respectful care for people undergoing VAD. They have established protocols for helping their staff have conversations with people about VAD. I guess what I am saying is that we need to have the same level of trust from Queensland MPs and the Queensland government that we can provide compassionate care in your state. We can be trusted to do this. We do not need to have prescriptions laid down in legislation to force us to make decisions about VAD. My colleague Phillip Good can add more about what happens from a clinical perspective when someone requests VAD.

Prof. Good: The experience from talking to colleagues in Victoria is that this idea that VAD is a very isolated process I don't think it's quite the situation. I think that often palliative care is looked upon as a holistic approach to dying. I do not think anyone in a palliative care—either in Victoria or Queensland—would see it as their role to convince someone to do VAD or not do VAD. That is never our role. It is our role to talk about what the person wants, what their choices are, what they would like. It is really just to listen to the person and to actually listen to what their concerns are. My experience from talking to colleagues in Victoria is that often people have asked for VAD in a general hospital environment because of their frustration in dealing with how they want to express themselves in end-of-life issues. VAD is part of end-of-life issues. That is one of the reasons it is really important to see it on a continuum and a spectrum. It is important to make sure that the person has opportunity to engage with palliative care as an access issue.

Mr MOLHOEK: Rebecca, I want to turn to some of the changes you are seeking that you referred to in your presentation, particularly Nos 3, 4 and 5, where you talk about an extra consulting or coordinating practitioner holding specialist expertise. The list goes right through to VAD focused capacity assessments. Fundamentally, I am with you; I understand the heartbeat behind those changes. At the risk of sounding incredibly pragmatic and maybe a bit hard, the health system is already to some degree struggling to cope with availability of resources and the supply of equitable services across the state—if you walk the journey with anyone in the public health system, particularly. It is perhaps easier if you have private health insurance. Some of these requirements are costly. I know that the emotive response would be, 'Well, what price do you put on a life?' and so on. I am not sure about the timeliness of being able to meet some of these requirements. I am hearing stories in parts of regional Queensland and even on the Gold Coast that it can take three weeks just to get an appointment with a GP.

Having walked the path with my sister and now, sadly, my niece, who waited 12 months just for what was supposed to be a routine stomach check that turned out to be terminal cancer, I worry that all of these things we are asking for are perhaps not so readily available unless you are wealthy.

What happens to the person who is already sick and in some form of palliative care who wants to go through the process of applying but now has to see a round of specialists and find the money and resources to do that? How do we balance that in a system that is already struggling?

Ms Burdick Davies: I think I am a little bit more optimistic at the opportunities for government to better fund and resource our health system.

Mr MOLHOEK: Come and visit regional Queensland with me!

Ms Burdick Davies: I would say that I am a little bit more optimistic about the powers governments have to reshape public health. One need only look at the experience of the past year and the absolutely outstanding job done by the Queensland government in managing the response to the pandemic to see the capability and capacity of government to really quickly make very significant changes to public health funding and resourcing. I do not think that should be a roadblock to introducing the changes that we are proposing. When we are talking about availability, of course it is not endless. Public money is not exhaustive, but the pool of people who would actually be going through this process—you mentioned before the statistics from Victoria. It is 200 a year in Victoria. Can we not have enough public funding for 200 people to be independently assessed for capacity? I think it would be an absolutely dire state of affairs in our public health system if we could not provide resourcing for that.

Secondly, you talked about the dearth of resources and accessibility in regional Queensland. That is an issue that from a policy perspective concerns us greatly at Catholic Health Australia. If we are looking at regional accessibility, one answer to that is telehealth. We certainly would not be supporting telehealth for direct conversations about VAD, but, if we are talking about capacity assessments, surely there would be an opportunity for telehealth to bridge the gap. Lastly, you were talking about vulnerable people in the public system perhaps not having access to specialists who could perform these assessments. Our fear is that vulnerable people in Queensland do not have access to palliative care, full stop. I will lean over to Professor Good in a moment because I know that he is an expert in this area, but it is a postcode lottery in Queensland. If you are in one part of Brisbane, you can have access as a public patient to palliative care; if you are in another part of Brisbane, you do not. Our fear is actually that vulnerable people will be skewed toward VAD because they simply do not have another option.

CHAIR: Can you clarify your remark around telehealth? You said that we should not use that. People living in regional Queensland—

Ms Burdick Davies: It is actually an offence against Commonwealth law at the moment. I am not giving a view on it, but it is an offence to use a carriage service. It has actually been covered by the media. It is not an area of expertise for me, but it is an offence at the moment to use a carriage service.

CHAIR: That is by definition.

Ms Burdick Davies: Under Commonwealth law. That is something that Premier Palaszczuk talked about a week ago. What I am saying is: in terms of having an assessment by a neurologist, I imagine that you could in some situations perform that by telehealth, but I would like to ask Professor Good whether that is the case.

Prof. Good: I am not sure about the neurologist, to be honest, but I can talk about palliative care. There are certainly palliative care services that are developing by telehealth around Queensland. I think everyone here agrees that there is inadequate palliative care for everyone to access it in Queensland. I am not sure if anyone disagrees with that. That is something that we all think should be improved. I do not have much to add to that.

Ms KING: Thank you both for being here and for joining us over the phone. Thank you for the work that your organisation puts into the care of Queenslanders in the last years of their lives and at the end of life. I am interested in this idea of compassionate and person centred care. Yesterday we heard from Dr Kris Cornell, a medical professional in Victoria who also had the quite remarkable experience of walking through the journey of terminal illness with her father as he accessed voluntary assisted dying. Additionally, their perspective was that of a regionally based family. Dr Cornell lives a couple of hours outside of Melbourne and, as you have alluded to, in Victoria the directions from Victoria Health are that telecommunications and telehealth are not to be used for the purposes of voluntary assisted dying. I look to your recommendations, particularly 2, 3, 4, 5 and some others. When we consider person centred and compassionate care, how person centred and compassionate would it be—assuming that a person does genuinely and ardently seek access to voluntary assisted dying and that they are regionally based—to put them in a position where they have to undertake all of this additional travel for the purposes of consulting specialists at the end of their life, not for a medical purpose but simply for additional assessments, capacity assessments, prognosis assessments and all of these extra layers that you are recommending in your proposed amendments. Can you speak about the person-centeredness of VAD?

Ms Burdick Davies: I turn this to you as a committee. I would hope that your concern would be that not one person is coerced by their family, that not one person with dementia is put through this process by mistake or on purpose—that there is not one wrongful death under this scheme. I hope that would be a concern.

Ms KING: That has certainly been the experience in Victoria, that there have been no deaths of that kind so far in the first 18 months.

Ms Burdick Davies: It is interesting that you say that. I will talk to that in a moment, because I know that was a remark that the head of the review board made in the media—that she actually does not have any powers to review or investigate allegations of breach. I am not sure how that claim could have been made with any accuracy. Going to your point about person centred care—

CHAIR: We just had Ahpra and the OHO here. I think there was one case that was being reviewed out of about 200 that had accessed it. Anyway, continue.

