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

Members present:

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

Staff present:

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

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

TRANSCRIPT OF PROCEEDINGS

THURSDAY, 4 JULY 2019

Brisbane

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The committee met at 9.03 am.

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

The committee is a statutory committee of the Queensland parliament and as such represents the parliament. The inquiry into aged care, end-of-life and palliative care and voluntary assisted dying was referred to the committee on 14 November 2018. The committee is required to report on the inquiry to the parliament by 30 November 2019.

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

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

This public hearing is being recorded and transcribed by Hansard, and witnesses will be provided with a copy of the transcript. All those appearing today have been provided with a copy of the instructions for witnesses, so we will take those as read. I ask that any media present adhere to my directions as chair at all times. I remind members of the public that they may be admitted to or excluded from the hearing at the committee's discretion. Please also note that this is a public hearing and you may be filmed or photographed.

FLYNN, Mr James, State Manager, Royal Australian College of General Practitioners

PULLE, Dr Chrys, President, Australian and New Zealand Society for Geriatric Medicine

WILLETT, Dr Bruce, Chair, Royal Australian College of General Practitioners, Queensland

CHAIR: I now welcome the Chair of the Royal Australian College of General Practitioners, Dr Bruce Willett, and James Flynn, the state manager; and President of the Queensland Division of the Australian New Zealand Society of Geriatric Medicine, Dr Chrys Pulle. Welcome everyone who will provide information to this inquiry. It is a significant body of work before the committee. The information that you will all give throughout what will be a very long day is invaluable to the committee going forward with respect to palliative care, aged care and end-of-life care. I welcome any one of you to start with an opening statement and then we will move to some questions.

Dr Pulle: I am the President of the Queensland Division of the Australian and New Zealand Society for Geriatric Medicine. Thank you for the opportunity to be a witness at this committee. First of all, the Australian and New Zealand Society for Geriatric Medicine represents specialist geriatricians and medical professionals who strive to provide the best possible health care and support for older people, working to improve their quality of life and wellbeing. We have over 1,200 members in Australia and New Zealand and 150 in Queensland who work across all healthcare settings, including residential and community aged care, and are experts in managing the complex medical and health related problems faced by older people.

The Australian and New Zealand Society for Geriatric Medicine strongly believes all older people deserve better access to specialists who are experts in managing their specific medical problems along with access to GP and primary care services within their place of residence, either in the community or in residential aged care. Medical conditions, often multiple and interacting, including dementia and other cognitive neurodegenerative cognitive diseases, frailty, osteoporosis, osteoarthritis and cancer are the main reasons older people move into aged-care facilities. Adequate management of these conditions requires the involvement of medical professionals, particularly those with expertise in caring for older people. There are numerous examples where the physical and mental decline of an older person is caused by an unrecognised underlying medical condition that can be treated or even reversed if managed well. This requires the input of a medical professional with expertise in the recognition and management of problems of ageing such as a geriatrician.

Geriatricians successfully treat many conditions common to older people and, through professional assessment and tailored intervention, help many older people maintain their independence and remain at home. They also contribute to maintaining a specialised, skilled workforce to meet the future needs and challenges of an ageing population. The society strongly advocates for improvements in policy and social attitudes to recognise older people as valued members of our society, seeing ageing in a positive light and recognising the importance of health for every individual irrespective of age and the support required to age well.

I will now move on to advance care planning and end-of-life issues. Advance care planning care is consistent with a person’s goals, values, beliefs and preferences and should be a routine part of a person’s health care within hospitals, community services and residential care services. Early advance care planning that elicits and respects older persons’ preferences can help to prepare the person and others to plan for a time when the person may no longer be able to communicate these decisions. Advance care planning is an ongoing process and needs cooperation between the person and their social and health supports. In the absence of advance care planning, decision-making at the end of life can be fraught and distressing for care partners if the persons themselves have lost decision-making capacity. Geriatricians, as part of the wider health and social support structure for a person, can help in these discussions, in particular with the impact of competing and multimorbid conditions on future life course. Education support and funding for issues such as mental illness—depression—increases in older age; issues with pain and difficulties with breathing are key aspects to patients’ preferences. Despite most people’s request to die at home, the majority still die in hospital.

With regard to voluntary assisted dying and the society’s position, the Australian and New Zealand Society for Geriatric Medicine acknowledges the wide range of perspectives and ethical views amongst geriatricians as well as in the wider population. The Australian and New Zealand Society for Geriatric Medicine opposes legislation which allows euthanasia, physician-assisted suicide or voluntary assisted dying. The society maintains that best palliative care practice is not in line with assisted dying. This is in accordance with the Australian and New Zealand Society of Palliative Medicine’s position statement. The society supports older patients’ right to refuse futile treatments and supports a dying older person’s right to death characterised by dignity, adequate patient symptom control and optimal access to expert palliative care management.

The Australian and New Zealand Society for Geriatric Medicine views that policymakers and funders of health care can best help patients by ensuring adequate provision and funding of high-quality palliative care and geriatric medical services rather than providing legislation allowing voluntary assisted dying. The society is deeply concerned about the potential consequences of legalising voluntary assisted dying for a number of reasons: first of all, portraying a conflicting public health message that suicide is the preferred option in certain circumstances; placing pressure on frail, older people who may feel they are a burden on others—such feelings are often due to underlying depression, financial constraints or family dysfunction or issues—the risks of involuntary or non-voluntary euthanasia in patients with cognitive impairment, dementia, delirium or reduced capacity; adverse effects on the funding for palliative care services and research; changing the concept of doctors being treaters, lifesavers and healers as espoused in the Hippocratic oath to being providers of life-ending services, and this may impact on the patient-doctor relationship, especially towards the end-of-life care; and increasing justifications for voluntary assisted dying and potential for abuse, for example, cost savings to the health system.

In summary, frail, older Australians with multimorbidity and receiving either coordinated care at home or living within residential care homes are among the most complex the health system has to manage and yet it can be difficult for these people to access the specialist interdisciplinary care that they so desperately need. The complex interaction of medical, psychosocial, physical and cognitive needs requires the care of person-centred teams that are experts in that degree of complexity and should include geriatricians. This needs to occur through the journey across the care continuum from the initial interface with assessment teams, through community service providers, into and out of acute and subacute services and through to residential care and eventually end-of-life care. No older person in Australia should have to access increased support or enter residential care for want of the management of a potentially treatable condition.

Finally, as a society, we should be judged on our support of the sick, vulnerable and frail elderly. Advances in medical care have resulted in the median age increasing substantially over the past century to approximately 85 years of age. By succumbing to the push for voluntary assisted dying legislation, are we abandoning the push for quality end-of-life care and palliative care and are we stating there is no more we can offer and that death is the only option? Thank you for this hearing.

CHAIR: Thank you very much, Dr Pulle. We will come back to you with some questions shortly. I appreciate the society's position and your submission. You would have been following our public hearings no doubt and the work that has been undertaken and the submissions that have been published to date including those from palliative care specialists. Yesterday in Longreach I quoted the position of Dr Will Cairns—he is from Townsville and is well known—and the views of nursing staff as well. There are opposing views, divergent views, on either side. I appreciate that.

When we come back to you I want to talk to you about the workforce—what the workforce looks like now in terms of geriatricians practising in Queensland. I will ask if you are familiar with this particular document, the *Ministerial expert panel on voluntary assisted dying*, from Western Australia and whether the society has considered their findings in Western Australia. Obviously voluntary assisted dying is a topical issue right across Australia. We will come back to those questions. Dr Bruce Willett, welcome. Would you like to make an opening statement?

Dr Willett: Thank you for the opportunity to appear and thank you to the parliament for undertaking this piece of important work. I am from the Royal Australian College of General Practitioners, Queensland. We represent over 8,000 GPs across the state in both rural and urban locations. With regard to voluntary assisted dying, the college has produced a formal statement on that since submissions closed. Rather than read that into the record, I seek leave to table that, if that is possible.

CHAIR: Is leave granted? There being no objection, leave is granted.

Dr Willett: The college believes that voluntary assisted dying is a subject that should reflect the wider social views of the community rather than the views of medical practitioners and the college alone. As such, it is up to the parliament as a representative of the people to decide policies in this area. With that having been said, the college believes that it is important that the legislation facilitates a patient centred approach and that there should be open and informed communication between physicians and their patients, family and carers, and the nominated decision-makers. This should be an ongoing conversation covering topics including goals of care and advance care planning which, as has been previously said, is extremely important and something that the college strongly supports—and it should not in any way diminish the palliative care supports for patients. Lack of palliative care services should never be a reason to examine these sorts of procedures.

Any legislation should be consistent across Australia, and it should be robust and transparent and have sufficient safeguards. Those physicians who choose to provide these services need to have adequate protection regardless of the way these services are provided, whether through an active or a patient initiated process. Likewise, those physicians who choose not to undertake these services and choose to conscientiously object to these services should be protected by law. Patients should of course be protected first and foremost and should be free of any coercion.

GPs build rapport with their patients over a number of years and this creates the ideal setting for end-of-life planning. GPs often have the contextual knowledge of the patients and their family. Trust and a long-term relationship between patients and their families over time helps facilitate these decisions and discussions and the preferences that patients may have in the context of their end-of-life scenarios.

On the issue of palliative care, while in the metropolitan centres of the state the majority of palliative care is provided through specialist palliative care services, it is still GPs who are conducting the vast majority of palliative care services outside the metropolitan areas. There are barriers to GPs providing effective palliative care. It is certainly poorly remunerated. GPs generally do it as a service to their patients. The Medicare rebates do not nearly cover the time that is spent. Certainly most of the work done in palliative care is often not face to face with a patient. It is spent doing paperwork and administrative duties and counselling families, and there is no remuneration for that work.

There are issues with providing palliative care services in nursing homes. Often there is insufficient training of nursing staff and often insufficient equipment in nursing homes to provide effective palliative care. Shared care arrangements with palliative care would be very helpful with Queensland Health staff in helping fulfil these deficits, as would the provision of equipment such as syringe drivers and other equipment. A formal collaborative model of palliative care with palliative care nurses within nursing homes would also be useful, as would an outreach model for palliative care.

The other issue is additional training for GPs in palliative care. There needs to be increased flexibility for GPs to obtain training in palliative care. Often, particularly for rural and regional GPs, it requires them to leave their towns to seek training usually in one of the major centres around the state. That dislocates the regular services they provide. It is difficult for GPs to find the additional training that they need in those centres.

CHAIR: Thank you very much, Dr Willett. Some of your opening comments are comments that we have heard before particularly in regard to the Medicare rebate for GPs who do look after terminally ill or palliative care patients whether in the community or in a nursing home. There are some good models that the committee has already seen where Queensland Health is working within a residential aged-care facility. I continually go back to Wynnum and the Blue Care model. That seems to be quite good. We were at Longreach yesterday and it is completely different there, but they spoke to us about the benefits of telehealth in accessing care.

I might go back to my questions for Dr Pulle. Either of you can answer this. At the end of the day, whether you are a geriatrician or a GP, you look after terminally ill patients, for example, in residential aged-care facilities. Dr Pulle, you said that they are providing adequate symptom control at end of life. Essentially you are giving medication at end of life to ease patient suffering. As geriatricians—we will get back to the workforce side of things in a moment. Whether you are a geriatrician or a GP, you are treating people at their end of life and providing medication to relieve suffering. That happens now, yes, at end of life?

Dr Pulle: Yes.

CHAIR: I want to paint a picture. We have heard this before: early access to good palliative care is wonderful. It can relieve suffering with symptom control. As we have also heard, there are times when even with the best palliative care there are gaps at the end of life when medication is needed to alleviate suffering.

Dr Pulle: Taking a step back, when is palliative care first instituted? I think the committee has probably heard this in previous hearings. I work in the state hospital system. The patients I see are usually patients with hip fractures or dementia. They usually have a 20 to 30 per cent one-year mortality rate. Oftentimes patients, families and carers do not understand. That is the fault of the medical system but also the patient and carers' expectations. We should start the discussion of end-of-life issues from the time they get admitted to hospital. They are requiring surgery. Even if they go through that hospital admission without significant issues, there is still a one-year mortality rate of 20 per cent. At that rate you should institute end-of-life care at that point. The issue is that, if we can get access to palliative care at that point, even having started the discussion, the aim would be to try to prevent the terminal suffering that you see in residential care facilities. Those discussions need to start right at the start—not just in hospital but, and I am sure my GP colleagues would agree, at that point—to manage patient expectations.

I do understand that there will be a point in time when there is not sufficient pain relief et cetera towards the end of life. If we can look at the broader picture, most of my patients do not have access to palliative care. Even in a city tertiary hospital with that degree of mortality, palliative care state that they can only take on patients with a three-month prognosis of death. I do not think even the best physicians have a crystal ball and can answer, 'Doc, how long have I got to live?' You cannot start that process, but we do know that when they have multiple conditions that is when the timely access to palliative care should start in terms of managing patients' expectations. That is way before what we are talking about which is right at the end of life. When patients do access palliative care, they do have a more dignified death, and I am sure that you have heard of those stories. I think we need to take a step back and look at the prognosis of that condition from the time it starts.

CHAIR: That might be around health literacy given to the family, the carers.

Dr Pulle: It is about education, exactly.

CHAIR: We continually hear this. We are hearing that there is a large proportion of people who do not have advance care plans. It is a time of crisis. The family just wants to see the best treatment given in the early stages.

Dr Pulle: I agree. Sometimes when patients come into hospital it is too much of a crisis situation. The family have not thought about that. I do agree that futile medical procedures occur in the last year of life. It is the most costly period of life for a patient. Discussions would need to be considered early on: 'Does this patient need this procedure given that their prognosis is poor?' That is a hard conversation to have. I am sure my colleagues would agree with me. I think we do need to look at starting that conversation. It may be that doctors are time poor or they are not renumerated sufficiently for those item numbers that we have talked about. It is easier to go through with a procedure or start a drug or something like that without having that difficult conversation.

From my experience, patients who have had that earlier conversation are more likely to have that support network. A lot of pain and suffering is not just purely physical. It is also mental. That is another big issue—older people having timely access to mental health services specifically for the older population. Men over 85 have the highest rate of suicide, but that is not widely known. What is more widely known is the number of younger patients who unfortunately end their life that way. The numbers are actually higher in older patients. A lot of it is due to a lack of community, a lack of support structure, a lack of family. It is a whole-of-community issue. I think that all feeds into the suffering. Palliative care can help with most physical symptoms, but I think we have to look at the broader community structures as well in order to try to answer that question.

CHAIR: That is probably twice in the last 10 minutes that you have mentioned that there can be suffering at a point in time where the drugs just are not enough in a palliative care space, where more treatment is given at the end of life. I appreciate everything you are saying in terms of accessing palliative care support early. That may be around funding. We will make recommendations at the end of our report as to where we go from here.

Dr Pulle: In terms of palliative care, you can give narcotics and you can give sedatives, but eventually that patient will have a reduced level of consciousness. That is how I see patients who die within the hospital setting who we deem palliative. The process is that they are given increased narcotics and eventually increased sedatives and it lets the natural course of the disease take over as opposed to a lethal concoction of medications.

CHAIR: It is a matter of interpretation. I had a death in the family. I am sure many people can relate to medical staff—I have experienced this recently—saying, 'If there is more suffering at end of life, we will give something.' That is relieving pain and suffering, but providing that medication is also causing an end point, which is the death of the person.

Dr Pulle: I suppose it is a moot point. Is it the disease? Is the end of life the disease that is of a terminal nature? We have withdrawn all medications, withdrawn antibiotics and withdrawn nutrition, so eventually that patient will die. The question is, though, is that of natural causes? You could argue that the narcotics and sedatives hastened one's death, but that is clearly still not voluntary assisted dying.

CHAIR: Not in a legal framework, no.

Dr Pulle: No. It is more a question of symptom control and pain relief. If you sedate someone they should not feel pain or suffering at that point if you have relieved their respiratory symptoms, pain management and hallucinations. A lot of the agitation you see as narcotics are increased are the side effects of the medications themselves, but it is using that cocktail of medications, sedatives and relieving pain—

CHAIR: Would you say it is a compassionate way of providing end-of-life care by giving that medication, be it narcotics or whatever?