Ms Burdick Davies: Apologies. I did not hear their evidence. We would say that you need checks and balances to ensure somebody is making a free decision. In Victoria, my understanding is that people do have to be reviewed by relevant specialists where they have a condition that might affect their capacity or their freedom to make decisions. I find it rather extraordinary that you do not think that a person with dementia, for example, would not have to undergo some kind of capacity assessment—

CHAIR: I will just ask you to pause there for a moment. The eligibility criteria is very clear in the draft bill. The issue of dementia—and the committee heard about it in its former inquiry—was raised time and time again; however, a lot of medical specialists, palliative care specialists and GPs who gave evidence assess capacity straightaway when someone walks into a clinic. You must have capacity to be eligible to access VAD. Someone with dementia—early stage, onset or advanced—would not meet that eligibility criteria. I just wanted to clarify the draft bill as proposed.

Ms Burdick Davies: I am intimately acquainted with those parts of the draft bill that you are referring to. First, within the very principles of the bill it states that a person may have capacity in some areas and not others. That very statement suggests that somebody who has, for example, an issue of mental ill health or a pre-existing condition such as dementia (inaudible) to make a decision about VAD. They are certainly not excluded. Secondly, yes, the bill does say that the VAD coordinating and consulting practitioners have to be satisfied that the person has capacity. Our issue is that neither practitioner necessarily has the skills and qualifications to make that decision in some, but not all, circumstances. Where a person has an issue of mental health or an issue like dementia, we believe that a relevant specialist should be involved. This is person centred care, because we need to be satisfied that every person going through VAD is making that decision freely.

We are not trying to stand in the way of choice. Of course we have an ethical objection to VAD but, as I said, our experience in Victoria is that our members consistently provide compassionate care and that they accompany every person within their care, no matter what their end-of-life choice is, to the end. I am really confident that that is the case. As I said before, I think we are a little bit worried that Queensland parliamentarians are not trusting us to do that.

Ms KING: With the amendments you propose, will your organisation support the amended voluntary assisted dying scheme?

Ms Burdick Davies: We oppose VAD in any form, but certainly want to have constructive conversations with MPs about amendments—absolutely. We want to be able to continue to operate and help Queenslanders.

Dr ROBINSON: Thank you for your input today. I had a number of questions. Most of those issues have been raised, but I have one particular area of interest. The bill sets out to do certain things. The question becomes: what do we learn in terms of experience of VAD type legislation in other jurisdictions such as Canada and now very recently Victoria? Is there a risk that vulnerable Queenslanders could be somehow coerced or steered towards VAD over, say, palliative care?

Ms Burdick Davies: There are a couple of issues there, and thank you very much for that question. The answer is yes. We are concerned by some of the patterns in evidence that have emerged from jurisdictions where that is lawful and how they might carry out in Queensland. If we look at Canada for instance, more than a third of people who selected medically assisted dying in

Canada stated a desire not to be a burden. They felt that they were burdening their families and that VAD was the best option as a result. Some 13 per cent cited being lonely and having no social support as a factor in their decision. It really says something very sad about our society if those psychosocial reasons are the factors that drive people toward a voluntary assisted dying scheme rather than undertaking palliative care. We should be looking at why so many people approaching the end of their life are lonely. Why are they feeling like they are a burden? How can we help them feel that they are not a burden and that we will care for them right up until the end? I can say that every person staying in our Catholic health and aged-care facilities can be confident that that is the kind of care we will be providing.

In terms of my background, I have only been with CHA for six weeks. Before that, I was the head of policy for a big suicide prevention and mental health peak. I do find it quite extraordinary that some of the conversations I was having only a few weeks ago about how worrying it is that so many people are expressing psychosocial risk factors such as feeling lonely and feeling they lack social support in the context of suicide are not a real concern when considering legalising VAD. It concerns me from an ethical perspective.

Ms PEASE: I want to pick up on a remark you made in response to the member for Pumicestone that you want to continue to operate in Queensland. Can you elaborate on what you mean by that statement?

Ms Burdick Davies: I cannot anticipate what will happen to any of our operations in Queensland if this becomes law. I am certainly not drawing any conclusions about that. What I can say is that the bill as its stands would make it very difficult for our members to operate in the way that they have; that is, operating consistent with our mission, which is to always care, never abandon and never kill. It would divorce us from our mission. That is all I can say on that point at the moment. My focus, really, is that I have been having really constructive discussions with MPs—and I would love to continue those discussions—about how we can make the bill better and how we can ensure that our hospitals and aged-care facilities in Queensland can continue to provide care that is consistent with our ethic.

Ms PEASE: Have you been able to continue your services in Victoria?

Ms Burdick Davies: Yes, we have—absolutely. It is interesting, and I should have mentioned this earlier. The key difference with Victoria is that the whole question of the role of institutions in VAD is left open. We have been able to find a space around how we operate in that environment. We have been able to develop the right kinds of protocols, procedures, mission statements and training for our staff that enable us to operate in that framework. The problem with the bill in Queensland is that it really makes that gap a lot narrower for us. It creates a very difficult situation where we would be forced to act contrary to our ethic of care.

CHAIR: Reverend Andrew Gunton from the Uniting Church appeared before us on Wednesday, He stated that, should this proceed, they would not stand in the way of allowing practitioners to go and assist someone in their facilities. That was his view. Do you have any comment on that?

Ms Burdick Davies: We would have exactly the same view. We would never abandon somebody we are caring for. We would never force somebody out. If a doctor is seeking to see a person in our care and that person wanted to see the doctor, then of course they can do that.

CHAIR: Thank you for the clarification.

Dr ROBINSON: When we add the dimension of religion and faith, sometimes the question becomes to what degree church leaders or managers of programs are representative of their constituencies. Questions have been put to a number of church ministers and faith based agencies about how much they represent the views of their people. Do you have any research or solid surveys that would help us understand the depth of the view against euthanasia as a practice within Christian society? We have heard from Anglicans, Catholics, Lutherans, Pentecostals and Baptists. Those who are insiders and who know the people say that, generally speaking, there is strong opposition to euthanasia or any form of it. As experts working with that community, is that your experience as well?

Ms Burdick Davies: Our workforce is very diverse. We have Catholic people working for us, we have people of no faith and we have people who are Muslim. We have people from every faith working with us as staff, and people of every faith live with us in our facility and have all been treated at our hospital. We represent a very diverse group of people. What I can say is that a high proportion of people who elect to join us as staff and a high proportion of people who elect to stay in our hospitals, particularly in our aged-care facilities, share our ethics. They join us because of our mission. As I said, our mission is to provide care, never abandon and never kill. That is a really important principle that I think a lot of people who lead this work share with us.

Dr ROBINSON: It would be fair to say that a high proportion of your people support the leadership views of the church?

Ms Burdick Davies: Yes. I have to qualify that. We represent hospitals and aged-care facilities. I am not a member of the religious, nor are any of the members that I represent, although of course a lot of them were started by religious organisations and that is a really important part of their history. Yes, I would say that a large proportion of people that live and work within our facilities share our mission and they have purposely chosen to be with us because of it.

CHAIR: Thank you, we have run over time for this part of the session. Thank you both for your contributions to the committee today.

MUIR, Mr David AM, Clem Jones Trust

CHAIR: Thank you very much for being here today. We might go straight to an opening statement before we move to questions.

Mr Muir: Firstly, I would like to commend your committee, Chair and Deputy Chair, for the work you are doing. I would like to commend the Queensland Law Reform Commission, headed by Supreme Court Justice Peter Applegarth, for the wonderful job they have done in drafting the bill that is under consideration here today. The reason I am here is because of the wishes of Clem Jones, former Lord Mayor of Brisbane. I will just quote an excerpt from his will, which indicates Clem's aspirations—

> If we have a definition of living of any sort, it cannot include the existence of people simply artificially kept alive against their will and in circumstances that can only be described as totally inhumane or, indeed, barbaric.

They are the words of Clem Jones. For the reasons outlined in our written submission, we urge the committee to recommend to parliament the bill as drafted by the independent Queensland Law Reform Commission. The bill draws on and improves existing laws in the model bill by professors Lindy Willmott and Ben White, who have given evidence here before the committee, as a starting point for the Queensland Law Reform Commission. Voluntary assisted dying law pioneer and Northern Territory chief minister Marshall Perron described the White-Willmott model as the best he had seen. It says a lot that the Queensland Law Reform Commission has improved on that.

In brief, the bill before us delivers equity of access for those seeking VAD, it contains necessary safeguards, it provides for conscientious objections and it aligns with human rights principles. In fact, the bill goes a bit further than the bills in some of the other states in the sense that it will allow entities a conscientious objection. It is important to realise that conscientious objection is not actually compromised by the provisions of the bill. As in the termination bill, there is no requirement for a referral. All that is required of these institutions is that they do not stand in the way of the welfare of their residents and patients. That is all that is required. The bill has a nice balance between the human rights of residents and patients and the objections raised by institutions.

Safeguards are essential, but we urge the committee to reject the arguments of opponents who would be happy with only one safeguard—no VAD law—which in fact is no safeguard at all when it comes to the unregulated current practice surrounding terminal sedation. Terminal sedation does not even have the word 'voluntary' in front of it. The intention they talk about in terms of double effect is not the intention of the patient at all; it is the intention of the doctors, nurses and family. The most important people in the room in this whole debate are the terminally ill. They are the most important people. They are the most vulnerable. They are the ones who need to be catered for. They do not have the safety infrastructure around them now that this bill would provide in terms of safeguards.

The evidence shows that the safeguards in the bill before us do work. Betty King, a former Supreme Court justice who chairs the Victorian VAD review board, which has examined every single VAD case since the law took effect in June 2019, told the ABC in April—

> I have not seen one example so far of anyone who has been pushed, coerced or inveigled in any way into taking the assisted dying medication.

The review board's latest report to December 2020 shows that there has not been a single example in 224 cases in the first 18 months of the scheme alone. US advocacy group Compassion and Choices has looked at the data from American states with VAD laws, what they call medical aid in dying. It says—

> In more than 20 years of experience since the first law was enacted in Oregon, and an additional 40+ years of combined evidence and cumulative data from the laws passed in other jurisdictions there is not a single substantiated case of abuse or coercion nor any civil or criminal charges filed related to the practice. Not one.

I urge the committee to reject scare tactics and misinformation about VAD. For a start, voluntary assisted dying is not suicide. We say that, but so does former Liberal premier of Victoria Jeff Kennett, former chair of Beyond Blue. So does the US research and advocacy group American Association of Suicidology. In fact, they issued a statement in 2017 which said, 'Typically, people who are seeking VAD desperately want to live but cannot do so by virtue of their terminal illness.' Importantly, so does the bill we are considering. Suicide is a choice between life and death, usually by a person in a rational state of mind and despite having reasons to live. Voluntary assisted dying is a choice between two deaths—a good death and a bad death—by a competent person whose life is already drawing to a close.

When it comes to genuine suicides, including those identified in the National Coronial Information System's reports, the very existence of a VAD law could help address the tragedy of those with terminal conditions who now take their lives early. Evidence shows that the mere fact of

VAD becoming available can relieve anxiety by offering a legislated option if a person needs and wants it. We want to see better resourcing and wider availability of palliative care, especially in regional Queensland. We note that some extra funds have been earmarked by the state government as a start.

Palliative care can help most but not all people. That is the evidence. That is the imperative of VAD. This fact was put to the previous committee's inquiry in evidence by several authorities. I draw the committee's attention to the evidence of Dr Edward Mantle, palliative care specialist with the Cairns and Hinterland Hospital and Health Service. Dr Mantle said that he was absolutely not a supporter of VAD, although he respected an individual's right to choose if they wished. He also told the previous inquiry—

> I think it is disingenuous, and it is probably closer to a bald-faced lie, when palliative physicians say that they can relieve all suffering for all patients. It is simply not true.

We have a VAD bill in front of us today because solid evidence led us here following the previous committee's inquiry. The bill, like other VAD laws, does not offer automatic access to voluntary assisted dying, but it allows people to seek access in line with legislative criteria and safeguards. Like other VAD laws, it accommodates the position of opponents 100 per cent with one single word: voluntary. This law will allow both sides of the argument their choice. A voluntary assisted dying law will never impact someone who does not want to choose VAD. Nobody should impose their views by denying that choice to others. Above all, let us all remember one very simple fact: under any VAD law there will not be a single extra death but there will be a lot less suffering. That is why we urge the committee to recommend the bill before us to the parliament unchanged.

CHAIR: Thank you very much, Mr Muir. I can see some note-taking down there by the member for Oodgeroo so I will leave it to you, Deputy Chair. Who wants to go first?

Dr ROBINSON: Thank you, Mr Muir, for appearing before the committee. The legislation we have before us now is a starting point in Queensland. Should it be passed or should it be amended, it is a starting point. Can I ask you to comment in terms of what picture has developed over the years in the Netherlands from their starting point? Their starting point was that it was mainly about the terminally ill, mainly about elderly people, though it could include others. In 2001 the legislation was amended and extended to children as young as 12 years of age. In 2005 it was amended and extended to children younger than 12 years of age, and more recently it has been extended to those who are 'tired of life' or feel they have had a completed life. It has gone well beyond the bounds of those who are terminally ill, those who are physically suffering and in great pain. It has gone well beyond that. Why would we open Pandora's box on the legislation here if other models like the Netherlands show that it will extend well beyond the starting point?

Mr Muir: Member for Oodgeroo, I would say to you that your starting point is not correct. The law you are referring to relates to a law that was never described as a voluntary assisted dying law. It is a euthanasia law that does not have the prerequisite that you have a terminal illness, so your premise is incorrect. Your premise also seems to be based on the philosophy of a slippery slope, which has been thoroughly discredited by the parliamentary inquiries of Victoria, Western Australia and Queensland. All I can say to you is that you are basically formulating a slippery slope argument which has no foundation.

Dr ROBINSON: Are you saying that what I have said to you in terms of what has happened in the Netherlands, in terms of it being fairly tight initially and what is available today under similar type VAD legislation, is wrong?

Mr Muir: What I am saying is that your premise, that it started off as a voluntary assisted dying bill, was wrong. They have altered their law. They have a parliament like we have a parliament. Our parliaments have a duty to make responsible laws for the common good. For you to make an analogy of what is happening in the Netherlands and transporting that into the Queensland parliament I say has no foundation.