Dr Pulle: Yes.

Dr Willett: I think the difference is the intent with which the medication is provided. If the medication is provided with an intent to relieve pain and suffering, it is a different moral and ethical framework—not just legal—than if it is provided with an intent to end life, even though the outcome may be similar.

CHAIR: It is a fine line.

Dr Willett: It is a fine line.

CHAIR: Having witnessed it personally, it is a compassionate thing to relieve suffering. That is what we see the medical profession do time and time again—relieve suffering.

Dr Willett: Like you, my family has just been through the same thing with my mother. It is something I understand from both sides of the fence, but I think it is a different thing. She fractured her hip, which was one of the examples we just saw in terms of providing adequate pain relief.

CHAIR: What would you say to those people who have supplied written submissions—and we have received quite a volume—who just want to see the suffering of their loved ones at end of life end and give them choice and control. We talked about the compassionate move of the medical profession by giving that medication. We have to consider, of course, the views of people who have spoken to us at public hearings or written to us with regard to providing choice at end of life or relieving suffering. You are getting to the point of relieving suffering by giving that medication, be it not voluntary assisted dying, but medication to ease suffering which can hasten death at the end of the day.

Dr Pulle: I suppose it all depends on each individual person's experience in context or with family members. The issue that I see a lot in a variety of health sittings is: does that patient or the family have access to appropriate palliative care? What is appropriate palliative care? There are a myriad different palliative care streams. How often is the patient reviewed? I would argue that a patient who is in palliative care is not just left at the end of the hospital ward but is actively managed. Does that patient have enough pain relief to relieve their symptoms? A think a lot of times patients and families get distressed because their mum or father, brother or sister is lying in that hospital room but there is no attention given to them. Family members are usually staying with them, seeing every last gasp, every agitated turn. The nursing staff is still giving proper pressure care, proper bowel management et cetera, and that requires the patient being turned. You could argue that this is causing more distress. Are they getting timely intervention? Have they had enough management in terms of narcotics as required? Is there a syringe driver? Are they getting adequate optimal increases in those narcotic agents? That is the issue really.

I would argue that if you did proceed with voluntary assisted dying, sure, that might take away potential issues regarding pain and suffering for the relative, but what about lifelong down the track in terms of that patient. Will they look back and say, 'I contributed to this'? Some people might say that is a good thing, but I would argue there are other issues. What about other family issues? Oftentimes I see patients and families at the time of death where the family is very close, but oftentimes it is difficult for them to see their loved one at that particular point when they may have missed certain years or times. I know that everyone is different, but we see a varying degree of patient and family expectations.

Mr HUNT: Dr Pulle, thanks very much for your comprehensive submission. It outlines almost a perfect model of care that is needed for older people. I particularly like the paragraph where you strongly advocate for 'improvements to policy and social attitudes to recognise older people as valued members of our society, seeing ageing in a positive light and recognising the importance of health for every individual irrespective of age and the support required to age well.' What are some of the practical things we can do to get it better? What is missing? What do we need to do as a state government to begin to reach this level of care? In the regional areas we have visited it certainly becomes more and more difficult. Have you identified the gaps and what we can do?

Dr Pulle: If we lived in utopia we would elevate the profile of older people. The numbers show that in 10 or 15 years time we will have 500,000 people in Australia with dementia. I do not think the health system is adequate or ready for that tsunami. There is a confluence of an ageing population and the lack of appropriate services. First of all, we need to educate older people and the wider public as to what they are likely to face once they have been diagnosed with a chronic neurodegenerative disease or chronic pain condition. The biggest issues that result in patients or family members requesting voluntary assisted dying are due to uncontrolled pain and advanced dementia. Nobody wants to be that agitated patient in the dementia ward; that is not who their loved one was. Oftentimes that reflects the wish to end somebody's life because 'this is not the person I know or have known in the past'. First of all, there needs to be education about these issues. As people get older, what are you likely to expect.

Futile treatments are another issue. Whilst it may benefit the patient in the short term, has that treatment actually benefitted the patient in the longer term? We need more holistic care. Far be it from me as a geriatrician to say that we know everything or we are able to provide services that would help older people. Certainly not. We have 150 geriatricians and trainees in Queensland. That number has increased significantly over the past decade but it is still not going to cover the population. It would be education—not just other geriatricians but also in collaboration with our general practitioner colleagues and other specialist carers.

Certainly I think palliative care does need to be supported to improve services, especially in regional Queensland. As we know, Queensland is the most decentralised state. If we are struggling to get adequate palliative care in the city, how would it be in regional and remote Queensland? That is an issue as well. Obviously in relation to funding we are constrained by Health budgets, but first of all where can we start? Where is the low-hanging fruit? I think it is educating not only patients but family members around what to expect. That is why I congratulate Queensland Health and their push for advance care planning because that helps, especially when patients come into a hospital situation. The advance care plan does not mean that the patient does not receive treatment when they come to a Queensland Health hospital or a private hospital, but at least it gives us an idea or a template of what the patient and family's expectations are. Then it is easier to have a conversation with the family about issues of end of life because they have actually talked about it. The number of times patients come through who have had no family discussion is a crisis situation. In certain conditions such as cancer that expectation may have been explored more than someone with dementia.

Mr HUNT: We do hear the word 'burden' a lot with regard to dementia. That is mentioned in relation to your concerns about voluntary assisted dying, dementia and understanding. There is a perception that there is no quality of life once you get to the advanced stages of dementia. Can you explore dementia in the last stages and how somebody might have quality of life or how quality of life might be described or enjoyed?

Dr Pulle: Once someone is diagnosed with dementia usually the patient has had two to three years of symptoms. Either they have not agreed that there are problems or the carer has covered up for them, so they have already had two to three years before they have been diagnosed either by a general practitioner or referred to a geriatrician or neurologist. Once they have been diagnosed with something like Alzheimer's disease they have a seven-year prognosis. That is often not explained at the time of diagnosis mainly because once they hear the 'D' word nobody hears anything else. 'That's it. Is my life finished?'

Whilst we do not have a treatment for dementia, we have medications. More importantly, an holistic lifestyle—adequate physical and social contact and mental stimulation—will help the patient in the early stages of dementia. We have found that patients with support and care tend to do better in the long term than patients who are socially isolated or who lack support. Structure needs to be brought in at the time of diagnosis so they can fulfil their lifestyles before the ravages of the worst cases of dementia. Oftentimes it depends on whether they have comorbid illness. The worst cases are patients who are physically quite well but whose dementia is progressing quite quickly. They are the patients who unfortunately end up in secure residential care facilities because of the risk of agitation. In that respect it is looking at the more holistic side. Do they have leisure activities? Do they have social contact? Is there mental stimulation for these patients? Do they have physical contact? Those areas need to be addressed as well.

Dr Willett: Could I answer the previous question? I actually think the government has been on the right track in terms of the push towards keeping people at home longer. I think that has been the right way to proceed. I think anything that furthers that end is going to be useful. That does mean team based care. It means general practitioners, community nurses and others providing those services in the home. I appreciate the government has been doing that, but anything further that can be done in that direction I think is the right answer. In terms of total costs of those services, I would agree with my colleague that I think there are a lot of services provided at the end of life of either no or minimal benefit that pose a significant cost burden on the community and actually often are a burden on the patients as well.

One of the things that we do as general practitioners, for instance—this is a simple example—is deprescribing. As people get towards the end of their life a lot of their medications are of limited utility and so often we will seek to withdraw some of those medications. Sometimes that will be supported by our specialist colleagues and sometimes they will go to some of the more specialised, not the geriatricians, but some of the other specialists, because this happens to the geriatricians as well I am sure, who will actually restart those medications because they have a more narrow focus. I think that is something we would have in common. That same principle applies to surgical procedures as well as medical procedures.

Mr HUNT: Is this futile treatment being caused by the medical profession and not so much pressure from the families?

Dr Willett: I think it is something that we, I think particularly these two disciplines sitting in front of you now, are very mindful of—that is, trying to reduce that burden on patients. It is a burden on the system as well. To see resources diverted away from that sort of treatment into more practical community support—these people often do not need their cholesterol medication, they need the community nurse—would be a far better use of those funds. I think we would all agree on that.

Mr HUNT: My final question relates to access to GP services. We are hearing in residential aged-care and at homes of the difficulty in accessing GP services. Where are we going wrong there and how do we fix that?

Dr Willett: It does get down to finances, unfortunately, and money. It will unfortunately cost me money to visit my nursing home patients because at the same time I am at the nursing home my practice is still running, it is still incurring all its costs and the rebates are very low in terms of those visits. It is similar to what I was saying. It is not quite as bad as the palliative care area, but it is a similar issue, where there is a significant administrative burden dealing with phone calls and issues from the nursing home. Well trained nursing home staff I think are really important. I think the training of nursing home staff is more important than numbers per person. Having sufficiently trained RNs in the nursing home is really helpful in supporting GPs in doing their work.

Mr HUNT: Increase the rebate, was the answer. Essentially there are financial concerns.

Dr Willett: It is not just increasing the rebate. The idea of block funding is a really important concept as well. A lump of funds to provide a service to that patient in a more holistic sense is probably the way to go.

CHAIR: Just to confirm, it is a matter for the Commonwealth to increase that. I am glad the member for Nicklin raised that because he can talk to his peers. It is something that we have heard right across the state. There is no doubt that GPs need to be better remunerated in the Medicare rebate area. That is something that we can take forward. Thank you very much.

Mr O'ROURKE: Thank you, doctors, for your submissions and your contribution today. You have both spoken a little bit around training and that more flexibility is required and that there is a lack of training. What training do GPs receive in palliative care and end-of-life?

Dr Willett: It is part of the curriculum of the college of GPs. All GPs will receive a basic level of training in palliative care and end-of-life care. Some GPs seek to get additional training in the area. There are diplomas and additional qualifications that GPs can get in that area. The idea of GPs with special interests is really important in this area. In a number of disciplines now across Queensland Health, Queensland Health has GPs working—and it has been a great initiative—within outpatient departments and getting additional skills. Then they can go back into their communities and apply those skills. Supporting GPs to do that is very useful. As I said, one of the issues is if GPs become very established in their rural and remote locations it is then difficult for them to take six months out of that to go back and work in the Royal Brisbane or the PA and meanwhile they are leaving their already understaffed community without a GP. I think we as a college need to work on more flexible arrangements with that in cooperation with Queensland Health.

Mr O'ROURKE: Whilst doctors are undertaking that training, do you think that there is enough training in that area?

Dr Willett: I think the training is adequate, but obviously for those who undertake that extra training they are able to do that better. I can give you my personal experience. I work in the Redlands in the south of Brisbane. When I was first in practice there were no palliative care services so I provided all of those services. I did not undertake formal training but I went and sought out a lot of training informally and you do quite a lot of it and you get good at it. If I were to do it now I would struggle because my knowledge is out of date because we have had palliative care services there for the last 15-odd years and I have become progressively deskilled. I would need to go and retrain now.

Dr Pulle: I would like to agree with Bruce there. The postgraduate medical course is only four years in most Queensland universities. Geriatric medicine is only a short course. Most of the patients in Queensland public or private hospitals are over 65. What tends to happen is that if you have an interest in that area of medicine you tend to seek further training, as Bruce mentioned. There are 150 geriatricians in Queensland, that includes trainees, so we have 27 trainees, and they are scattered around the state. That is the most number of trainees we have ever had. Geriatricians give advice to general practitioners and specialist colleagues in terms of trying to help coordinate care. At the end of the day geriatricians can do some palliative care but we are not palliative care physicians. I work in a tertiary hospital here in Brisbane. I can do the basics, but I would need support from palliative care physicians. At the end of the day, whether GPs are doing extra training in palliative care or other specialties are doing palliative care, you do need palliative care physicians.

Dr Willett: Often what the rural and regional GPs will need is actually someone to ring up when they get stuck because there are no palliative care physicians in those areas. When they get an unusual or difficult problem it is about having someone to consult with. That is a problem that probably cuts across a lot of outpatient referrals. Often GPs have a simple single problem and often the patients actually do not need to see one of our specialist colleagues. Often the telehealth situation, often just running the scenario by them and getting a couple of quick pieces of advice, is sufficient to deal with a lot of problems. It is an area that Queensland Health is working on expanding, but it would be great to see more of that shared care model in all sorts of areas, but particularly in palliative care and aged care.

Ms PEASE: Thank you very much for coming in, doctors. It is great to see you. Thank you for your submissions. I would like to ask Dr Chrys Pulle some questions around some of the comments you have made in your submission, in particular around the statement that voluntary assisted dying would potentially reduce palliative care services. I am wondering how you arrived at that comment.

Dr Pulle: It was more about voluntary assisted dying reducing the need for things like palliative care research, looking at improving the quality of end-of-life care. That would be our concern.

Ms PEASE: That is your concern?

Dr Pulle: Potentially because there is supposedly an end, you go down the voluntary assisted dying path, are we then limiting the scope and the need for palliative care especially in regional and remote Queensland. That would be a concern of the society.

Ms PEASE: It is just really around a hypothetical situation. You did not base that on any research that was undertaken overseas or anything like that?

Dr Pulle: No.

Ms PEASE: With your submissions, both of you, did you put it out and ask for feedback from your membership base?

Dr Willett: Yes.

Dr Pulle: Yes. The Australian and New Zealand Society for Geriatric Medicine had a position statement on euthanasia and voluntary assisted dying back in 2013. This is the current view of the society of Australia and New Zealand. As I said, there are wide variations in terms of the membership. This submission was put through the Queensland division and then needed federal council support at the start of this year. It is the current position.

CHAIR: You answered my earlier question on the workforce by saying there are 150 geriatricians in Queensland and 27 trainees.

Dr Pulle: The 27 trainees are part of the 150.

CHAIR: How many of those 150 provided evidence and feedback to your submission?

Dr Pulle: I distributed that to the 150 members and we got between 10 to 15. They had access to the report and the submission.

CHAIR: Can I make an observation that 10 or 15 is hardly representative of 150.

Dr Pulle: Those had direct views, but all 150 had access to the submission.

CHAIR: For the record, to clarify, 10 or 15 replied?

Dr Pulle: Specifically, but areas of support.

Ms PEASE: Similarly, Dr Willett, you put that out to your members as well.

Dr Willett: I think as a proportional thing we probably did worse. Needless to say there is a wide variety of strongly held opinions in this area. This is a consensus statement and by no means would all GPs in this country sign up to what we have said and we have tried to reflect the views that we have got back in this statement.

Mr Flynn: If I can just add to Bruce's comments there, the position statement that we provided the committee earlier has been pulled together by the RACGP as a national organisation that represents over 40,000 GPs across Australia and our colleagues in the WA office and the Victorian office have also gone through similar processes in recent times with their parliaments which is where the college combined that approach in bringing this position statement together.

Dr Willett: We have sought national feedback from GPs all around the country.

Dr Pulle: For the Australian and New Zealand geriatric medicine society, that position statement came from the Australian-New Zealand organisation that had 1,200 members. That is current. It is on the website.

CHAIR: With respect, we are looking at Queensland potential reporting and recommendations. I appreciate your clarification.

Dr Pulle: It is hard getting feedback from doctors.

Ms PEASE: Further to your submission again, Chrys, today you made some commentary about the future and advance care planning. Do you discuss that with your patients as they come in—that is, that they should be doing an advance care plan?

Dr Pulle: I work in an acute hospital in Brisbane, so it is difficult at the point of admission to talk about advance care plans when the patient has an acute hip fracture. However, what we do start the process of is having an acute resuscitation plan because there is a 10 per cent mortality rate for my inpatients. Once they have been discharged, we have then utilised the Queensland Health push for advance care planning, which I am sure you might have heard of, and that has been very beneficial in that patients are over their acute phase of their condition and they are more in a position to discuss these issues—when their acute confusional state has improved—and the family members are more in that time frame. In that acute time frame it is not the right place to discuss it.