Dr ROBINSON: You do not think their euthanasia or VAD type experience in the Netherlands has any relevance today, although our legislation tends to be looking around the world and mirroring parts from other parts of the world like the Netherlands? You have just said that they have extended the legislation to be much broader.

Mr Muir: Of course they have, but your premise is incorrect. You are comparing apples with oranges. What you ought to be doing, with respect, is seeing what is happening in the Australian jurisdiction. The original template effectively was in the laws passed by the Victorian parliament, and there is a significant mirroring around the states of Australia with Victoria, Western Australia, Tasmania, South Australia and hopefully Queensland, which has used as a basic template a law called voluntary assisted dying.

Mr MOLHOEK: Thank you for being here today and for your tireless advocacy. We have had many conversations over the last few years. I am really wrestling with some principles within the legislation. I am inclined to think that freedom of choice should be a fundamental issue. In fact, I googled earlier the constitutions of both the Australian Labor Party and the Liberal Party, and both sides of politics talk very clearly about freedom of conscience, freedom of expression, freedom of religion and the right to practise and support those views. My concern in the legislation, and I would appreciate your comment on it, is where at the outset it says that a medical practitioner cannot offer VAD advice freely—it has to be requested—and then there is a prescription of certain penalties or rules around that within the legislation. Equally so, if someone is deemed to have tried to talk someone out of going down the path of voluntary assisted dying then there is the potential that they could face up to seven years in jail. Do you think that some of those measures are a step too far and that it is a bit of an offence in that on the one hand we are saying the dying should have freedom of choice but medical practitioners, counsellors, pastors and institutions are not able to have that same freedom of choice?

Mr Muir: Rob, I think my answer to that would be that the committee obviously and the parliament will be rightly concerned about coercion in any way. The way that I understand the bill has been written is that it is not a matter of mere discussion or mere suggestion or advice; it is a matter of something which is done in a coercive or dishonest way. I think any person would say that it does not matter which side of the coin you are on, trying to influence somebody, if you are using unfair means and coercion and dishonest practice in trying to switch that person's view one way or the other, either side of the coin ought to be penalised. My understanding of this bill is that if somebody in honest and good faith is seeking advice about whether they should take up the VAD option or not and that person gives them advice, no, they shouldn't for these reasons, that will not be an offence, is my understanding.

Mr MOLHOEK: We heard from a representative of Catholic Health Australia. I think it was the chair who asked what they would do in certain scenarios and they said, 'Well, of course, we will go back to our mission, which is never abandon, never kill'—I cannot remember the other one.

Mr ANDREW: Always care.

Mr MOLHOEK: The implicit plea I think I heard from her was: 'Can you please trust us?' I just worry: are we overlegislating here?

Mr Muir: My response is that there is one person in this room that we need to trust and that is the terminally ill person. You will be hearing some evidence I think from Tanya Battel and others shortly. Their voice needs to be heard. My fear has been that up until today their voices have not been heard. They are the people we need to trust. We need to trust those people who are terminally ill to make the right decision in their own interests for their own reasons. That is where the trust ought to reside, in my view.

Mr MOLHOEK: I cannot argue with the fundamental principle you espouse, except that often people when they are at end of life, when they are in extreme circumstances, do not always know what they want themselves. I think about my sister's journey, and we heard testimony from some other doctors around the chemical changes that occur under duress—challenges around the ability to reason and make those decisions.

Mr Muir: I understand all of that, but my understanding is that there are safeguards wrapped around this. What we are talking about here is somebody who is of sound mind, somebody who is competent to make a decision. The safeguards around this are not only the fact that there is a three-step process and you have at least two doctors—probably more but at least two doctors—mandated to be involved; you also have two independent witnesses mandated to be involved who cannot have a vested interest, who cannot have an interest in the estate or any other person. You have four people at least. Their credibility is on the line here. They have to certify that this person is making a decision of sound mind.

I think that thing about the chemical composition of the mind and all the rest of it is a furphy in the sense that this bill will actually ensure that people are of sound mind, are competent, and there are safeguards put in place to ensure that—and rightly so. I think we ought to be concerned. We would hate to see anybody coerced in any way in terms of taking VAD, but the evidence I think is what we need to rely on—the evidence that is in already in the state of Victoria, the evidence that is already in in relation to Oregon and other places around the world.

I think the best we can do is to make laws in this state that are based on fact and evidence and put the safeguards in there. Safeguards do not exist right now for terminal sedation, as I indicated earlier. That is what worries me. For good reasons usually people are terminally sedated in Queensland, I would expect. We have a review board here, too, that examines each step of this process. They are not just doing it after the process has finished; they have a torchlight on each step of the process as well, so we have another safeguard of this review board that is examining each step along the way. You have also opportunities to go to QCAT if anybody wants to challenge any part of the process. These things are all in place ahead of that final decision, the administration of the drug at the end of the process. My sense of it is that the evidence is compelling in Victoria, and that is the best evidence, I would have thought, in terms of how this kind of bill might operate.

CHAIR: I refer to this issue of access and equity for people in rural, remote and regional Queensland. Who is best placed to resolve this telehealth carriage service issue?

Mr Muir: I have no doubt in my mind it is the Commonwealth. The Law Reform Commission was obviously of the same mind. There is an interim measure—apart from legislative change, which might take some time—that there ought to be prosecutorial guidelines issued by the Commonwealth Director of Public Prosecutions to indicate that if there is compliance with a state law then the Commonwealth would not prosecute.

CHAIR: I will draw your attention to division 4, clause 8, ‘Voluntary assisted dying not suicide’. The carriage service law talks about suicide. If this bill is passed and this is considered as the definition then that should negate that, you would imagine.

Mr Muir: It ought to. There is conflicting legal opinion about that. There is some Queen’s Counsel opinion that says that nothing needs to be done, that clearly whatever is happening under the Queensland bill would be lawful and there would be no Commonwealth offence, but there is some legal argument about that and it behoves the Commonwealth to step up to the plate and legislate or, at the very least, the Commonwealth Director of Public Prosecutions to indicate a guideline for the benefit of the doctors and the nurses and the people of Queensland, particularly in remote areas. I come from the bush—born and bred in Longreach—and I can tell you that we need to keep in mind regional Queensland at all times with the operation of these laws. On that basis, the Commonwealth must step up to the plate to give clarity to protect medical practitioners in this state who may be anxious about this.

Ms KING: I am interested in your comments that there is one person in this scenario we need to trust and that is the terminally ill person. One issue that has not been much explored over the course of these hearings is one that might loosely be termed reverse coercion: the pressure brought to bear on a terminally ill person. In some cases it might be to pursue treatment that may extend their life at the cost of quality of life. It might be to not pursue voluntary assisted dying options that the person might have. Could you speak to that?

Mr Muir: Yes. I think there is certainly anecdotal evidence I have heard and seen about that. It often is the case where a father or a mother or a loved one says, ‘Look, I have done all the things that I can do to cure my condition. This is unbearable. It is awful. I don’t want to go on any further,’ and their loved ones just want to hang on to them. There is that dynamic where a son or a daughter does not want to lose a parent and, really, to some extent in their own interests, they would try to convince their parent not to use the facility of VAD. It is interesting, because human life is such that, quite frankly, most people even with a terminal illness will want to hang on to life as long as they can. That is just the natural human condition. We want to live. We have this drive to live. People who use this facility of VAD are not going to use it in an arbitrary or a peremptory way. They will live for as long as they can, as long as they can tolerate their condition. They will have a family dynamic often, usually, to be frank, in my understanding, that, ‘We want you to live an extra day or an extra week,’ but that person has the right, and we ought to trust them, to know what is best for them. The whole fulcrum of this bill will put the power back where it belongs. It will put the power back to the person in the bed, to the person who is terminally ill. That is the driving fulcrum here. For too long they have been voiceless and disempowered. The beauty of this bill is that it shifts the power to where it ought to be: with that person. That is the most important person in the room, I keep on saying, and we cannot lose sight of that.

Ms KING: I want to briefly reflect on the words of the member for Stretton in his valedictory speech. He spoke as a person of deep Catholic faith. He said, ‘Terminally ill people fight to live every day. I fight to live every day.’ He very much wanted people to have the choice of voluntary assisted dying.

CHAIR: Well said, member. I thank you, Mr Muir, for your contribution today and advocacy for people.

Mr Muir: Thank you, committee, for hearing me.

McLEAN, Ms Therese, Private capacity

YOUNG, Ms Beverley, Private capacity

CHAIR: Welcome. I understand both Tanya Battel and Lyn Bailey are too unwell to join you today. We thank you for your considered submission titled 'The Gang of Four', and I see you have pictures of both Tanya and Lyn there, so they are here in spirit. Which one of you ladies would like to begin? Procedurally, we need to deal very quickly, members, with tabling additional documents in relation to the palliative care services review. Is leave granted? Leave is granted.

Ms Young: I have a copy of that for each of you of all. That leans towards what I believe would improve palliative care. It is in line with the palliative care legislation set down in 2019. It also shows where there are some deficits, I believe.

CHAIR: Thank you. To clarify, there are two documents that have been tabled.

Ms Young: Thank you for the opportunity to speak. Before I start, I would really like to acknowledge the other two members of our team who are not here, Tanya Battel and Lyn Bailey, who are both too unwell to appear today. It is very unfortunate. In truth, if it was not for Tanya Battel we would not be here today. She was the instigator of our gang of four and we all have a very vested interest in seeing this bill passed.

I came to express my views on voluntary assisted dying in line with my experience as a palliative care nurse. This bill, if accepted, will have far-reaching effects into the future, not only in eliminating unnecessary suffering for those who might seek voluntary assisted dying but also for the countless loved ones left behind commonly traumatised by the experience. Many people, like the other three members of our gang of four, will recount compelling stories which suggest voluntary assisted dying as the most compassionate validation for those suffering intolerable side effects of terminal illness. I can attest that each one of the other three ladies have already suffered greatly and are desperate to live, yet here they all are supporting voluntary assisted dying.

Those in opposition may be equally passionate to see this very well considered and constructed Voluntary Assisted Dying Bill 2021 fail. I do not for one minute minimise the gravity or difficulty of decision-making in this instance. I fully respect an individual's right to conscientiously object for any reason, as long as such objections are based on factual concerns, not scurrilous suggestions that proposed such legislation would impact the elderly in aged care or those with dementia, that they may be coerced into choosing voluntary assisted dying by greedy relatives eager to access their assets. Likewise, I respect any doctor who declines to assist or participate in any action pertaining to voluntary assisted dying, so long as they do not impede access for that person to seek voluntary assisted dying outside of their control.

What I bitterly oppose is that those against voluntary assisted dying have the right to impact on my end-of-life decisions and choices should I suffer any one of a number of terminal illnesses for which the very best palliative care is ineffective. I have listed a whole lot of those particular instances where I have nursed.

The proposed Voluntary Assisted Dying Bill 2021 is about choice and equity. It has safeguards to protect the vulnerable and an excellent framework for implementation which I believe will be overwhelmingly supported by the people of Queensland. Last year, over 48,000 people in Australia died from cancer. This figure does not take into account deaths from many other terminal illnesses. The majority of people affected by terminal illness will fortunately have the disease well managed with access to effective palliative care. Those who may seek voluntary assisted dying will most likely only be a very small percentage. Regardless, any unnecessary suffering is significant, not only for those people forced to suffer but also for the loved ones called upon to stand by and watch them experience a horrendous death. You will hear harrowing tales from families, many of whom, I believe, have been scarred for life by these experiences.

The other significant reason some deny the need for voluntary assisted dying legislation is the mistaken belief that increased palliative care funding will deliver better palliative care and negate the need for such legislation. Might I say here that the proposed increased funding for palliative care is a significant and positive step in addressing some of the identifiable needs, especially for people in regional and remote areas. There is, however, also an imperative to address the reasons palliative care is not better utilised where it is readily available, where its current efficacy is questionable. You cannot just allocate a number of beds in either a hospital or an aged-care facility, designate them as palliative care beds and expect that effective palliative care is being delivered without the skilled assistance of appropriately trained doctors and nurses. Like every other specialty—cardiac care, orthopaedic care, surgical care, paediatrics et cetera—palliative care is a specialty that requires complex knowledge of multiple diverse terminal illnesses and the ability to understand and prescribe the specialised medications required for effective management.

In conclusion, one of the most distressing aspects of my 12 years in palliative care, the last four as a level 3 supervisor, is to hear eminent doctors, even professors, state that good palliative care can address any side effect when I know this is patently untrue. I would suggest such learned colleagues actually spend some more time at the bedside in any hospice where someone with end-state pancreatic cancer is in full bowel obstruction and is faecal vomiting, or at the bedside of someone suffering advanced cervical cancer from fistulas which have tunnelled into the bowel, causing faeces to leak continuously from their vagina unabated until they die, which could be many weeks away. I could recount many instances of similar horrific side effects that occur with numerous terminal illnesses. These are not rare occurrences and cannot be addressed by the best palliative care possible. I am, have always been and will always be the greatest advocate of palliative care, but I also recognise and acknowledge its limitations, making the most compelling reason to accept the Voluntary Assisted Dying Bill 2021 as legislated for Queensland. Thank you, ladies and gentlemen.

CHAIR: Thank you, Bev. How many years did you nurse?

Ms Young: I was in palliative care at a leading hospice in Sydney, at Calvary Hospital—I am quite happy to say where—under the Hospice of Little Company of Mary for 12 years, the last four as supervisor. I was a clinical nurse specialist. I had lost my dad under terrible circumstances before I was nursing and I always knew I would go into palliative care. I was a late starter. I went to Sydney specifically to do palliative care and then did postgrad studies at the University of Technology in Sydney in advanced palliative care. I love it with a passion and I still miss it, but I understand it has limitations.

CHAIR: Thank you very much for the work you have done. Therese, would you like to make an opening statement?

Ms McLean: Thank you so much for the work that you are doing. Patients do not have a voice, and I think David was very kind in suggesting that. The issues of patients are not well known and when Catholic aged care say, ‘Trust me,’ I just want to die now because I know that we cannot trust any institution to make decisions for the dying. My mum died in Catholic aged care. She was beautifully looked after and there was absolutely no doubt that those practitioners in that institution loved her as a part of their family. They delivered the faithful wishes of those people in terms of pastoral care, but in terms of practitioner support and the ability of patients to influence the outcomes that doctors predetermined for them, there is a total absence of that.