Ms PEASE: Do you see patients who are not acute? As a specialist at the hospital, do you have appointments with patients who come in who are not acute but whom you are meeting for the first time and you are assessing their condition and diagnosing what the situation is? At that point do you have a discussion with them about advance care planning?

Dr Pulle: Certainly. For patients who come in—my general outpatients patients, and they are the ones you probably discussed—I would discuss with them at the appropriate juncture. When patients come in where there are issues relating to whether or not they have dementia, it is probably not the right time to have that discussion in order to have that doctor-patient relationship. The worst thing I do to patients is take their driving licence away from them and they are not likely to come back to see me again, mainly because we have lost that doctor-patient relationship. Once you have built up rapport—and Bruce might agree with me on this—that is then probably the right time to have that discussion, certainly in subsequent consultations.

Ms PEASE: Thank you.

Dr Willett: I would agree with Dr Pulle. I think that is unfortunately probably a question for me rather than him. It is an area that I think we need to do better in in general practice in getting more patients to do advance care planning. Likewise, I do appreciate the support we have had from Queensland Health in advance care planning in terms of the simplification in the forms and the process. If you are talking to your federal colleagues, it is a major problem that we cannot upload it to the My Health Record. It is one of the many inadequacies of the My Health Record, so patients have to do that and they just never do—never. If I can make the excuses, it is actually a difficult process. We have to try to build it into some routine practice processes. Patients generally do not come in for no reason. They want to talk about something else. They generally do not like you bringing this up. It is a difficult conversation. It generally needs to be done over a number of consultations. People need to get their head around it and understand what it is for and it is a very time-consuming process to have people understand it, but it is really important and it is something where we as a profession need to try to do a little better.

Ms PEASE: Finally, I would like to make a comment. My husband’s family are all GPs and I would like to acknowledge the great work that our local GPs do not just in my community but across all of Queensland in terms of how they look after their patients, many of whom who become palliative have been your friends and you have watched them grow from young people to not so young people. Thank you for your dedication.

Dr Willett: Thank you very much.

CHAIR: Hear, hear! Well said.

Mr McARDLE: Thank you for being here today, gentlemen. It is much appreciated. Dr Pulle, you had an exchange with the committee membership in relation to increasing the dosage or changing a drug that would lead eventually to a patient passing. Is that called palliative sedation?

Dr Pulle: Sorry, but can you just repeat that?

Mr McARDLE: You had an exchange with committee members in relation to increasing a drug dosage or changing a drug that led to a patient passing. Is that called palliative sedation?

Dr Pulle: As I said, I am not a palliative care expert, but there is a cocktail of medications. You can give narcotics for pain relief. You can give sedatives such as haloperidol through a syringe driver. The narcotics I am talking about are things like morphine, Fentanyl and buprenorphine that are administered via a syringe driver through a subcutaneous injection in a needle site, say into the abdomen, and giving medication over a 24-hour period. The aim would be to increase pain relief via narcotics and if patients are still agitated giving sedatives to try and relieve their distress.

Mr McARDLE: If I read to you that palliative sedation would be used as it had long been recommended by clinical and ethical experts as a preferred and more accurate term to describe the practice of using sedation with the intention to relieve—that is, palliate—intractable symptoms and distress during dying, would you agree with that?

Dr Pulle: Yes.

Mr McARDLE: Okay. The primary objective in that scenario is to alleviate pain.

Dr Pulle: Pain and suffering.

Mr McARDLE: The secondary suggestion is the death of a patient, which is the distinction between voluntary assisted dying and what I have just described as palliative sedation. Would that be right? Voluntary assisted dying is the primary objective of causing the death of a patient. Palliative sedation primarily is to alleviate pain and distress, leading on to death as a secondary outcome.

Dr Pulle: Eventually, yes. That is a fine line—

Mr McARDLE: Correct. I agree with that.

Dr Pulle:—but that is the difference between the act of giving a lethal injection of drugs—

Mr McARDLE: A deliberate lethal injection to cause death as opposed to alleviating pain.

Dr Pulle:—to cause death as opposed to alleviating pain and the patient eventually in the sedative state dying of their natural disease.

Mr McARDLE: Correct. You mentioned that there are 150 geriatricians in Queensland and 27 trainees.

Dr Pulle: Yes, 27 of them are trainees.

Mr McARDLE: So 133 are practising. Taking Queensland and the eastern seaboard, how many of those 133 practise from Cairns, Townsville et cetera all the way down to the Gold Coast and how many practise in Western Queensland?

Dr Pulle: I could not give you the exact numbers, but most of the geriatricians would be in the south-east corner. I think we have five geriatricians in Cairns and four in Townsville, but even in regional centres like Hervey Bay, Mackay and Rockhampton there would only be one or two geriatricians at the most. These are large centres with older populations, so we are not even talking about Western Queensland. I do not think there would be anyone west of Toowoomba. I think there are three or four in Toowoomba, but there would not be any west of Toowoomba and certainly not in more remote centres. Even in big centres like Hervey Bay there is a lack of geriatricians.

Mr McARDLE: Your paper talks about—and you use the term—utopia in relation to potential outcomes. That is not a reality in Queensland, is it, because we simply do not have the geriatricians across the state to undertake the work you are suggesting here?

Dr Pulle: With the number of trainees coming, there are 27 trainees. Training takes three years after their immediate basic physician training. Physician training is six years. Basic physician training is three years. Advanced training in geriatric medicine is three years. We have 27 trainees in that three-year window, so every year we would have about 10 or 15 trainees becoming geriatricians. You would at least need two or three in those larger population centres of 20,000 or 50,000 or if you had a hospital, say, the size of Hervey Bay Hospital or Mackay Base Hospital where there is a significant older population in those larger centres. We would be able to help with the care needs for that region.

Mr McARDLE: Again, Doctor, we are talking here about an ideal world.

Dr Pulle: Yes.

Mr McARDLE: I think the scenario is that the bulk of your profession operates in South-East Queensland. You cannot make them go anywhere.

Dr Pulle: No.

Mr McARDLE: There is no-one in Longreach, Barcaldine and Mount Isa. To put this in context, we need to work on the basis that your paper deals with the utopia—again, your words—in relation to geriatricians working in conjunction with the health services across the state, that is, public, private, NFP and NGO. Would that be right?

Dr Pulle: Yes.

Mr McARDLE: What I would like to look at a little bit is the comment that you make at the base of page 2 and you refer to psychotropic medicines under the heading 'Appropriate use of medicines' and you say—

> Research shows that more than 80 per cent of aged care residents with dementia receive psychotropics ... even though as few as 10 per cent might benefit from them ...

You then referred to two studies from 2005 and 2013. You then say—

> ... only 10 per cent of the psychotropic drug use for neuropsychiatric symptoms in patients with dementia is fully appropriate ...

That is a very worrying statistic—80 per cent—and of those only 10 per cent actually derive any benefit from it. Are you implying that these drugs are given to dementia patients to keep them sedated and quiet?

Dr Pulle: This position statement was also submitted by our national president, Dr Eddy Strivens, at the aged-care royal commission which is looking into these issues. I would agree that the use of psychotropic medications is inappropriate in, as you say, the majority of circumstances.

Mr McARDLE: It is not me; you say it.

Dr Pulle: As we have stated in the position statement for the lack of appropriate diversional therapy—things like leisure therapy in residential care homes and activities for patients. I can give you an example. For instance, there is a dementia unit in the hospital that I work in where these are the patients who are admitted to hospital where residential care facilities are not able to undertake their behaviours. We do sometimes have to resort to use psychotropic medications so that these patients can have basic hygiene cares and basic showering assistance to give them some quality of life. There is a point where you do need to give some psychotropic medications, but the problem is that in the majority of areas it is easy to give a psychotropic medication first and then ask questions of things like leisure therapy and diversional therapy as a secondary measure, mainly because it is more costly to employ a leisure therapist or a diversional therapist or give them some exercise or give them some supervision in that area. That is a worrying concern because—

Mr McARDLE: You would say the use of these drugs in the quantity is inappropriate for the need of the patients?

Dr Pulle: Again, it needs to be patient specific.

Mr McARDLE: That is what I am saying.

Dr Pulle: It needs to be patient specific, not a wide blanket 'give everyone sedatives'.

Mr McARDLE: I read from your data here that it is a wide use of these drugs more so for the benefit of the residential facility than the patients themselves.

Dr Pulle: Unfortunately. The problem is that—Bruce might agree with me or disagree—it is hard for GPs to look after the patients in residential care facilities, especially when there are issues such as agitation in dementia patients.

Mr McARDLE: Yes, exactly.

Dr Pulle: It is easier to prescribe an antipsychotic—

Mr McARDLE: It is a quick fix.

Dr Pulle: Potentially so, but it has potential side effects of cardiac and stroke et cetera.

Mr McARDLE: In relation to palliative care, my understanding is that there is no statewide policy specifically on that. We have end of life but nothing touching upon that issue as a statewide rollout. Do you believe there is a need for such a procedure to be put in place so that palliative care becomes a stand-alone issue across Queensland in relation to government and private health facilities?

Dr Pulle: I would agree.

Mr McARDLE: I certainly understand your point that palliative care and voluntary assisted dying are different matters ethically and psychologically, but is it important that, when we are discussing voluntary assisted dying, we understand palliative care? I want you to comment on that, because I do not think that the public gets palliative care. I think that people believe that palliative care is in the last week or so of their life. Would you agree that discussing those two topics together is most important to this committee?

Dr Pulle: I would agree. That is what I mentioned at the start of my hearing here. We need to have that discussion right at the start—when the patient is approaching end of life. I think approaching end-of-life issues is difficult at the best of times let alone when patients are at their terminal state, or their final days or weeks. I think that discussion needs to be brought forward much earlier, hence I think we can educate the public on those issues. These are difficult areas. They are not as snazzy as talking about things like cancer care. They are all important, but if we can educate patients about end-of-life issues patients can come into hospital with advance care planning. That might change the dynamics completely, but at least that family and that patient has had that discussion. The problem is that patients have not had the discussion. Nobody is talking about it. The next point is, 'Would it be easier if we did proceed to voluntary assisted dying?' before we had—

Mr McARDLE: They need to be discussed together, do they not?

Dr Pulle: It needs to be discussed.

Mr McARDLE: To try to separate them highlights one and diminishes the other. They are both coming to a point in the patient's life where the patient passes. Is it the best method to get to that point, though?

Dr Pulle: Yes.

Dr Willett: I would agree strongly with that assertion. Unfortunately, there is a group of people in society who equate the term 'palliative care' with withdrawal of treatment. That is what it means to them, which is, of course, not at all what it means.

Mr McARDLE: Dr Pulle, I want to take you to your commentary in relation to legalising euthanasia and the concerns that you have, which is on the last page of your submission where you have 'e' to 'f'. You raise a number of issues. Let us leave aside the issue of palliative care being diminished, or funding being decreased. Let us focus on the issue of the frailty of people being a limb that people may try to trigger to get an outcome that they want. Is it not possible for a government to put in a bill the appropriate safeguards? For example, you would have to have an independent assessment in relation to a person seeking the application of voluntary assisted dying. You would eliminate family members, beneficiaries in wills and also people who are in the nursing home, or are involved in any way with the treatment of the patient. Would not those safeguards be sufficient to at least provide initial protection that a person seeking voluntary assisted dying is not put upon by people who may try to gain some benefit from their death followed by a review of legislation down the track? Could that not be done?

Dr Pulle: I can give you an example. For instance, I get older patients undergoing hip fracture surgery. The first decision made is, 'Do they have the capacity to consent to that procedure?' That means do they understand the nature of the procedure, the risks involved, the potential risks for things like death on the table. When a patient comes in acutely unwell, they have had pain relief on board. I have never met them before so I do not know their underlying cognitive capacity. Have they been acutely affected by their pain management? Are they what is called in a delirium or acute confusional state? That is in the best settings. We have family members who then come and discuss the issues. Most of the time family members concur with the patient's wishes, or have an enduring power of attorney. It always helps to have an enduring power of attorney, or advance healthcare directive. The issues usually go smoothly but the problem is if there is conflict between the enduring power of attorney and the patient. My philosophy is that the patient has to lose capacity before the enduring power of attorney is enacted, or the statutory health attorney is enacted.

A couple of weeks ago in my practice there was a disagreement between the patient, who was 94 years of age, who wanted the procedure to go ahead but the family member said, 'No, this should not go ahead. He has dementia and he is delirious. The procedure should not go ahead.' This man would die with a fractured hip. I believed that that patient had capacity. Eventually, the patient needed the procedure and went through without, thankfully, any significant complication. If the capacity of that older person is questioned, my concern is that their rights will be taken over by the enduring power of attorney for whatever reason. Granted, that is in an acute setting but these issues could also occur in a non-acute setting. The issue also arises if there is secondary gain. Oftentimes patients have underlying depression, or mental illness that is nonexacerbated and they wish to die using voluntary assisted dying potentially as a means to an end.

Mr McARDLE: My concern with your comment is that, if a patient does not have capacity, they cannot legally ask for voluntary assisted dying. That is the problem. Is it not then up to the doctor to make the assessment? That doctor might be a psychiatrist. A doctor can make an assessment of capacity on the day. Is it not really up to the doctor to make that call? The doctor is charged under a proposed bill with protecting the rights of the patient. If that doctor forms an opinion that the patient has capacity, it does not really matter what the enduring power of attorney says; that patient can revoke an enduring power of attorney and a health directive at the stroke of a pen. I am really saying to you that, I would have thought, the power of the doctor is uppermost in providing protection for the patient. That alleviates the concern that society may have of family members, or other people, trying to gain a monetary outcome in their favour. Would you agree with that?

Dr Pulle: Because of the wide range of medical opinion, everyone has an inherent bias. I suppose it depends on who that doctor is. I know in Victoria they need two doctors to make a decision as to whether to proceed with voluntary assisted dying. It depends on which doctors you see. It may not be Bruce or me. The doctor could have an inherent bias.

Mr McARDLE: I am going to assume that all doctors are ethical in this set of circumstances.

Dr Pulle: It depends on the doctor's own ethics as well.

Mr McARDLE: I am not going to go down the line of debating the ethical position of doctors; I am simply trying to take a doctor as being ethical to begin with. I think that is a proper and appropriate place to start. Are either of you gentlemen aware of the document produced by Queensland Health titled *Queensland Health palliative care services review—key findings?* That was published yesterday or the day before on the Queensland Health website. That deals with palliative care. Have you seen that document at all?

Dr Willett: I have not.

Dr Pulle: I have not.

Mr McARDLE: That is fine. The document is 45 pages long and at page 14 it refers to a literature review of palliative care services completed in January 2019. That review dealt with demand and unmet need for palliative care, best practice, the effectiveness of palliative care services and other issues. I would have thought that that particular literature review would be important to inform this committee on what is and may be required in palliative care. Would you both agree with that?

Dr Pulle: Yes.

Dr Willett: Without having seen the document, yes.

Mr McARDLE: Dr Willett, are you saying that your college does not have a position on voluntary assisted dying?

Dr Willett: My college's position is that it is up to the Australian people, that it is a societal decision and that the proper way to make that decision is as a society and the vehicle to make that decision is the Queensland parliament.

Mr McARDLE: Say I am a doctor and I come to you as chair and I ask, 'What is your position to give me guidance in relation to this matter?' You would say, 'No, it is up to you to make that call.'

Dr Willett: Are you talking as a chair?

Mr McARDLE: As the chair.

Dr Willett: Or as an individual doctor?

Mr McARDLE: As a chair.

Dr Willett: As the chair of the RACGP I would say that it is my duty to be compliant with the legislation as it stands and advise patients accordingly.

Mr McARDLE: Would you advise—

Dr Willett: My personal decision—

Mr McARDLE: No, no—

Dr Willett: My personal answer as a patient would be different.

Mr McARDLE: Would you agree that, as chair, a doctor with a conscientious objection to voluntary assisted dying should have a legal obligation to refer that request on to a doctor who supports voluntary assisted dying?