The willingness for any institution to say, ‘Trust me,’ is beyond my belief. I do not want to be shopped around to a range of practitioners to prove that I am dying. God has chosen that I am coming early, and I am quite happy with that choice. I am not afraid to die. I am only afraid that institutional objection will have a greater power in the state of Queensland than the power of the people. I call upon MPs—you are blessed to have been elected and to have been given the trust. When we elect you, we say, ‘We trust you to look after Queenslanders.’ That is not the same as going into residences in aged care or into a hospice where we go frequently because there is nothing else. If we could care for ourselves at home, we would. If we could be sure that the funding would be available as required to top up services, we would be more than happy for that to happen.

We do believe in palliative care as much as we believe in VAD being an option at the end of life. For churches to come forward and say that the state should find all the money—churches do not pay tax. They have significant wealth and they have significant capacity to invest in services and improve services, but they would rather blame institutional breakdown and patient care breakdown on the government.

It is somewhat similar to saying that the paramedics are at fault because they want to work a shift that is manageable and safe and ensures they can deliver the services to the people of Queensland. It is not their fault if we do not have enough of them. It is not anyone’s fault that patients who are dying sometimes need more than is available.

I commend the committee on your demonstrated commitment to be in the country, in the rural and remote areas, inviting patients to talk for themselves, and inviting communities to say, ‘We care. We want to be there.’ I look at Steve and I think, ‘You come from the middle land.’

Mr ANDREW: I certainly do.

Ms McLean: Often the middle landers are forgotten. We go to the great north and we are pretty good up in the remote areas at accessing information and availability and pretty much naming that services do not exist. When we come to the middle, we tend to say, ‘Fend for yourself. You can drive to Brisbane.' That is not good enough. There are people dying in the Mackay Base Hospital for lack of palliative care services. They are not choosing to not go where services are available and they are not leaving their faith based caring groups. They belong in communities that want them. They will look to Steve to say, 'Thank you for bringing your colleagues to our area. Thank you for going to Townsville. Thank you for going further than anyone has ever been in terms of asking the middle east like Rockhampton, "How are you feeling? What are you needing? Where can we go?"' That has been the blessing of this committee, that you have asked a lot of people a lot of questions, and you have invited them back if you did not feel you had enough information. That is the greatest gift that parliamentarians give to their community. It is the listening, not so much the talking. I believe in you and I trust you to look after me and everybody else who fronts up to a system that says, 'Yep, cancer has its eyeball on me. It's going to win.' I am going to go one day without the kind of care that might have saved my life, but I am not frightened of that because I know we are giving it our best shot. If there is any place in Australia where we will be cared for, commensurate with the need that we present with, it will be Queensland.

Our friend Tanya, who could not be here today, has a petition with 82,500 signatures of Queenslanders saying, 'Help. Bring VAD to Queensland.' Increase the egalitarian society that we have chosen to live in. Care for the dying while also caring for all the constituents of the state. What we ask for is not that you take from anyone else to give something to us. Do not take from palliative care to find money for VAD. Give the funding that is available from the state and ask the contributors who want to have the say. Ask the churches for their share of the taxes that fund state public health and, in a way, fund private health options in Catholic aged care. It is not just the Catholic churches that do not pay taxes; it is other churches that are quite wealthy and have large constituency bases that they claim are anti VAD. That is not the evidence that is available from the faithful and from the worshipping at churches.

For instance, Bishop Tim in Townsville I find a very worthy opponent. I enjoy his company. I enjoy his argument. I enjoy his courage in putting forward continuing views. Eighty per cent of his own constituency do not support the views of the church. That is because people in Townsville and Thuringowa are particularly smart. They are very smart. They know how to make their views known. They take strength from each other in stepping forward. But they do not run down other parts of the country or the state or their MPs or their doctors or their nurses. They join together, raise people up and say, 'We can do this together.'

I truly believe that this committee can do what the will of the people has prescribed and that you will. I have total trust in this committee. I must say I had total trust in the last one. I see some of you are new to this, stepping up to take on what other people would say is a poisoned chalice. You have been given a job that many people did not want and many people perhaps discouraged you from taking and maybe will even name as your legacy that you failed because you did not kick VAD to the curb. But be proud. We ask you to take pride in your courage in being here.

When we speak about dying, we speak not of any impoverishment or any lack of opportunity or lack of choice. We only speak about inclusion and choice. This committee has given choice by inviting so widely people to submit and to participate; by having open doors at so many hearings and being willing to allow people to speak from the heart; by not saying, 'Don't give us the gory details. We don't need the gory details.' You have actually said, 'You can speak to us as if we were your mum, your dad, your brother, your sister, your carer, your local community and, most of all, your elected representative.' That brings with it great honour, which we respect. We hope you will claim it, that you will claim your honour as champions of the dying and that you will see us off like you saw Duncan off. That you will attend, you will cry for the man, you will be there for his family and you will invite us to continue the work that Duncan began by putting in the hearts of his colleagues, his MPs, a passion for delivering VAD because it is a good thing.

There is no evilness in the VAD legislation. There is nothing for us to be afraid of us as a country or a state. It is something that belongs with the heart of the people. We know that you are here for us and we thank you for that. We thank you for taking on a job that is exhausting. I am surprised you are sitting up today after we have seen what you have been through all week. It has been strenuous and exhausting and you are here and we thank you for being here. Some of you probably mostly want to go home and that will happen tonight and that will be the gift of what you deserve most of all—rest in the knowledge that you have done the right thing.

CHAIR: What an amazing lady. I love it when people speak from the heart. Therese, thank you so much. We are honoured to have done this work. This is a great way to finish after starting in 2018. I will open up to questions.

Mr MOLHOEK: I certainly echo your sentiments and thank you for speaking so openly and candidly with us today and sharing your heart. These are heart-wrenching decisions that we have to make. I have been known to say on many occasions that the devil is always in the detail. I do not think there is a single one of us on my side of the House who is not compassionate around the issue but is just concerned that the detail is right. Beverley, you talked a little about your extensive involvement in palliative care. In their submission, Palliative Care Queensland talked about the need for more dollars and more robust systems and supports. They also raised the issue of statutory reporting and greater accountability. In part the dilemma is that not every palliative care bed that is used for palliative care is necessarily seen as a palliative care bed, and then there are specific dedicated palliative care facilities and beds around the state. I guess my question simply is this: do you think there needs to be greater accountability around what is actually allocated to palliative care?

Ms Young: I do. I have worked in general care as well as seven years in aged care. I have seen both sides of it where, with the best intentions, beds were designated as palliative. I am sure in all instances doctors believed that they were giving palliative care, but I can assure you, having worked within a hospice, that it is so complex because of the differences in so many disease states. Cardiology is cardiology and orthopaedics is bones, but terminal illness or a life-limiting illness—whatever term you want to put—is so varied and so multifactorial. They all require very different modalities. Often in general you would say 'pain' and doctors will lump that under an umbrella whereas in palliative care, for instance, very simply, with breast cancer at the tissue site you have somatic pain. Then it will go through into the brachial plexus so now you have nerve pain. Over the longer term it will go into the bones so now you have neuropathic pain and orthopaedic pain. You have different modalities that all require really complex medications to address each and every one of those together.

My biggest point is that regardless of even that, with the best palliative care and the best doctors and the best drugs available, in some instances—and I have listed many of them—you cannot address those things. You cannot stop that suffering. As I say, I have nursed so many people in so many ways a long time before they have actually got to the dying stage and said, 'I wish I wasn't here; why doesn't God take me?' I have the deepest faith. I do not believe God wants us to suffer until the day we die under untenable and horrendous situations and have families sitting around and watching that happen and being traumatised by it.

I know it sounds crass, but there are a lot worse things than dying—seriously. You sit at the bedside and you experience it and the family beg you, 'Please do something', but you cannot. Staff are traumatised. I had a meltdown recently when it was recounted to me about someone who died with a tumour in their neck. I can remember sitting on the floor with a man who had a very similar thing. At 2.00 in the morning he buzzed, ready for his morphine. I said, 'I'll go and answer it.' I got there and it had popped. He had been laying like that and it burst. He was down on the floor. I got down on the floor and held his hand and talked to him. I said to the nurse, 'Go and get midazolam.' She ran off and I talked to him and said, 'You're having a little bleed', knowing that it was the very end. I sat there holding his hand until there was no more blood for his heart to pump and it stopped. Then I had to go to the phone and ring his family and, God forgive me, I fibbed. I said to her, 'Dad's having a little bleed.' They lived at Penrith. She said, 'If I come now will I get there in time?' I said, 'No.' She said, 'Go back inside and tell him I love him.' He had already been dead for 10 minutes, but she did not need to know that and I did not tell her that.

I am still traumatised. I reckon every nurse who has done palliative care probably has PTSD. Would I change anything? Absolutely not! Would I go back today and do it again? I would! I worked until I was 68 doing nursing and palliative care. Do I know in my heart of hearts that voluntary assisted dying is the most compassionate way, although not for a lot of people? I think in Victoria it is less than one per cent so far. That will not change all that much, but one is too many when there is an alternative that is regulated, that is monitored, that is set there to safeguard vulnerable people. I cannot answer it any other way.

Dr ROBINSON: This is more a short comment to thank you, Beverley and Therese, for appearing before the committee. Providing palliative care is so critical. I speak from my own experience with two grandfathers and my father dying from cancer. One had bowel cancer, one had multiple cancers and another died from a terrible cancer in the neck, similar to what you just described. I have seen that firsthand in my family and from broader experiences of life and as a pastor working with people as they pass away. We try to do everything we can to help them, to be there and to care. I think we have to find ways to be a more caring and tolerant society, whether or not this legislation is the way forward and, of course, there are very different opinions as to whether it is the way forward. I commend both of you for your attempts to bring those who are suffering to a point where we can relieve their suffering, the symptoms and the pain and for doing all that you have done at the coalface right where people are at. It takes a certain type of person to be able to do that. I thank you for the work that you have done over your years to relieve suffering for people. Thank you.

Ms Young: I recognise that funding is going to be $170 million extra towards palliative care. I have addressed some of the issues in there. There were some things of real concern with obviously regional and rural areas. At least we have telehealth, which goes a long way towards addressing that. One of the things that concerns me is that standard 9 in the palliative care services guide in 2019 stipulates that there were 49 registered medical practitioners and they estimated that we were about 50 short. There were 749 registered palliative care nurses. With standard 9 they estimated we needed to allocate 50 palliative care specialist doctors for every 100,000 people in Queensland. My suggestion is that unless you have a red ‘S’ on your chest and a cape, that is a big ask.

I do not know what the answers are. They are not for me to hypothesise on. Certainly, yes, give the best palliative care possible but it still does not address the need. They are not exclusive of each other. They go hand in hand and I still believe there is a case for voluntary assisted dying, without question.

Mr ANDREW: It is lovely to see you and thank you for your stories. They are very to the point. We do have a big gap in our area; you are quite right. I have seen some sad things myself over time. Is there something else that we have missed? Do you think everything that we have we have right?

Ms Young: I have been audacious enough to probably put it down in there. Certainly you need a really big campaign for palliative care in general. I had an argument yesterday with my hairdresser about palliative care. You say the words ‘palliative care’ to most people and they go, ‘Oh, end of dying!’ Then you mention ‘hospice’ and they think, ‘Well, I am ready to die!’ It is so not true. Palliative care has never been about dying. Palliative care is about living the best possible life you can until you die. That is what is getting missed in the public. They are not connected with palliative care.

Everyone I know has said in there that from the minute you get a life-limiting illness diagnosis from your doctor, who is your first point of call, you are technically palliative. It does not matter whether it takes one week, one month, one year or 10 years before you actually die from that illness, you are palliative. There is a big need for that conversation early in the piece from your general practitioner—it is not an easy conversation—and then to impart that palliative care is a supportive thing.

I believe we need groups of, dare I say, nurses in line with doctors, but registered nurses. We had a palliative care team at Calvary. We were a team of six and we had 335 outpatients on our books. Our palliative care team used to go into the community and sometimes there would be a phone call to monitor that they were okay. If we thought they had deteriorated a bit they could call in at any time; 24/7 we had someone on call and we would go out and visit. I have admitted them into hospital. I ended up as night supervisor and I would bring people in. We had that constant check. People would come in, get their symptoms controlled and go back home again after three days.

People in general do not know that. They still see palliative care as the end of the road: ‘We’re going to go in there and we’re going to die, that’s it.’ They are saying, ‘We’re not going to come back out.’ There needs to be a really big public campaign to understand that palliative care is a supportive measure to give you the best possible way to live at home.

Mr ANDREW: It is like electricity; it is there, but you just cannot quantify it. I know myself I have learnt so much about these things being on this committee. I thought I knew a bit about some things, but I did not know anything; I will be honest. You are right, I think it is about education.

Ms Young: Exactly.

Ms McLean: One of the things that we do really well in Queensland—and I know that the people of Mackay and Sarina are in it; they are lined up to help—whenever we have a disaster and we say, ‘We need help in the country,’ everyone goes. We have armies of people who will go. There is no need for us to say to devastated people, ‘You have to come to Brisbane.’ We know how to go out. We have proven as a state for so many years that when we are needed people mobilise to serve. That is why politicians go for preselection and there is competition. There is an abundance of people who want to serve and in our state there are more people than we have ever known. We can provide outreach services really well in Queensland. We have been doing it forever. We are very well practised at it and we are very accountable for our outgoing service. We are probably a bit more accountable and transparent than we are for our city based services.

We do not need to apologise for going into community. It is not that we go out and take over a community; we go to participate. We go and the very first things we can ask are, ‘What do you need? How can we help?’ We do not often send a practitioner with a suite of skills in their briefcase; we often send the person who can say, ‘Steve, if you need to go out and help with the interviews we could mind your office,’ or to housing people, ‘You need to go out and find the homeless people and bring them in and find the beds,’ or, ‘Here, we are sending up some people who can mind your office and make sure your doors are open and people can come in and talk to you.’ We are great at that. Queensland is superb at outreach services. We are even good at telling the truth about where a service in a metropolitan area is underutilised and the funds should go to where they are needed.