Dr Willett: I think that is a reasonable—

Mr McARDLE: You have a position?

Dr Willett: They should be under no pressure or coercion to provide that service themselves. I think that it is very important that they are able to conscientiously object.

Mr McARDLE: If the law says they must refer, is that a coercion?

Dr Willett: If they must provide the service?

Mr McARDLE: If the law says that, if they have an objection based upon conscience, they can refuse but the law then says that they must, in those circumstances, refer to somebody who does not have such an objection. Is that coercion?

Dr Willett: I think it is reasonable for the law to require them to provide probably not a formal referral but to make the patient aware of where those services could be obtained.

CHAIR: I want to ask a clinical question. How many years have you each been practising?

Dr Pulle: Twenty-two.

Dr Willett: Thirty-one.

CHAIR: In your practice, would you have had patients with terminal illnesses diagnosed—end of life—asking just to give them something to end it all, to take away the pain?

Dr Pulle: Yes.

Dr Willett: Absolutely.

CHAIR: I am going to my own clinical practice in paramedicine. Given enough narcotics, that would stop you breathing.

Dr Pulle: Yes.

CHAIR: As the deputy chair did, I refer to the last page of your submission, which states—

e. Changing the concept of doctors being 'treaters', 'life savers' and 'healers' to being providers of life-ending services…

When you give enough narcotics, you are bringing on death. You had a discussion with the deputy chair, and it will be in *Hansard*, about giving cocktails of narcotics or sedatives that will relieve—and it is in a compassionate way; that is my understanding of what you were saying—pain and suffering and end of life, but you said that that would allow them to die of their natural disease.

Dr Pulle: Yes.

CHAIR: Can you contextualise that for a moment. When you are giving narcotics that stop breathing, that is not dying of their natural disease; that is bringing on death. I know that under the double doctrine by law you are allowing that—and this is within the legal framework of relieving pain and suffering—but the end result is that the person will stop breathing.

Dr Pulle: But it is not from the narcotic; it is from their natural disease.

CHAIR: I just asked that, when you are giving a medication at end of life—and I have certainly had my own personal experience with this and I have seen it in practice—people stop breathing. Given enough drugs—

Dr Willett: There is a great deal of debate about whether good palliative care with pain relief extends life or shortens it. The answer to that is that it is often not clear. Probably sometimes it is one and sometimes it is the other. People debate it. I think, on average, no-one could give you a clear answer, although I think we all have an opinion on it. From a scientifically proven point of view, I think that it would be very difficult. It would be—

CHAIR: Impossible

Dr Willett: I have a personal opinion, but a scientifically provable answer to that is probably more difficult than it would actually appear.

CHAIR: Dr Willett, you have 32 years of experience. You have treated people. What is your personal opinion?

Dr Willett: My personal opinion—that is an awkward question—in terms of voluntary assisted dying? My personal opinion—to be quite clear—is that there is a role for it, but it is for an incredibly small number of people. Good palliative care services will provide excellent end-of-life care for the vast majority of people. The number of people who would benefit from this sort of approach would be literally handfuls of people across the whole state. The situations are quite unusual. Again, that is my personal opinion.

CHAIR: I know that was a difficult question.

Dr Pulle: I think it depends on what the client is dying from.

CHAIR: And the dosage of drug?

Dr Pulle: You are talking about the mechanisms of what causes that death. Oftentimes if a patient is in end stage lung failure and respiratory failure or end stage cardiogenic shock or kidney failure, there is a mechanism whereby the patient dies of that terminal illness. If they have widespread pneumonia with comorbid conditions, all that giving the drug does is relieves the distress. It is the same thing with someone in advanced heart failure: you are giving the drug to relieve the distress, but they are actually dying of their condition. In kidney failure you stop dialysis if the patient is of that approach. The medications used there are to relieve the distress. It is not the act of giving the medication that causes the death.

CHAIR: I said before that enough narcotics will stop someone breathing, so advanced—

Dr Pulle: In palliative care when you institute subcutaneous infusions you start the lowest possible dose to relieve the pain and suffering. You are not wishing that patient to go into a sedative state at the moment of institution of the medication.

CHAIR: What happens when you give enough narcotics?

Dr Willett: It is the way you do it. I would not come to a patient who is dying and give them 200 milligrams of morphine.

Dr Pulle: Exactly.

Dr Willett: I would give them enough to relieve their pain and then keep titrating up as needed to relieve their pain. I cannot scientifically tell you whether or not I am shortening or lengthening their life. I have an opinion on what that might be, but it is unprovable. What I am actually doing—

CHAIR: We rely on evidence based research. It is a bit hard when the patient is deceased to say whether it was the drug or the disease.

Dr Willett: It is very difficult to do a double-blind controlled trial on that where we do not treat the—

Dr Pulle: You could do a post-mortem—

Mr McARDLE: Is it not the intent of the physician giving the drug that is critical?

Dr Willett: Yes.

Dr Pulle: I agree.

Mr McARDLE: If the intent is to alleviate pain as opposed to ending a life, that is quite distinct from a drug being given to end a life. There is an ethical and a moral question that the doctor or the relevant person has to be answer. If it is the former, that is to alleviate pain, it is not voluntary assisted dying.

Dr Willett: Exactly.

CHAIR: I am not saying it is, deputy chair. With respect, we know that. When you give enough narcotics there are side effects of bradycardia and reduced breathing.

Dr Pulle: In relation to anyone who dies, you could go to the coroner, do a post-mortem and they will give you the cause of death. If you have given narcotics, they are not going to come back and say it is the narcotic that caused the patient to die when they have advanced heart failure or advanced kidney failure.

CHAIR: Of course, it would be a combination of both. I was conflicted with (e) on your last point, ‘Changing the concept of doctors being ‘treaters’, ‘life savers’ and ‘healers’ to being providers of life-ending services,’ when you are providing care that brings on the end of life at the end of the day.

Dr Pulle: I would disagree with you there because you are changing the doctor-patient relationship. That is the crux.

CHAIR: Can I say the Canadian doctors that provided evidence to this committee—

Mr McARDLE: That is a private one.

CHAIR: I cannot comment on that, but at a point in time the report will reflect other views. Thank you for reminding me on that one, deputy chair. I thank both of you for your significant contributions in representing the views of both organisations and doing so respectfully. It is public?

Mr McARDLE: My apologies.

CHAIR: I thought it was. The Canadian doctors did say that it actually strengthened the patient; it was a very close relationship. These are providers in Canada where legislation has been there for some time. They provided some viewpoints on that very close doctor-patient relationship, which is in contrast to what you just said.

Ms PEASE: One of the comments that one of the doctors made was very telling in that to begin with, he considered himself to be a conscientious objector. However, after the relationships he had built with his patients and the review of the legislation, he became a conscientious supporter of it and realised the value of it.

CHAIR: In summing up, you both made considerable contributions today. We thank you for your time. I would recommend to organisations the paper from the Western Australian Ministerial Expert Panel on Voluntary Assisted Dying—it was published last week—is worthwhile passing on to the broader network as is the palliative care review from Queensland Health that will help guide us. There is no doubt the Victorian Voluntary Assisted Dying Act 2017 will provide Queensland with the opportunity to examine potential legislation going forward in this space. We must take on board the views of stakeholders including health practitioners and consumers. Thank you both for your time. We will take a five-minute break and resume the hearing shortly.

Proceedings suspended from 10.43 am to 10.49 am.

GRIFFIN, Ms Kym, Secretary, Palliative Care Nurses Australia

PRENTICE, Mr Daniel, Professional Research Officer, Queensland Nurses and Midwives' Union

SMITH, Ms Catherine, Treasurer, Australian College of Nurse Practitioners

TODHUNTER, Dr Elizabeth, Research and Policy Officer, Queensland Nurses and Midwives' Union

WARD, Professor Kylie, Chief Executive Officer, Australian College of Nursing (via teleconference)

CHAIR: Good morning, welcome. Kylie, being on the phone, we might start with your opening statement. Would you like to make an opening statement?

Prof. Ward: The Australian College of Nursing would like to thank Queensland parliament's health committee for the opportunity to provide an opening statement relating to the inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying. The Australian College of Nursing is the preeminent and national leader of the nursing profession and is a member in collaboration with the Australian Nursing and Midwifery Federation of the International Council of Nurses. The Australian College of Nursing is also a higher education provider and registered training authority and provides extensive continuing professional development and education for nurses throughout Australia.

We acknowledge and pay respect to and know that health professionals and the community will have different views about the topics being discussed today. The Australian College of Nursing strongly supports access and equity for patients, particularly the right to quality care in old age and when suffering from life-limiting illnesses. The Australian College of Nursing has four policy chapters, two of which are end-of-life care and ageing. I pay particular attention to the end-of-life care policy chapter where our chair is distinguished Professor Patsy Yates and deputy chair is Dr Melissa Bloomer, both nationally and internationally renowned experts in this area. This policy chapter produced a white paper which we would like to table as evidence *Achieving quality palliative care for all: the essential role of nurses*, and last year also produced a position statement *Voluntary assisted dying in Victoria*.

CHAIR: Thank you, Kylie. Procedurally, when you say 'table that' I do not know that it is the same document.

Prof. Ward: You may already have it because it was presented with our submission.

CHAIR: Thank you. Please proceed.

Prof. Ward: The Australian College of Nursing urges the Queensland government to consider that nurses have a unique role in end-of-life care, palliative care, voluntary assisted dying as well as in healthy ageing and urges the government to consider to invest in education and support for both health professionals and of course the communities. The white paper outlines a nurse-led, innovative model of care which provide better cost, quality and reach for underserved populations. It must also be noted that nurses in all settings require education and support, and we urge that this not be ignored. Because of industry demand, the Australian College of Nursing has just written and is about to commence delivering a graduate certificate in palliative care and would happily work with the Queensland government to support nurses in Queensland. The government should only offer options of voluntary assisted dying and/or palliative care or end-of-life care if there is support, infrastructure and investment in palliative care services, because both health professionals and the communities at large require this.

CHAIR: Thank you very much, Kylie. Catherine Smith, good morning.

Ms Smith: Good morning. The Australian College of Nurse Practitioners would like to thank the committee for the opportunity to represent the people who need or choose palliative care services, the nurses and the nurse practitioners who provide these services. The Australian College of Nurse Practitioners supports all efforts to improve the autonomy and choice of people in relation to their health. This relates to their preference for care and their preference for care providers and improving their access to health care services in general. All healthcare practitioners who work across the spectrum of health care especially in palliative care and end-of-life care see the full extent of the value of this inquiry. All palliative care and end-of-life services should be designed around the choice of the patient to choose their best possible health outcomes. Nurse practitioners work collaboratively in aged-care teams and palliative care health teams who are supporting the end-of-life care.

Nurse practitioners are aware of the current challenges which make care of these patients especially complex and, as a result, the possible patient outcomes are not truly autonomous to the patient's choices achieved in this current system. The growing number of chronic disease patients who presently are not well suited in our current palliative care services must also be considered in this space, especially the younger ones. There is much work to be done. We must be able to support aged care and palliative care as authorisers of advance care directives and death certificates, particularly in the voluntary dying process. As you will have already discussed in the recent WA ministerial expert panel on voluntary assisted dying, nurse practitioners have been included in that process. Consideration must be given to people living in regional and remote areas as well as in metropolitan areas as there are particular challenges in access to services of their choice.

Nurse practitioners can improve access and choice in these areas where currently no palliative care services are available. However, to truly enable this we must be acknowledged and enabled to work to our full scope of practice as providers. As nursing leaders, the nurse practitioner role in this area of health care is clinical, educational, advocacy, monitoring of fellow nurses and other health professionals. We provide holistic care which always includes support of the patient, the family and the carers as well as collaborating with the wider health team.

CHAIR: We will come back to questions, but I put on record the great admiration we have seen already with nurse navigators being put into the acute system. Regardless of whether it is QNMU, ACN or palliative care nurses, there are remarkable stories of success with nurse practitioners navigating patients through patient care. We can talk to that a little bit later, but I am a huge fan.

Ms Smith: Thank you.

Ms Griffin: Thank you to the committee for inviting us to speak. PCNA is a national member based organisation. We are the peak lobby group for nurses working with people living with and dying from progress life-limiting conditions and their families. We are an affiliate member organisation of Palliative Care Australia. We have a memorandum of understanding with CRANAplus and with Palliative Care Nurses New Zealand. We have members across Australia in all sectors of health. About 20 per cent of our membership is in Queensland. We have special interest groups that inform our workers and organisation. Those special interest groups include aged-care nurses, nurse practitioner groups and those representing and working in rural and regional parts of Australia. In fact, we have had only two meetings of that particular group and both came from Queensland, so that was awesome. We also have collaborative agreements with CRANAplus, which is the representative body for allied health and nursing professionals who work in remote areas. We have recently re-endorsed their position statement on palliative care in regional Australia.

As outlined in our submission, we believe that palliative care is everyone's business. From a nursing perspective, there are few areas of contemporary health care where death is not a possibility or expected outcome. We know that about 70 per cent of Australians want to die at home, and from our perspective 'home' includes a residential aged-care facility. In the community about 14 per cent achieve that, and obviously with good care and aged-care facilities that is slightly higher. To do this we require an adequate number of nurses with specialist skills.

I will turn to remote and regional areas, and I acknowledge my colleagues at CRANAplus who have informed me about this. Aboriginal and Torres Strait Islander people constitute up to 60 per cent of the population in remote and regional areas. We know they have poorer health outcomes. This includes end-of-life care. They are less likely to access palliative care services in mainstream facilities. Indeed, we have very little data about their admission into palliative care services or specialist end-of-life services nationally. For end of life to be appropriate in rural and regional areas, particularly with Aboriginal and Torres Strait Islander people, we need to embed good cultural respect and cultural safety as essential elements. This must be considered in the provision of palliative care. We have an increasingly multicultural population in regional Queensland, and again this provides challenges. It increases the complexity of care when we are discussing palliative and end-of-life care. The one issue that was outlined to me by a regional practitioner is access to appropriate translators for some of the communities.

For health practitioners who want access to palliative care, I believe you have already been informed by our medical colleagues that that is quite commonly done by telehealth. The relationships are ad hoc; there are no formally embedded networks for that support to be given. We encourage the use of technology, including telehealth, to be made freely available to improve consultations and collaborations between health professionals and better access for community members. Education and training is key for us. Although we are not an RTO, we work with many. We have reviewed and informed the Australian College of Nursing's module update in palliative care. We also have tight collaborations with CareSearch out of Flinders University and the modules they provide.

When we look at aged care, our submission to the royal commission adopted the term ‘slow stream’ hospices. The hospice of the future has been around for a while. A slow stream hospice is more appropriate because people take a little bit longer to die in aged-care facilities, with the average length of stay being 34.5 months. About a third of the people who go into aged care and die there are in there for less than a year. There is other work that we have done around the skill mix. We believe there should be appropriately skilled staff supervising the highly complex care of some of our most vulnerable people in our community.

I believe we provided our updated position statement around euthanasia and persistent assisted dying. The WHO definition of palliative care underpins our work at all times. We believe that palliative care nurses provide support for the person and their family with regard to decisions relating to all aspects of care, including requests for assisted dying. It would be our position that palliative care nurses need to seek understanding of why the request has been made, either by the person or the family, which they may not have identified before. By understanding the person’s perception of their quality of life, their hopes and their wishes and their perception of suffering, then perhaps we can do some more. It also can highlight to us the family’s involvement in that decision-making.

With the recent legislative changes in Victoria, which did indeed pre-empt the update of our position statement, we had to look at supporting our members. We have adopted the position that we will support our members who may be called on to make a decision whether they conscientiously choose to step out or whether they conscientiously choose to step in to the assessment and the act itself.

Mr Prentice: We provided a very detailed submission to the committee that responds to the questions in the discussion paper. We note the committee has received more than 5,000 submissions, which is an important indicator of community interest in these matters. Our opening statement will touch briefly on aged care, palliative care and voluntary assisted dying.

For many years the QNMU has been actively lobbying and campaigning to improve quality and safety in aged care. We have a number of key priorities in aged care. In our view, the aged-care sector must be person centred and not profit focused. Services must be appropriate and delivered when and where needed, irrespective of location. Aged-care facilities must employ appropriate numbers of registered and enrolled nurses to address significant and endemic staffing and skill mix shortages which have contributed to the current crisis in aged care. All aspects of medication management and aged care must be undertaken by registered and enrolled nurses. The role of unregulated carers must only be in assisting cognitively competent clients to take prescribed medications when they request assistance to do so. State governments have an ongoing role in the provision of aged-care services, whether that is filling service gaps in regional, rural or remote areas, acting as service provision exemplars, providing services for those requiring complex care not available in the private sector, or advocating on behalf of, and assisting, older Queenslanders to navigate the aged-care system.

The QNMU has several priority areas in palliative care, including: a commitment from the Queensland government to the development, resourcing, implementation and evaluation of a comprehensive palliative care and end-of-life care strategic plan; a commitment by the Queensland government to increase the coordination of service delivery for palliative care services and other intersectorial issues such as aged care across the hospital, acute, private, primary care and aged-care sectors; and a particular focus on equity for palliative care and end-of-life services for regional, rural and remote populations, Aboriginal and Torres Strait Islander communities and other special needs groups.

The QNMU recognises that there are some circumstances in which palliative care cannot alleviate all pain and suffering. Therefore, we support legislative reform to enable persons who have an incurable physical illness that creates unrelieved, unbearable and profound suffering to have the right to choose to die with dignity in a manner acceptable to them. Voluntary assisted dying legislation must have a number of safeguards in place to protect the individual, the public and health practitioners. We ask that the committee give particular consideration to the needs and circumstances of young people aged under 18, Indigenous Australians and those from CALD and LGBTIQ communities. We also recommend the Queensland government provide funding to support the uptake of advance healthcare directives and that health practitioners are provided with ongoing professional development on voluntary assisted dying.

CHAIR: I will begin with your submission in relation to aged care. On page 11 you say that residents receive an average of 2.61 hours per day compared to the research based requirement of 4.3 hours, and you quote Willis et al 2016 as some research. What staff skill mix would QNMU suggest is best practice in aged-care facilities? We ask that question based on what we are seeing now in private residential aged-care facilities in particular. We are obviously working with the royal commission in terms of looking at aged-care residents perhaps putting a burden on the public healthcare system if levels of care are enhanced at private residential aged-care facilities. We have seen both good and not so good models of nursing care. What is the QNMU's position on best practice in a residential aged-care facility for a staff skill mix?

Mr Prentice: As you may be aware, the QNMU is part of the ANMF, and the ANMF nationally has been running a campaign around staffing and skill mix in the aged-care sector. The ANMF aged-care campaign believes that a staffing and skill mix in aged care of 30 per cent registered nurses, 20 per cent enrolled nurses and 50 per cent unregulated care workers represents a good mix of staffing and skill mix. This is based on the study by Willis et al that you referred to in your question. That is the basis for identifying that particular staffing and skill mix. Our experience is that, generally speaking, that current staffing and skill mix does not exist in the aged-care sector.

CHAIR: I understand you conducted an audit, so you would have current figures.

Mr Prentice: We did; that is right.

CHAIR: What are they compared to?

Mr Prentice: In May last year we did an audit of a little over 80 private aged-care facilities in Queensland. The figures that we gained from that audit align with national labour force figures. For example, if you look at the Australian Institute of Health and Welfare around the categories of staff in residential and community aged care where the percentages are far greater skewed towards an unregulated work force, often greater than 70 per cent, I should say—

CHAIR: Yes, I was going to say that I found the figures here. For the record, from that audit of skill mix percentages RNs represented 16 per cent, ENs nearly seven per cent and unregulated care workers 77 per cent.

Mr Prentice: That is right. That mirrors—

CHAIR: Would it be your position that if you increase registered or enrolled nurses to the point of 30 per cent, 20 per cent and 50 per cent—you would describe personal care workers as Certificate III or Certificate IV?

Mr Prentice: That is right.

CHAIR:—what would the benefits be in terms of aged care being delivered?

Mr Prentice: I think the first point to make is that aged care has a significant health care and clinical care component to it. The healthcare needs and chronicity of conditions that older Australians experience is increasing over time, and we have seen that in the data. If you look at the Aged Care Funding Instrument data, for example, the number of residents, particularly in residential aged care, who meet high-care needs has increased significantly over time. Just like any healthcare environment where you are looking after a group of people who have often multiple chronic ongoing conditions, decreased mobility, nutritional issues and often polypharmacy as well with often exactly the same drugs—which have lots of medication safety mechanisms in place in hospitals—having an appropriate level of nursing expertise to manage that care and delegate that care to the unregulated workforce is essential to providing an appropriate level of care to those people in residential aged care. We would suggest that, irrespective of your age or where you are, the same standards of care should apply to you no matter where you are within the healthcare or aged-care systems. To achieve that, an appropriate balance of nurses and unregulated carers must be in place in aged care.

CHAIR: If that were the model that could be put in place, would that reduce things like falls, complaints, transfers to public hospitals? The most common complaint is people waiting to get assistance to be toileted. In nearly every residential facility we visited, bar the last public one we visited in my electorate of Thuringowa—Parklands—where the nurse-patient ratio was different again, the ratio was different to what we saw in some private facilities where no nurses were available over a night shift.

Mr Prentice: That is right.

CHAIR: The risk therefore would be higher in some of those private facilities in terms of medication errors, falls and complaints?

Mr Prentice: Yes, that is very true. Until recently, I worked most Sundays for about the last 11 years in aged-care. My personal experience is such—and also being a nurse for probably the last nearly 40 years—that I know the standard and quality of care is intimately linked to the people providing that care. The higher the quality of staffing and skill mix, I think there is considerable evidence these days to suggest that there are substantial linkages there. We already have achieved nurse-to-patient ratios in the acute sector. Those same kind of benefits can be achieved by looking at what is an appropriate staffing and skill mix in the aged-care sector as well.

CHAIR: Catherine, you commented on patient choice. We might get clarification with a minute or two comment from each group. In regards to voluntary assisted dying, I want a clear position from your organisations on whether it is supported, whether it is a middle road or whether it is not supported. Can you articulate that? A lot of what I heard from you related to patient choice.

Ms Smith: As a college, we believe that our patients should always be the key and the centre of any care delivered. Therefore, their choices in who they choose to go ahead with their care should always be considered. Their choice as to what goes next should always be considered. As a college, we will support our members to decide on where they stand in this position. We are not enforcing that they decide to assist in voluntary dying. We have contributed in Victoria. Recently, one of our board members was invited along and involved in the WA work that has been done on this process. We will support our members either side of that. A number of our members obviously contributed evidence to be submitted for this inquiry. They are quite passionate about the fact that the patient chooses. Obviously it is about the patient choice, related to what Kim said, where they have to be educated and provided with the right information to make that choice. We do not need to say that the first statement they come out with may not be the statement that they continue with for the whole of their care.

CHAIR: I note that the West Australian ministerial paper to which we referred earlier goes further than the Victorian model where a nurse practitioner can assist?

Ms Smith: Yes, they can be involved in the process. We would support members who would like to be involved in that process. Obviously they would need the correct training and resources to ensure that they could do that. We have a number of nurse practitioners across the country and a lot in Queensland who do work in palliative care and in aged care. I recently started working in aged care so I understand the processes and how we can support in that system. A lot of times it can be the right education at the right time, spending the time with the relatives and the family members and engaging at the right stage of it—not at the final or end stage.

Can I make one comment about the workforce numbers? The key with getting the right mix is what an RN and a well-trained enrolled nurse can make a difference in. It is that early identification of the transition of health. I am seeing this myself. Generally speaking, the comorbidities of the patients in our aged-care facility are much higher than we have seen before. People are living longer with lots more chronic diseases. People sit down to read a PD on a patient that they are about to see in the aged-care home and they are still sitting there five minutes later reading it. They are extensive and they are long with long histories of things and that sort of thing. They are complex. To say that an untrained person can improve their quality of life and their end of care is totally devaluing what our health system has achieved so far.

CHAIR: Nurse navigator in aged care; I will come back to you on that one.

Ms Smith: We have a big space in that. We can make a big difference. I see that when we resource the RNs and ENs we can help them feel much more comfortable in the care they are delivering. We can get involved earlier and make some decisions to prevent transfers and to enable patients or clients to do what they want to do—that is, that choice. I want to stay there.

CHAIR: Kylie, did you want to comment on the question I asked on voluntary assisted dying?

Prof. Ward: Yes. Before I do so, I would like to clarify that, in my opening statement and the white paper in the submission we sent, it is regulation of the unregulated healthcare workforce across the health system. We agree with the comments that the dilution of registered and enrolled nurses is unacceptable and contributing to unsafe care. That white paper speaks to that. The white paper to which I referred around achieving quality palliative care for all the essential role of nurses is not hyperlinked and we would like, with your permission, to submit that as it has innovative nursing models to consider moving forward.

CHAIR: If that can be emailed to us, we can have a look at that and consider it for tabling later.

Prof. Ward: Yes. In relation to voluntary assisted dying, we did put out the position statement *Voluntary assisted dying in Victoria.* We do understand that both health professionals and the community will have different perspectives. Voluntary assisted dying should not be viewed in isolation from the need to ensure that all people with a life-limiting diagnosis receive high-quality, evidence based health care. We reinforce that there is a very strong role for nurse practitioners in this space. Just to clarify from our understanding, nurse navigators are more likely to be advanced practice nurses than nurse practitioners. We see it as a very strong role for both, particularly as the coordinators of care and the interface between the acute health setting and the aged or palliative care setting.

I bring attention to the inspired model of care led by Nikki Johnston in the ACT being rolled out in different parts of the country. She is a nurse practitioner entering into aged-care facilities. It is well written, has won national awards and contributes to excellent care outcomes as well as cost-effective delivery of care. I highly recommend that the committee seek that out as an option.

In relation not only to voluntary assisted dying but all care provided, it was mentioned earlier around the benefits of having a registered and enrolled nursing workforce. I would like to present to parliament the notion of nurse-sensitive indicator outcomes where there are specific nursing-led models that do drive excellence in care. Some examples where nurses can have a strong influence in care, cost and outcome include pressure areas, medication areas, falls, urinary tract infections, transfers to hospital, as was mentioned, but most importantly the assessment of a deteriorating resident or patient that an unregulated healthcare worker is unable to detect. They simply do not have the training and expertise.

CHAIR: Thank you, Kylie. Can I move to Ms Griffin?

Ms Griffin: I can start with the RN ratios as well. I agree with everything said prior to this. We also highlight that the lack of mandated RN-to-resident ratios impacts on the management of symptoms for palliative clients in aged care. We are aware of more than one—and probably you have heard about them as well—where people have had to wait for longer than two to three hours; indeed, the worst case I ever heard of is 10 hours waiting for the RN who had gone home to her property in regional Queensland. She was the access to RN overnight, with limited phone contact. Without those RNs in place, it is hard for us to provide best practice care at end of life for our older people. With that pressure for RNs and ENs in aged care, it is an incredibly stressful environment. Professionals are leaving the sector, so there is constant training and retraining. We need to value our RNs and ENs who chose to go into aged care. We need to put more of them in there so our older people get best practice care. Certainly, the nurse navigators are a wonderful thing. If I can add in on top of what Catherine and Kylie said, having NPs out there in those roles or indeed as part of the teams with nurse navigators in them keeps people out of hospital. You are seeing the evidence as much as we are. People are happier staying out of hospitals. Our acute sector is less burdened.

CHAIR: No-one wants to go to hospital.

Ms Griffin: No-one wants to go to hospital. Again, with the RNs, if we look at rural and regional—and Dan probably has better statistics—they have RN vacancies of up to 11 weeks in some parts of our state, and that is untenable.

CHAIR: We are certainly cognisant of that. I will move on to the QNMU.

Ms Smith: Our viewpoint about voluntary assisted dying is pretty much as the college of NPs. We will support our members. We already have members working in Victoria. We have spoken to the WA inquiry and to the ACT inquiry a couple of years back. Indeed, Victoria had a member of PCNA sitting on that expert reference group. Palliative care nurses have been heavily involved in this. It is choice. It is about a person's choice and the person asking for the act, and about the staff around them.

CHAIR: Thank you. I put on the record that on page 7 QNMU recommends that the Queensland government draft a discrete legislative framework contained in a standalone act making voluntary assisted dying legal in Queensland subject to a range of the following. How many members did you consult with in Queensland to arrive at that view?

Dr Todhunter: If I can just set the scene a little bit, in 2016 the QNMU council endorsed the policy position of the ANMF, its federal body, on voluntary assisted dying. When this inquiry was announced, we had a policy committee of the council that has nurses from all across the state, all different classification levels, working across all different sectors. We put all the questions in the discussion paper to our policy committee and discussed them at length when they all came to Brisbane for a full-day meeting. That is how we derived our position on a lot of those matters in response to those questions. Subsequent to that or around that same time, we notified our members on Facebook. We did quite a bit in the social media space. We asked members if they wanted to submit their own individual submissions as well. I imagine that the committee has quite a number of individual submissions.

CHAIR: I will note that as a comment only. We have received a large number of submissions from nurses—people who are directly caring for palliative care patients at end of life.

Dr Todhunter: The Facebook response overwhelmingly supported voluntary assisted dying. We had a good basis and a lot of discussion around this. Subsequent to having drafted the submission, that then went back to our council—again, very representative of all of the nurses and midwives across the state. They endorsed the position arrived at by the policy committee, so it was quite a rigorous process.

Mr HUNT: Is it fair to say that there would be a large number of your members who would object to voluntary assisted dying?

Dr Todhunter: There may be, yes. We recognise that in our submission—that individuals may have a different view, of course. That is the same on any of our social policies, not just this.

Mr HUNT: When we are talking about staff ratios, quality care and what quality care looks like—in the last session we heard from the geriatrician in relation to this holistic team approach and I think the phrase ‘health utopia’ came up a couple of times. It gets more complex as we get more remote. Yesterday we were in Longreach. In an aged-care facility there they had to source a lot of their staff from overseas because we cannot get people to do the work. Does the nurses’ union have a strategy to get nurses to go to remote areas? Do you have any ideas on how we improve the levels of staff and expertise in remote areas?

Dr Todhunter: For some time we have been agitating for national and certainly statewide workforce planning to take that into account. There are some restrictions though. We have to bear in mind that it is not just the fact that registered nurses in aged care are necessarily remote. We have to realise that they are paid significantly less than their colleagues in the public sector. There are things that are not just tied to distance. They are tied to pay and conditions and other structural issues that make it more difficult to recruit into those positions.

Mr HUNT: Also, the nurses’ union recommended in their submission increased funding for education and public awareness in the palliative care space. Is there anything going on there at the moment that you are doing that would be enhanced by increased funding or are we starting at a base here where there is not much happening and it needs to start?

Dr Todhunter: We have made a number of recommendations about palliative care. Dan can address those. There are a lot of initiatives, not just education.

Mr Prentice: One of our reference groups is a palliative care reference group made up of a number of palliative care nursing practitioners across the state. They have identified a range of issues that they believe are very relevant to this discussion. Raising public awareness is something that is very important. I think attitudes towards dying and the care of those who are on that trajectory is very important. I think we referred earlier to advance health directives again as a way of raising awareness. We would be very supportive of any initiatives to do that within the broader community. It is very important to have the community on board when we are talking about issues particularly like end-of-life care and that much shorter period which we would constitute as palliative care at the end of that period. I think that is something that our members would be very aware of in their own practice.

Mr HUNT: What role would they play in education then? What role do you see nurses or the nurses’ union or nursing have in that education space if funding was made available?

Dr Todhunter: Perhaps my colleagues might be able to answer that.

Ms Smith: I think the key to understand is that nurses are very well trusted in the community. We always score very high on trust.

CHAIR: Just behind paramedics, I believe.