I commend this committee for its work in country areas and for the superior understanding you have shown of what we would call ‘remote areas’. Aaron knows those. People come from the islands to speak with their MP and with their community and they ask to be included because they know they are valued. I do not believe we cannot reach out to the communities in the middle as well as bring to the middle the people who would say, ‘I belong there. That is actually my community of interest. I trust those people and I’ll come and work with them.’ I reckon we have thousands of people in Brisbane—practitioners and people being trained now in palliative care—who will say, ‘I’ll go there. I’ll stay there. I’ll be with those people. I’ll walk with them till the end.’ We just have to get them there.

Mr ANDREW: We need them.

Ms McLean: You do.

CHAIR: I would like to get a few things on the record, but first I am going to ask members for any concluding remarks.

Ms PEASE: Thank you very much for coming in. Thank you, Therese, for your passion and to Beverley as well. There has been much talk about coercion, that family members and loved ones might be pushing people into accessing VAD. There has also been talk about people who are terminal feeling they do not want to be a burden on a family. There has been a bit of discussion about that being a form of coercion as well—personal coercion.

My mother and father both passed away in terrible circumstances. My mother was an incredibly proud woman and I had never seen her other than fully dressed. Her end of life was awful. She was ashamed that she had to get her daughters to see her naked and shower her and wipe her bottom. I do not discount her shame because it was hers. Would you agree that her not wanting her family to see her in that condition is enough of a reason as well as insufferable pain and meeting all of the other criteria—that that is a valid and real—

Ms McLean: I always say I have no quality of life if I cannot care for myself. I think that is entirely truthful of most dying people; we do not want to have our personal hygiene managed by a stranger or by our family and that that would constitute a lack of quality of life, of real living.

Ms Young: I would suggest that of all the people I have nursed—and for hundreds and hundreds of people I was there when they passed—90 per cent of the ones who were putting off going were the patient themselves. They did not want the burden of leaving their loved ones behind. I used to say to family, ‘You’re going to have to give them permission. You actually have to say, “Mum, Dad, it’s okay. When you’re ready to go, you go.”‘ That would happen more often than not because it was the person who did not want it. Often they would sit by their bedside and when they actually went, their loved one would be at the toilet or having a shower or whatever because they did not want them to suffer the last minute of seeing them go. They would hold on for their loved one rather than the loved one saying that to them. It was more them making the choice of when that time came, other than when it was taken out of their hands by God of course.

Ms KING: Throughout this committee’s hearings over the last week we have heard a lot about what is important to institutions, about what is important to doctors, about what is important to churches and about what matters to practitioners. I really value your comments today about returning the focus to the voices of dying people. At the end of the day, they are the very important voices we are really here to hear about.

Something that I have found really interesting was a few comments along the way about the palliative value of the voluntary assisted dying process in itself. We heard submissions and saw evidence that in areas where voluntary assisted dying is available at least one-third of people never consume the substance. I want to hear particularly your views on that, Therese, as a person who has a serious illness. What is the value of knowing that you have that option in a palliative sense? Could you give us your reflections on that?

Ms McLean: That is a great question in terms of why do people get the drug and then not use it. That tells you everything. It is like why do we ring the ambulance even when he comes and says, ‘You do not need me.’ We ring because we know we will be cared for and will be given what we need at home on the spot. If anyone asks dying people, ‘Who’d be your preferred practitioner to be at your farewell?', it is the paramedics, it is the nurses, it is the people who will let you live and let you die. One of the things that I have found most interesting about the debates from institutions and institutional conscientious objectors is what is in it for them? Why would they want to say no to people who are choosing to go with the safety net of a proper legal process of farewell? What is in it for them to deny us?

For me personally, I will welcome the involvement of my doctor. I would not want to take it myself. I would not want my partner to administer it or to go to the chemist and pick it up. I would want to be part of a system of care that has treated me all the way through and given me hope. That is because that is where we vest our trust. We vest our trust in the person we ask to help us and that often is not a specialist because a specialist is not available when you are really crook. You are on a kind of call-back system if you are in an oncology bed. The NUM will be able to get the oncologist to ring them, but they will not ever be able to take a call from us after hours. That is where your suffering happens: when your service is not available.

For me, if I had in my first aid kit the means to ring my practitioner, local would be my preference. I would say, 'I've got your card because you've agreed to help me say goodbye. My family are here now. We can be here for as long as you need us to be here, but we would love you to come and be the practitioner that administers the farewell drug.' For me, that is about the last 10 minutes of my life. It is not about suffering at all. It is about saying the law now provides for me to say goodbye to my family and my friends in a dignified way and to not be in a system where I am not known, not needed and not valued. I am grateful that we can self-administer, but I would not choose to do that.

Ms Young: To answer your question, it comes back to one word; it is called choice. There are many who will not use it but will want it and maybe seek it. There will only be a small percentage—maybe even one per cent. If there were 48,000 people who died in Australia of cancer last year—not counting motor neurone disease or any of the other terrible things—even if there is only one per cent, that is 500 people. Again, that is one per cent too many as far as I am concerned. Even if they have it there—many of those will not have it, but if it is there and they get to a stage where they believe their discomfort, dignity, all of those things are so compromised they do not want to go on any more, it is there. It is about choice. It comes back to choice.

CHAIR: Thank you very much. I will make some concluding remarks because I cannot think of a better way to finish this round of consultation than having the four of you—and I am reflecting on Lyn and Tanya who, no doubt, are either watching or listening. You have represented the gang of four beautifully, Bev and Therese.

It was 975 days ago, on 14 November 2018—and Joan will remember this—that the former Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee—thank goodness we are now called the Health and Environment Committee—was asked to go out and hear the views of Queenslanders in conducting a broad-ranging inquiry of aged care, palliative care and end-of-life care. For the first time we got to hear the views of people across Queensland through 40 public hearings, and thousands of people wrote to us and shared their deeply personal stories. That resulted in recommendations to introduce the bill. We acknowledge the significant work that the Queensland Law Reform Commission has done in its considered bill that is before us. We can now add another 4,000 or 5,000 submissions that have come in on the bill.

I want to thank every single person who came before us in either this committee or the former committee. I want to thank the former committee deputy chair, the former member for Caloundra, Mark McArdle; and the former member for Nicklin, Marty Hunt. We also had the member for Maiwar, who has again joined us this week, Michael Berkman. I want to thank the current members of the Health and Environment Committee who have joined in this considered inquiry with a bill before us—the member for Mirani and the member for Oodgeroo might have divergent views, but it has been a respectful debate—as well as the Deputy Chair. I say thank you very much to the member for Pumicestone and the member for Lytton, who have also been on this journey. It has been a heavy burden, but it is certainly nothing like the burden of someone facing an end-of-life choice.

Mr ANDREW: That is right.

CHAIR: We look forward to tabling our report on 20 August. Then, of course, there will be a debate in the parliament. We look forward to seeing this come to a conclusion. I must thank and acknowledge the former secretariat and the current secretariat. There are a lot of people—an army of people—behind the scenes who have also read those submissions. We thank everyone for their contributions. I think we can now draw this to a conclusion. I now declare this public hearing closed.

The committee adjourned at 12.44 pm.