Ms Smith: No, we are higher than them. Particularly as nurse practitioners, when we go out and provide education and we do that as a core part of what we do in our services, we can change the way people think about their health and change the way they engage with their health. We could look at strategies in that sense, but I think the key is that we have to have those earlier discussions about end-of-life planning and advance health directives. Nurse practitioners cannot sign off on those, yet we are the ones who spend time having more of those conversations. It can be very limiting. We could be having those conversations earlier and things could be put in place earlier and patients could be making a choice about what they want to do.

CHAIR: Is a recommendation then that we should suggest that nurse practitioners or registered nurses can sign off on advance health directives and advance care plans?

Ms Smith: We would definitely like to see nurse practitioners able to do that. Whether you want to go down the route of RNs, we could investigate that further too. We would also like to have the opportunity to sign off even death certificates. We have colleagues working particularly in regional areas or even in metropolitan areas where the GP goes away. We are the nurse practitioners in that service and we need to be able to go in and do that for the families to assist the process and ensure that it continues. It seems restrictive in a sense to stop that and is adding to the burdens that we are putting on our health system.

Ms Griffin: I absolutely support what Catherine has said. I would add to that that I would only stop at NPs at this stage. Specially trained RNs can and should be signing off. If they are specially trained, they can sign off the AHDs, the advance health directives. We are already able to countersign advance care plans. Declarations of death have been done by RNs for many years in our community. We need to be able to have NPs be able to write, 'Death is an expected outcome of care,' and bypass some of the QAS and QFS issues that arise if a death is somehow perceived to be unexpected even though everyone in Health is expecting it.

Ms PEASE: Thank you very much for the great work that you all do in your various fields. I know that in the palliative care sector we have some great palliative care nurses in the Wynnum Manly area. To all of the nursing staff across the state, thank you very much for all that you do. You are face to face with the public all the time, so thank you. You do a great job.

Daniel was saying before that different aged-care facilities have different levels of care and provide a different standard of care. Much could possibly be said for the trained staff that go in as well. Catherine, you also mentioned that well-trained RNs and ENs make a huge difference to the provision of palliative care. Talking about that, is there a difference between the training providers? What are the standards of the training providers and is there an expectation that they meet their requirements? Can any of you comment on that?

Ms Smith: When you do a nursing degree there is a lot to learn in a limited period of time. At times there has not been the ability to focus as much on just aged care because nurses come out and work in so many different areas. Unfortunately, the numbers of postgraduate RNs going and studying postgraduate things in aged care is limiting to the extent that QUT postponed their course recently because they could not get enough numbers into it. I think it comes down to, if you are not being paid at a really economical level compared to other RNs in acute care, you do not have the money to spend on doing extra training. There is not a lot of additional training out there. We hope to be addressing that and looking at that. My college is presently looking at how we can improve that. We now have quite a number of our members who are going out and teaching in aged care to try to improve that process. We are a limited number. It needs to be bigger than what it is. Yes, we could definitely be teaching more. Until you increase the numbers and increase the way they are paid, we are probably sticking a bandaid on.

Ms PEASE: The other area I am focusing on is the personal care worker and the enrolled nurses who would not have a university degree but are getting their training provided by training providers. How does that equate to turning out outstanding personal care workers and enrolled nurses? On that, do they get trained in any areas of palliative care, particularly the personal care workers because in many of the aged-care facilities they have more personal care workers? What experience and expertise do they have in providing palliative care?

Prof. Ward: As I mentioned earlier, we are a registered training authority and an ASQA accredited higher education provider—the equivalent of a university—as a college. I also sit on the aged-care industry reference group looking at the unregulated worker curriculum. There are concerns that we have tabled as a college and with our reviewing because there are only 120 hours to become a certificate III worker. In the competition of clinical work and in the competition of the requirements to meet an unregulated healthcare worker certificate III, you are absolutely right—the specialty areas like dementia, end-of-life care and palliative care are not coming in or maybe considered an elective. It then becomes the requirement of industry to support that.

Again, for the diploma of enrolled nursing that is a concern that we are seeing. So much content is going into the requirements for a nursing diploma—and it would be the same as the undergraduate. There is not often the opportunity to provide specialised education. Enrolled nurses, for example, do not become enrolled nurses in aged care. They become enrolled nurses and then choose where they are employed. That could be in primary and community acute, rehabilitation or aged care. Then they would be looking for either education providers like ourselves or their employers to provide that education, and that is where the vulnerability lies.

Ms Griffin: Kylie has picked up most of it, but at this stage end-of-life palliative care is not mandatory in any nursing course in this country. Indeed, if you want to do postgraduate studies there is one single postgraduate pure palliative care nursing course in the country. Most courses have gone to multidisciplinary streaming. You do the cross-disciplinary training and then you choose your palliative care line. That is how we end up with some fantastic palliative care NPs. They will do it in their masters but they start as multidisciplinary. PCNA has done some work with a couple of universities around the country including QUT—Patsy Yates is one of our members, so of course she is on our side—trying to get a pure nursing course or at least better streaming through tertiary studies. Kylie has covered most of it.

Ms PEASE: That is offered through QUT. Is that correct?

Ms Griffin: QUT has had discussions with us. The other thing through QUT—and you probably found—is an online learning module called PCC4U through the collaborative group. Again, that is high level. It is federally funded. It has been running now for a number of years. It is cross-disciplinary. We still struggle to get uptake. It is much better, but in our nursing schools we are still only looking at about 75 per cent of nursing schools using those already planned modules.

Mr Prentice: For graduate nurses, registered nurses and enrolled nurses education does not stop. Unlike, for example, the public sector where there are excellent transition-to-practice programs to support beginning practitioners in the area as they enter the workforce which often can last up to a year, our experience is that those transition programs, particularly in aged care, simply do not exist. There is a bit of a double whammy there. You are a new graduate and at the same time if the area that you work in, for example, is aged care in the private sector there is often not the support that a graduate would expect to receive should they work in a hospital. That is certainly a problem. We have raised that issue of ongoing education with the current independent review of nursing education that is currently been undertaken by Professor Schwartz.

I would also like to make the point that I think both working in aged care and palliative care are areas of expert practice. I think it is very important that we emphasise that that is not a place that you go when you cannot find a job anywhere else, but that it is an area of expert practice. Certainly when I started working in aged care, even my clinical background, which ranged right across a range of areas, I think was really the bare minimum of what I needed to manage the complexity of older Australians, in particular in the residential aged-care setting. The same as for palliative care. I think certainly our reference group would feed back to us to say that there is the need for capacity building in that area and acknowledgement that this is an important part of health care.

CHAIR: Well articulated.

Mr McARDLE: Thank you very kindly for being here today, one and all, and you too, Kylie, on the phone. I want to start with the QNMU. You mention on page 5 of your document that you have 60,000 members working in this state across a variety of settings. How many of those are employed by the state government?

Dr Todhunter: I think it is roughly around two-thirds. I would have to take that on notice, but it is roughly around that.

Mr McARDLE: I might ask you to take it on notice to be accurate in that regard.

Dr Todhunter: Can I clarify that it is about our membership?

Mr McARDLE: Yes. You refer to 60,000 on page 5 of your document. You also refer on page 12 to a study on an audit done in 2018. I think you mentioned in evidence there are 80 centres that were audited. There would have been an executive document prepared for the QNMU executive committee, for want of a better term. Is that document able to be tabled to give the committee some oversight as to exactly how the audit was done, who was audited and what the outcomes were across the spectrum?

Dr Todhunter: At this stage that is unpublished data.

Mr Prentice: We have distributed that report to other organisations—for example, the Australian aged-care quality agency—and certainly there was a report prepared for that.

Mr McARDLE: Could you table that within 24 hours to this committee? Is that possible?

Mr Prentice: Yes.

Mr McARDLE: Does that break down the type of organisation—for example, government, private, NFP—that was audited and how the audit process took place? I do not want you to go into detail, but does it provide that detail in the report?

Mr Prentice: We did not audit any of the 16 public sector aged-care facilities. That data was not included in the audit. Our focus was on the private sector because certainly, on the basis of our information, the staffing and skill mix in those 16—

Mr McARDLE: Just to make it very clear here, you did not audit the government run aged-care facilities as part of this process?

Mr Prentice: No, none of the data included in that included aged-care—

CHAIR: Just to clarify, that was in regard to skills mix. That data for those 16 facilities has been provided by Queensland Health to the committee for comparison.

Mr McARDLE: Thank you. Did you also not look at the community based Queensland Health facilities that also provide aged care?

Mr Prentice: No. You would be referring to, say, the multipurpose health facilities that have a number of aged-care facilities?

Mr McARDLE: Correct, yes.

Mr Prentice: No, they were out of scope of that as well.

Mr McARDLE: On page 22 you talk about the 25,000 aged-care patients who were taken to an ED in 2016-17, an increase of 17 per cent, and you start by indicating that the sector could look at better facilities and provide primary care services and facilities on site. I think the point you are making is that that would then reduce that 25,000?

Mr Prentice: That is right.

Mr McARDLE: Of the 25,000 who were taken to EDs, how many do you say need not have been taken to an ED if those services were in place?

Mr Prentice: I do not have any data on the 25,000, but certainly other research undertaken by organisations such as the AMA, I believe—

Mr McARDLE: They will be here soon and we will ask them.

Mr Prentice:—had suggested that a significant proportion, I think one of the studies that we used was about a third, were inappropriate.

Mr McARDLE: You did not do any research on that?

Mr Prentice: No, that is referencing the data.

Mr McARDLE: I accept that the health minister made that comment. Catherine, you want to make a comment on that, do you?

Ms Smith: There was a study done out of metro north, based out of Prince Charles, I think it is called the GOAS report, that was done for Queensland Health and that actually did look at the numbers of hospital admissions from the aged-care facilities that could be reduced.

CHAIR: QAS has provided some data in regard to all of those transports HHS by HHS. I think you asked for that.

Mr McARDLE: I did, but I think Catherine is referring to a particular study that was undertaken in metro north which details greater in-depth analysis of the figures. Is that report public?

Ms Smith: I believe it is published, yes. I was presented with a copy of it. They actually wrote a letter of support for us for our MBS review related to that.

Mr McARDLE: Can you check if it is public and, if it is, undertake to file that with the committee? If it is not public, of course, you cannot do so, I accept that. I want to talk to the QNMU. You advocate that voluntary assisted dying should apply to those under the age of 18 years.

Dr Todhunter: No, we do not advocate that. We have asked the committee to consider that.

Mr McARDLE: Do you have a position on that?

Dr Todhunter: No, we do not have a position. If I could just go back to how we arrived at our position. We have nurses from all across the state, different categories, different locations. You can imagine that those nurses and midwives see lots of different people across the whole population. That was an item that was raised by one of our palliative care nurses to say look perhaps we should consider the whole idea of informed consent. The committee may or may not be aware that there are informed consent provisions in Queensland Health that take into account the idea that there can be people under 18 years of age who live quite independent of their parents and there are a number of criteria they have to meet before they are able to undertake some sort of medical procedure. We are simply asking the committee, we are not advocating for it, in the scope of its inquiry, to look at those sorts of groups, the LGBTIQ communities as well. We want everyone's voices heard.

Mr McARDLE: You say at page 10 of your submission that the Queensland government establish an independent VAD panel responsible for deciding matters involving young people. How is that not recommending there be consideration or there be a process in place for young people to access VAD?

Dr Todhunter: We anticipate there could be a number of individuals, a number of cases, that do not fit neatly into perhaps what the legislation looks like. We have considered that, as a panel, it could perhaps look at cases that do not fit the mainstream and that could possibly be one area that they look at, considering an individual who makes that request and they are under 18 years of age. We are not necessarily advocating for it, we are asking for them to be considered.

Mr McARDLE: A panel to be established within the confines of the legislation.

Dr Todhunter: Not just for them, but for any sort of problematic cases, any area that may require special circumstances.

Mr McARDLE: You also refer on page 41 that one of the considerations that may be taken into account in determining if a young person should have their wishes considered by referring to 'from the age of 14 a young person can choose to take control of their own My Health Record and decide who sees the information'. That is quite a distinct issue and I would have thought a much lower issue.

Dr Todhunter: Of course it is, but we are just simply saying that there are other considerations out there that we would like the committee to look at in terms of this consent or looking at young people under age 18 who may find themselves in those circumstances. We are not advocating in particular. I am not sure what you are trying to get me to—

Mr McARDLE: I am just quoting the documentation you put to us as an example.

Dr Todhunter: And we have used that as an example for you to consider.

Mr McARDLE: My comment would be I think that they are poles apart in relation to a My Health Record—

Dr Todhunter: That is your response then.

Mr McARDLE:—and in relation to a young person determining to take their own life in relation to VAD.

Dr Todhunter: That is fine. That is totally fine. That is just one instance.

Mr McARDLE: Good. Let us move on then. I want to talk about palliative care per se. All of you have a perspective on palliative care. I made the comment on several occasions that it is grossly misunderstood in the public arena in that the public generally, not those who are here today, understand it relates to the last two days or two weeks of life before a person passes on. It can be two years, it can be longer than that, based upon a diagnosis of a terminal illness. The point is if we are going to discuss palliative care and voluntary assisted dying, though they are not linked medically, ethically they should be discussed at the same time. Palliative care can get a person to a point, but palliative care should always be part of the discussion if the voluntary assisted dying piece of legislation comes into play. I do not see that you can differentiate between the two in a discussion as the way forward. Catherine, would you agree with that?

Ms Smith: It should be included. Patients should be informed of all options. I totally believe that. I think your point about palliative care, that the community do not know, I would like to say that health literacy is pretty low anyway. It is across the board. This is not special in that sort of sense, in general speaking. We need to be able to provide them with all options whenever we do anything. This should be included in anything. When you sit down to talk to a patient about any of their health decisions we should be always giving them all options. They should be making the choice, not us.

Mr McARDLE: Exactly. I agree entirely. Kym, would you like to comment?

Ms Griffin: I absolutely agree. For some years now palliative care in this country has taken the view that the discussion of palliative care and the discussion of assisted dying is part of the same discussion. We are approaching it very differently in this country from a palliative care specialist sector. We are approaching it very differently to what Canada did. We are staying in the discussion because we know that we are already having these discussions, and those of us who have been in the game for a long time have had lots of them, so why step out when it is another choice that our clients are coming to us with. I would agree with Catherine, I think it is not just our community, I have constant conversations with my health professional colleagues trying to explain that palliative care and end-of-life care are kind of the same thing and they are just language that we use to make ourselves feel better because palliative care has a bad stigma around it. Supportive care is the other term now that is creeping into our conversation, but I absolutely agree, same conversation.

Mr McARDLE: Mr Prentice, would you like to comment?

Mr Prentice: I would agree with my colleagues that it is very difficult to separate the two issues. I echo what my colleagues said but I would think irrespective of the outcome of any voluntary assisted dying inquiry there is a whole lot of work to be done in the palliative care space and certainly there are a range of issues around community attitudes and fear around the dying process. While we have probably made a little progress perhaps over the years, there is still a lot of work to be done in that space.

Mr McARDLE: Kylie, would you like to comment?

Prof. Ward: Voluntary assisted dying is and would be via a very strict process. I agree that the conversation should be held collectively, but in reality it would be a very small percentage of the population that would actually access or qualify for voluntary assisted dying. When we refer to palliative care or those requiring palliative care, we are talking about it could be years in building relationships. Palliative care would be required in the acute in primary and community health and in aged-care settings. I think the biggest importance for the discussion for organisations such as ourselves and governments is really the discussion around end-of-life care and to be holding those discussions early so that family and loved ones really understand a person’s wishes. We would reinforce that for underserved communities, for vulnerable communities—obviously Queensland when we hear back from our members has very remote and isolated areas, it is reinforcing access and equity in terms of infrastructure support and education, which is why we would be happy to work with the government to make sure that all nurses everywhere have a level of education around end-of-life care and palliative care and an awareness of voluntary assisted dying.

Mr McARDLE: My final question is to the full panel. Does anybody disagree that Queensland needs a stand-alone palliative care strategy going forward—not as part of end-of-life care, which is a much broader topic, but palliative care as a stand-alone strategy? Given where we are with the cohort of older people coming through et cetera, is that a position that you could endorse? I will start with you, Kym. You are very keen to answer I suspect.

Ms Griffin: We do not separate the two terms. It is the one term. When we start talking about palliative care, it is the health practice that we put in. It is a specialist knowledge that we put in. End-of-life care starts a long way before they get to us, quite commonly managed very beautifully by general practitioners and primary health nurses. People tend to come to palliative care when something goes wrong or a medical officer decides that they are in the last six to 12 months of life. We believe that by taking that conversation out earlier and getting things in place then we are going to do better for our community, and that is what I started to say before.

One of the things that is coming up that we are noticing and getting feedback from our members in Victoria on is that the community are more ready to have conversations around death and dying because of the inquiry and the changes to the legislation. Those of us in this state are hopeful the same thing is going to happen here. PCQ is running Compassionate Communities. The conversations are happening. If our community understand what we do in our specialist sector of health, then they are going to have more knowledgeable conversations with us when the time comes that they want to choose one way or another. As Catherine said a number of times, and we have all said, it comes down to choice and people understanding their choice and us being better at giving our messages. We would ask that one of the things to come out from this inquiry is better community conversation around the whole topic of health and life-limiting illness itself and what we do and that it is not all about curative. Some of it is about living.

Mr McARDLE: Are there any other comments from anyone on the panel for yes or no or you do not agree?

Ms Smith: I do not think you can put palliative care just on its own. I think any time we only focus on one part of health care we are not acting holistically which is against everything that nurses are trained to do and particularly nurse practitioners are trained to do. I struggle with you pigeonholing that one area. I think we will miss too many people and not provide the outcomes we want.

Mr Prentice: Yes, we would agree. It is a continuum—that is, end-of-life care flows into palliative care essentially. I guess where our members would like to see a focus within an overall plan on the issues that they have identified in the delivery of palliative care services is around the funding, the resourcing, the infrastructure and the coordination of those particular services. That certainly was the focus of our reference group but, again, we need a plan for end-of-life care basically which includes palliative care.

Mr McARDLE: It is an in globo topic, isn’t it? It needs to be filled with a number of issues. Kylie, would you like to comment?

Prof. Ward: The Australian College of Nursing would certainly not be opposed to Queensland developing a palliative care plan, but we would like to see that aligned to the National Palliative Care Strategy that was released in 2018 with the six guiding principles. In terms of how that plan is going to be developed, I would also welcome the committee giving great consideration for nurse-led models and interventions that will take us into the future knowing the challenges with the supply of the workforce. The World Health Organization has just released figures which show that by 2030 there will be an 18 million health workforce shortage and half of those workers will be nurses, so we really need to show nurse-led innovative models. The most satisfied nurses in all research that is produced are those who generally work in community and primary health because they are autonomous. I would urge or plead with the government to consider how to have satisfying career pathways for nurses to provide the care that we love and desire to provide.

Mr McARDLE: Thanks, Kylie. Thank you, Chair.

CHAIR: As the deputy chair mentioned earlier for those who were at this morning's session, Queensland Health have published a palliative care plan or first steps, if you like. I do not know if you have that document handy there. It is key findings. That was put together in consideration of the work that we are doing, too. There are no recommendations in that. It certainly leads us to some points of making recommendations at the end of the year in all three areas—aged care, palliative care, end-of-life care and voluntary assisted dying. That guides us in some direction but so do the contributions that you have each made today. Whether it is staff mix in aged-care facilities or nurse practitioners, you have informed our committee considerably and I put on the record for all of you—including you on the phone, Kylie, from ACN—that we thank you for your significant contributions today, for your submissions and pass on to your organisations our deep appreciation for the work that they do in caring for the Queensland community through aged and palliative care and end-of-life care. Thank you very much. We will suspend the hearing until 12.30. Thank you.

Proceedings suspended from 12.07 pm to 12.32 pm.

DHUPELIA, Dr Dilip, President, Australian Medical Association Queensland

MOY, Dr Chris, Chair, Australian Medical Association Ethics and Medico-Legal Committee; Federal Australian Medical Association Councillor; President, Australian Medical Association South Australia

Dr Dhupelia: Thank you for inviting me to present the views of the AMA Queensland to your inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. The committee would already be aware of the *AMA position statement: Euthanasia and physician assisted suicide 2016*. At the outset it is important that I emphasise to the committee the very first line of our position statement, which states—

> Doctors (medical practitioners) have an ethical duty to care for dying patients so that death is allowed to occur in comfort and with dignity.

This statement alone should provide reassurance to you and the Queensland community that doctors will always be there to care for their patients until the very end. Having said that, for a doctor there is a major difference between palliation of a dying patient and giving a substance with the specific intent to end life. My comments today come on the back of three separate submissions that AMA Queensland has already submitted to the inquiry on aged care, palliative care and voluntary assisted dying.

Today I will be strongly advocating for the Queensland government to make the changes that the AMA recommends to truly support good end-of-life care for patients and the community. There are three things: firstly, genuinely and adequately fund palliative care services; secondly, a strong focus on advance care planning, including education strategy for the public; thirdly, and importantly—and I am sure my colleague, Dr Moy, will have more to say on this—legislative change so that doctors do not have to provide treatment of no medical benefit—that is, futile care—so that doctors can make end-of-life decisions for patients that are consistent with good medical practice.

The AMA Queensland council does not support the introduction of voluntary assisted dying in Queensland. In line with the federal AMA's position, we believe that doctors should not be involved in interventions that have as their primary intention the ending of a person's life. The committee needs to be aware that the AMA Queensland's position is consistent with that of the World Medical Association, the British Medical Association, the American Medical Association and the New Zealand Medical Association. At the same time, we do understand and appreciate the diverse and strong views on this matter and respect the views of others, including our doctor members who support voluntary assisted dying. Returning to the *AMA position statement: Euthanasia and physician assisted suicide 2016*, paragraph 3.3 states—

> The AMA acknowledges that laws in relation to euthanasia and physician assisted suicide are ultimately a matter for society and government.

However, there is one important question that we need to consider here: what are the majority of Queenslanders really seeking in the push for physician assisted dying? We contend that they want to be reassured that they will die in comfort and dignity alongside their loved ones and, most importantly, with a level of self-determination and autonomy which they currently do not feel they have.

We put it to you that the way to fulfil this wish is to do three things: firstly, better palliative care; secondly, meaningful advance care planning; and, thirdly, solving the ambiguity that arises from current legislation in Queensland which we believe is flawed. AMA Queensland will do all that we can to work with you as a committee and others on each one of these three aspects. These should be the government's priorities. This is what should be done to really address the end-of-life needs of the Queensland community, and it must be done before you consider the issue of euthanasia or voluntary assisted dying, despite what the media wishes to talk about. Let us not put the cart before the horse. I would make the point that even in countries where euthanasia and physician assisted dying operates, it is an expensive option for a very small percentage of people who die. While the subject continues to occupy the headlines, it represents the tip of the iceberg of the end-of-life care needs of the population.

If, however, the government does proceed to draft legislation for voluntary assisted dying, the AMA Queensland believes that doctors and medical facilities have the right to conscientiously object to voluntary assisted dying and they should not be legally bound to participate, nor should they be legally bound to provide a referral to another doctor outside of the practice or facility. AMA Queensland also recommends that the medical profession must be involved in the development of any legislation, regulation or guideline which protects all doctors within the law, vulnerable patients such as those who may be susceptible to undue influence, those who may consider themselves to be a burden to their families, carers or society, and patients and doctors who do not wish to participate in the functioning of the health system as a whole.

In summary, I put it to the committee that, if it is genuine about finding solutions to help Queenslanders at the end of their lives, it will focus on the question that I asked previously: what are the majority of Queenslanders really seeking in the push for voluntary assisted dying? The answer to this question is the serious resourcing of palliative care services; promoting advance care planning; supporting AMA Queensland's Fifty over Fifty campaign regarding advance care planning; and clarification of the current Queensland legislation. By providing this the committee will address the needs of Queensland's ageing community and the consultation will not become a public popularity exercise, but one of serious consideration of an important issue for Queenslanders today and in the future. I thank you for allowing the AMA Queensland to be present here today.

Mr McARDLE: Welcome to the hearing today and thank you for your submission and your oral presentation. I want to take you to page 1 of your submission. You deal with question 6, adequate numbers of home care packages available in areas at the levels required. You refer to 90,000 approved home care packages and another 127,000 on the waiting list. One of the things we have discussed is the issue of the patient-to-staff ratio. One of the things I want to better understand is through the current cohort going through university, are we able to ramp up these ratios to an acceptable level if the 127,000 places were allocated by the federal government?

Dr Dhupelia: The issue here about minimal staff ratios is a contentious one for aged-care providers in the sense that the population in a residential aged-care facility at any one time fluctuates from low care to high care, and then it depends on what is actually the right highly skilled nursing quota that we require. That is a difficult assessment. Largely, what is happening is that financial decisions are being made rather than making sure that we have registered nurses 24/7 in the right quota in aged-care facilities. We are getting a larger influx of carers. I am not saying that they do not do a good job. I work in an aged-care facility myself and the carers do an amazing job, but they are not RNs and we do not actually have access to RNs 24/7. The issue of how we fund the quota of nurses we would ideally like and how we balance that with a fluctuating residential aged-care population of low need and high need occurs constantly. It is a moving feast at the moment in any particular residential aged-care facility.

Having said that, as you know, in Queensland we recently introduced quotas for nursing, and I think that there is a discussion that really needs to be had about that. When our doctors go to a residential aged-care facility we want to speak to highly trained residential aged-care nurses who have additional skills in aged care.

Mr McARDLE: Do we have enough nurses being trained now to fill this gap? That is my real point. We can talk about ratios—and I accept that is a very valid argument—but in reality are the nurses coming through in numbers from universities to fill that gap, or is there going to be a shortfall irrespective of what this body recommends?

Dr Dhupelia: I do not have the data on the number of people going through nursing school. As you know, nursing is a very popular occupation. I know that we are large exporters of qualified nursing staff to other countries in the world and they are not returning. We know that a large number of all Queensland trained nurses also end up in interstate institutions, but I do not have the physical numbers of those going through nursing college.

Mr McARDLE: I note that the AMA does not endorse voluntary assisted dying, as it is known in the public arena. Do you endorse palliative sedation?

Dr Dhupelia: You might ask Dr Moy, who was the chair of the committee that drafted our position statement, because this has been debated at great length with our profession. I will defer to Dr Moy for that answer.

Dr Moy: Palliative sedation is recognised within the realms of palliative care. There is always confusion, and I think that is part of the problem with the public debate. I do not think people totally understand the difference. I do a lot of palliative care. I have been involved with the GP Palliative Shared Care Program in South Australia and the development of the South Australian advance care directive legislation. A lot of the confusion is about what you are trying to do in palliative care. To be frank, it cannot be complicated, because if it is complicated then in the middle of the night when you have to make this decision, or when you are running around at lunchtime trying to make end-of-life decisions, you get a problem. Ultimately, with palliative care the intention is to maintain the comfort and dignity of the individual; with euthanasia the intention is to end life—assisted dying. The only difference is the medications provided to the patient. It is down to intention. In terms of how I sleep at night, it is actually whether I sleep at night. If I could put it in football terms, it is whether you are playing the football—which is palliative care—you are dealing with the symptoms. Your focus is purely on the symptoms. If you are playing the man or the woman, you are trying to tackle that—ending their life. That is euthanasia, physician assisted suicide.

As long as my intention is to continue to maintain the comfort and dignity of the individual—and that means I give a medication dosage that I think is within the bounds that is required and I keep on escalating it in a graduated fashion until it stops the symptoms—that is palliative care. Terminal sedation as the end result is probably the ultimate in that. That is for certain groups of people where the symptoms are so great that the individual is unconscious. They are put in a state where their symptoms are so great that they need to be held in a position where they cannot respond and they will not be responding—much like anaesthetic. That fits within the gamut of palliative care.

Mr McARDLE: The primary outcome of palliative sedation is to help with the pain and distress?

Dr Moy: Absolutely.

Mr McARDLE: The secondary outcome is the patient passes.

Dr Moy: No, that is a potential side effect that is within the realms of the concept of double effect.

Mr McARDLE: The primary outcome is really—

Dr Moy: Yes, and the intention of the treatment is always focusing on symptoms. That is what I go to sleep at night with.

Mr McARDLE: With euthanasia, or voluntary assisted dying, the outcome desired is the death of the patient.

Dr Moy: Correct.

Mr McARDLE: You mentioned also that palliative care has been the mainstay for the AMA as a way forward. Would you envisage that there is a need for a palliative care strategy in Queensland as a standalone strategy or as part of end-of-life care coupling it with the National Palliative Care Strategy of a few years ago?

Dr Dhupelia: I do not believe that we can separate things. We at the AMA Queensland for some time now have been calling to come up with a palliative care strategy. As you know, the 2018 Productivity Commission's report on end-of-life care revealed that 90 per cent of the 29,500 Queenslanders who die in Queensland will benefit from palliative care but do not receive care that fully reflects their choice, especially in rural and remote areas. We also know that a parliamentary committee in 2013 indicated that there was significant unmet need for palliative care services in Queensland. The need is continuing to grow as we get older and our population gets older.

Three factors came out of the 2013 report, which the AMA agrees with. Those three factors were the age and location, diagnosis and cultural background, the level of education of their health care and of the professional. AMA Queensland is just about to release its Health Vision part 2. We are calling for the Queensland government to sufficiently resource palliative care services. In the budget announcements only a few weeks ago there was a positive first step, which I call a deposit, of $17 million—and we all know that $17 million is not going to go very far. I am saying to you that we want a specific multidisciplinary palliative care service. We are calling for each training hospital to be resourced to set up a highly skilled palliative team and that each training hospital should have a specific palliative care unit.

We want an office of palliative care that will coordinate palliative care services so that people, especially in rural and remote areas, can access palliative care at home or closer to home where they want to stay. Not only that, we want the information given to those people in communities in rural and remote Queensland so that they know that anybody who is seeking palliative care knows exactly what services are available in a one-stop shop within their area. I think that is an important thing. We require a large investment in palliative care. I said to you at the start that the three things that the AMA Queensland would like to achieve is a massive, genuine, non-tokenistic contribution to palliative care that includes training, education and making sure that the right doctors and specialists and nurses and allied health are in those rural and remote areas.

The second thing is that part of it has to be the advance care education package. That is why we have come out with Fifty over Fifty. For those who may not know what the Fifty over Fifty campaign is, we are pushing for 50 per cent of Queenslanders over the age of 50 to have an advance care directive in place with their GPs by 2022.

Mr McARDLE: Thank you.

Dr Moy: What Dilip said is correct. I would say that there is a slight issue with combining the two issues—voluntary assisted dying and palliative care—for two reasons. Firstly, one of our position statements is that voluntary assisted dying should never replace palliative care. That is a really important thing. I think a lot of people do not totally understand at the real point of palliative care the difference between the two. They really have to be separated. That is for two reasons. Firstly, so there is not this fudgy thinking that happens. I get worried about it, even among health practitioners. Sometimes they do not get what they are doing. There is confusion about that. There is definitely confusion in the community about the difference.

The other thing is that you do not slip into this thinking of the easier option, especially given the flaws in your current legislation about withdrawal, which are really confusing. Doctors can be compelled to provide treatment of no medical benefit and also stop the withdrawal of treatment. Also, worse, under your current legislation, if a substitute decision-maker stands up for a patient and says, ‘They would not want this life-sustaining treatment,’ a doctor can still override that decision against that wish. It is really odd legislation. It does not support patient autonomy. You have this really slightly confusing legislation that leads to this.

This is the *End-of-life care: guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*. I brought this in for a reason. It is 180 pages that a doctor has to familiarise themselves with to make a decision. Because of your rather confusing legislation, these are decisions that have to be made sometimes at lunchtime when I am running down there. That is why we are saying that you need to sort out your legislation first before you start thinking about voluntary assisted dying. Currently, doctors are all at sea to some degree because they cannot make a proper decision. Your patients do not have proper autonomy.

In the past, pneumonia used to be the older person’s friend. You have heard that term before. I have had elderly patients who have said, ‘I would like to fly away when I get pneumonia.’ Currently, if they were to have pneumonia, were dying from pneumonia and needed antibiotics but the substitute decision-maker says, ‘Don’t give them antibiotics because she’s happy to pass away and that is her wish,’ that should be allowed. That is not euthanasia. That is palliative care. What can happen now is a doctor can override that, because it is in their best interests. You have very strange legislation in Queensland and I think you need to sort that out first.

CHAIR: Can you table that document? Leave is granted for that to be tabled.

Ms PEASE: I want to go back to a point that you made when you were having a conversation with the deputy chair, Mr McArdle, about palliative sedation. What training does a doctor have to have to undertake that palliative sedation? Is it just a general practitioner or people at home, for example? Is that what happens?

Dr Moy: Usually, when it gets to palliative sedation, generally, a palliative care specialist would probably be required at that stage. It depends on what realms you are going to get into. I work in aged care. Quite often, when an elderly patient is passing away, they are being treated palliatively. We give them enough doses and they are unconscious. Some people might call that palliative sedation but, as long as my treatment is covering the symptoms and we do not feel that they are registering pain scores and we are not seeing levels of distress from the patient, we are covering that. We are doing palliative care. That patient may stay unconscious for some while, but that is part of dying, anyway. If you think about it, a lot of people would be dying.

Ms PEASE: One of the comments that you made to Mr McArdle was about palliative sedation—that the purpose of that is to keep them comfortable and make them pain free. There is no intention of euthanasia; it is to treat their symptoms. Are they ever likely to wake up from palliative sedation?

Dr Moy: We are not making a decision about the destiny of the individual. There is some possibility that that individual could recover. It is very unlikely, because by that stage it is almost certain that they have a condition that is diagnosed as clearly terminal, but stranger things have happened. I have certainly had individuals—again, not talking absolutely—who have defied terminal sedation. The job in palliative care is not to make a judgement on the destiny of the individual. You are treating symptoms. Sometimes people recover. They get through their pneumonia, for example.

Ms PEASE: I understand that but, as a non-medical person, I am trying to understand that, if you are palliatively sedating someone, are they ever likely—

Dr Moy: Generally no. They are in a state probably where they have had such significant symptoms for a long time and they are being sedated because the control of the symptoms has been so difficult.

Dr Dhupelia: May I make one further point on that question? Currently, in a lot of rural and remote areas, a lot of the palliation care especially falls on rural doctors, rural GPs and rural generalists. There is a need for training in how to look after these people. As part of the investment in these specialised units that we are talking about, that should come out of the training hospitals. Years ago—and I am going to age myself here—the Mount Olivet Hospital used to have palliative care training for GPs. I did that. It was a two-week intensive in-house course on palliative care. It was funded by Queensland Health. It took us away from our private practices. Those of us who wanted to be skilled came down and worked together with a group of doctors. We learned our palliative care training—everything from the right medications, the right doses, to the empathy that is required in how we deal with families and how we deal with the grief and the counselling. It was all done very well. It was fully supported by Queensland Health. That does not happen anymore. I think it was a good thing.

Mr HUNT: You both mentioned you are currently working in aged care. Earlier today we had a geriatrician who made a submission in relation to cultural values—how we value older people—and their concerns about voluntary assisted dying where people may seek to have that because they feel as though they are a burden on society, or on others, or on their family. To what extent do you see that attitude as part of our culture in aged care? Do you see that a lot—that people feel as though they are a burden and they want to pass away because of that predominant reason?

Dr Moy: I will just take a step back, if you do not mind, and talk about why we have loaded this document. This position statement was written in a special way. We were trying to see past the current emotional debates that go on. For us, our main game, as has been indicated by the AMA Queensland president, is to focus on autonomy and to make sure that we control comfort and dignity. The three things that we have asked for are the main games in town, because they are going to cover 97 per cent to 98 per cent of all people who you need to focus on. If you are really genuine about fixing end-of-life care, that is what you need to focus on.

This three per cent argument is in section 3, which is this issue about voluntary assisted dying. The reason we put that in there is that we understand that it is not our job to make a decision. It is a societal decision, but society needs to understand what it means. As regulators you have this problem and I get it. You are trying to deal with a situation where people are talking about the terrible situations that they are in. You are hearing that. It is a rights issue. When you are creating legislation, you are moving a needle one way or the other and you can create unintended consequences. For us, our concern is the unintended consequences, because we know that suddenly what you are doing is opening up the issue of value of life. That is not just from other people imposing their values of life onto individuals, which is a problem, but the second part is the individual starting to value their lives in a different way as well. They may not even be elderly—they are disabled, they are children. You are opening it up.

Again, we totally respect the distress of the people who you are going to hear from. I will name the people: they are the people with motor neurone disease and other neurodegenerative conditions. We understand that. We believe that there is a possibility to alleviate a lot of the symptoms with what we have if we do it properly, but you need to understand that, if you move the needle, the bit that society does not understand at this stage is opening it up for the potential for the imposition of values that are different from what they have been in the past. I think that is a real threat.

Mr HUNT: Did you want to comment at all?

Dr Dhupelia: Yes. Why would they seek that if they have a legislative vehicle by which they can make a decision? Older people in aged care fear what the future holds for them, especially if they have some terminal diagnosis being made as well. They fear that they are a burden to others. Should we allow them palliative care in conjunction with curative care? Palliative care is usually given very late. Palliative care is not end-of-life care. In these people, palliative care should be given in conjunction with any curative or any alleviating care that we give. I think that giving them this opportunity of feeling in the mind that they are a burden to society is wrong. That value does not sit right with me, that we are saying to them, ‘You know, you are a burden to society and do you know you have an option now?’ I think that we should be strongly thinking about that value.

Mr HUNT: Just changing tack to something you said before about the ambiguity in these laws in the 180-page document that you tabled before and the right to refuse treatment. I am interested in how that affects younger people. For example, if a younger person gets pneumonia and refuses treatment but by all accounts could probably be cured and live a long life. Does that come into the ethics of decision-making and whether or not to intervene, or should we look just at autonomy for everybody?

Dr Moy: The question is whether you are ultimately talking about autonomy. At the moment, if I walk up to you and say for whatever reason, 'I am going to stick a needle in you; I do not care' and you refuse, have decision-making capacity and do not have a mental illness which impairs your decision-making capacity, I cannot do that to you. This current legislation is strange because it potentially overrides that to some degree. When we set up the legislation in South Australia, the individual making the decision should apply a thing called the substitute decision-making standard. That means they are supposed to put themselves in the individual's shoes and make the decision they would make; they become the individual. They are defending the individual's rights to say no. If I come up to you and you do not have decision-making capacity and your substitute decision-maker says no, I should still not be able to put it in you, because they are defending you.

I should be asking why and, if there is a reason such as they are trying to get the proceeds of your will or they hate you, they are not really doing it for you. I should be able to go to a dispute resolution process, which is the Public Advocate or whatever. That is how decisions should be made, because that is the balance of it. Ultimately, you can still refuse anything when you have a decision-making power. What is the difference when there is a substitute decision-maker who should be acting as if they are you?

Mr HUNT: Is the South Australian model good for the law we should be looking at?

Dr Moy: Basically, the AMA position was bolder. I come from South Australia. The balance of the decision is that in the South Australian legislation we made sure we protect double effect, so in simple terms doctors are basically given enough ammunition to give enough.

Mr HUNT: That is in effect in Queensland, too.

Dr Moy: Queensland is fine. The second thing is there is no ambiguity. Doctors should not offer treatment of no medical benefit. Then there is no confusion. In terms of common law, I do not have to provide anything to you that I do not think is of a medical benefit. Strangely in Queensland, in terms of end-of-life, life-sustaining measures, I could be compelled to provide treatment. The flipside is true autonomy. If the substitute decision maker is acting in your shoes and defending what your true wishes, they should be able to say no and I should respect that. That is true autonomy. It may seem a difficult thing to understand, but that is true autonomy. To me, that is what the community wants. They want self-determination and to ensure that if the time comes we can give them enough so they do not actually suffer.

Mr HUNT: For how long can somebody be sedated?

Dr Moy: It can be for a very long time.

Mr HUNT: Indefinite?

Dr Moy: It can be a long time.

Mr HUNT: Is it sometimes weeks and months?

Dr Moy: Months, yes.

Mr HUNT: It can be? Thank you.

Mr O'ROURKE: Earlier today, doctors were talking about being almost discouraged financially to work in the aged-care area. Has that been brought up with the AMA and has it gone to the federal government for consideration? Has there been a response from the federal government?

Dr Dhupelia: It is a federal issue. It is federal funding. It is MBS funding. The payment is shameful in terms of a GP getting out of his consulting room, jumping in his car, driving to an outer-lying residential aged-care facility and giving care to one or two patients and driving back, because of the time that it actually takes. A lot of GPs would leave it till after hours to do that, because they have very busy schedules. That answers Mark's question about access when we go there after hours. Quite often, there is not a registered nurse that we can access as well.

The rebate for the MBS has been kept shamefully low. The AMA has been fighting very hard on this and has been able to save an incentive that GPs get. It is called the aged-care access incentive payment, ACAI, where if a GP regularly sees aged-care people we get an incentive that is broken up into two bits—$1,500 after you have seen 60 patients in a year and another $3,500 if you have seen 140 patients a year. That $5,000 incentive is to make up for things that we do at home that are not paid. For example, the time the nursing home rings you and says, 'What can we do with this? Shall we send them in an ambulance? Should we keep them until tomorrow when you come?' or when the pharmacy wants a script in the middle of the night or weekend or whatever it is. That unpaid work; that is what it is there for. They were going to take that away. The AMA won that back in the budget. It has never been indexed since it came in. It has remained at $5,000 a year for those doctors who want to visit aged people at home.

The second part of it is that the fee for aged care went onto the multiple patient rule. It got divided. You got so much for the first patient. If there were two in the same visit, it was watered down. If you saw three, it was watered down further—up to seven dilutions. The AMA managed to get that part removed; however, the economics still are not right. There are GPs who do only aged care. They do not have any other practices and only look after aged-care people. Currently, the economics show that if you see more than 16 patients in a day and if you spent your whole day looking at aged-care people, you will see more than 16 people. You are financially disadvantaged. The last thing the AMA wants is a flag fall fee for you to get in your car and go. You get a once-only flag fall for your $55. That has all come up as a result of AMA advocacy, but we still have to fix the rebate that aged-care people get because it will not be long before nobody will bulk-bill them and then we will have a bigger problem.

CHAIR: Good luck with championing that issue. We have heard it right across Queensland in our discussions. Thank you both for being here today. Dr Moy, for the committee's benefit in terms of that end-of-life care for adults document, what is the particular section of the legislation to which you are referring?

Dr Moy: On several occasions she mentions the fact that if a patient does not have decision-making capacity you cannot withdraw treatment without the consent of the substitute decision-maker.

CHAIR: That could be the enduring power of attorney?

Dr Moy: Whatever legal substitute decision-makers you have here. I also refer to the QUT end-of-life decision-making site that does talk a little bit about this. We have the references to the various legislation, which is ambiguous because section 79 of the Guardianship Administration Act is the issue. It makes it an offence for a health provider to carry out health care for an adult with impaired capacity unless appropriate consent is obtained. Health care is defined but includes withholding and withdrawal of life-sustaining measures.

CHAIR: You were not here this morning, but the RACGP and geriatricians highlighted a case where a 94-year-old had an infection in his hip. The family member, the enduring power of attorney, said, 'No, does not need the operation. It is not in the best interests.' The doctors disagreed and said that it was in the best interests. He recovered from that. There is the flipside to what you are saying there.

Dr Moy: That is interesting. The question is: the individual is making a decision on the quality of life. You are saying that because he survived, that was the result he wanted. What is it?

CHAIR: No, sorry. We are just getting to that particular point because he was assumed to have had dementia. It was all about capacity and decision-making. The doctors absolutely thought he had the clear intent to make an informed decision on his treatment, but the family did not want him to have the treatment.

Dr Moy: In that situation he wanted the treatment?

CHAIR: Yes.

Dr Moy: He was cleared, so it was not best interests. Again, in South Australia, the intention of the Advanced Care Directives Act is not best interests anymore; it is the patient on a substitute decision-making standard. We try to make the decision the individual would have made in that situation. For example, a doctor believes that the patient would have wanted treatment and that is what they would have wanted but the substitute decision-makers are going against it for other reasons and are not aligned with that. For example—and this happens—they have financial troubles and they need to get the proceeds of the will, we need this dispute resolution process on tap at that point because the doctor needs to be able to go to that dispute resolution process and say, 'This does not sound right, I know that they are after the proceeds of the will, I believe that I should be able to provide treatment in the situation.' However, if the doctor thought that in fact the patient would have wanted to be let go and the substitute decision-makers were acting as if they were acting in the patient's shoes, treatment should not be provided at that point. That is not what is happening in your legislation because it allows the doctor to override it purely on the best interest standard, which is different.

CHAIR: I congratulate the AMA on the work it is doing with the Fifty over Fifty campaign. We have heard about health literacy, poor planning and poor advance care planning. Generally, it is done in crisis when someone has been diagnosed and the family is not prepared for it. The sooner we get better education out there around this particular issue, the better. You were here earlier for the panel of nursing bodies that represented nursing and palliative care, aged-care and end-of-life care. I conclude that you concur in a better model of registered nurses in terms of staff-mix ratio, so when people go to a residential aged-care facility there is a clinical handover. They spoke to the benefits of having nurse practitioners in aged care. Certainly, we are on the same page there. You would be familiar with the Queensland Health Palliative Services Care Review that did not have specific recommendations. Again, it is for us to put in recommendations. We concur that the $17 million announced in the state budget is a good starting point. We will make recommendations on that going further. In relation to voluntary assisted dying, AMA Queensland's submission does not support the introduction of voluntary assisted dying in Queensland. On page 3 of eight the submission states–

> The AMA recognises that there are divergent views with the medical profession and the broader community in relation to euthanasia and physician assisted dying.

Dot point 3.3 states—

> The AMA acknowledges that laws in relation to euthanasia and physician assisted suicide are ultimately a matter for society and government.

This is a very similar view to the RACGP. They sort of have a middle road. It is left for society and government. They did not go one way or the other. Of course, we need to hear the views of health practitioners, certainly the views of the AMA and consumers on where we land in terms of making the report in this space. I know that you are from South Australia—and we will get to that in a minute—but in terms of consultation with AMA representatives in Queensland, how did you land on that sort of position?

Dr Dhupelia: The policy machine of AMA Queensland is our AMA Queensland council. This subject has not been taken lightly, and you would expect us to take it very seriously in any case. Our council represents groups of all the different medical specialties including geographical representation in Queensland. We rely on council to drive policy within Queensland. My job as the state president is to deliver what council actually wants. I became the spokesman of the organisation to say, 'This is what our council has decided.' The answer to your question is that where we have landed is as a result of significant debate. We looked at the position statement of our federal colleagues to see whether or not we agree with it. We debated clauses 3.1, 3.3 and 3.4 that you just read out. Council has concurred that currently the position statement as it stands suits the purpose and fully recognises that it is for the lawmakers and society to come up with the legislation. But, as I said in my opening statement, if you decide to legislate, we want to be the first ones at the table to protect the vulnerable and protect our doctors who have an objection.

CHAIR: I applaud you for section 3.2: that if we do proceed with development of legislation that vulnerable patients in particular are protected.

Dr Dhupelia: Absolutely.

CHAIR: That is clarified in your submission and we thank you for that.

Dr Dhupelia: One of the things on the advance healthcare directive that I should probably highlight here is we are calling for a registry. I know that Tasmania has come up with a registry. Other states are looking at whether it should go into the My Health Record which is still in an immature state as we all know. It is no use having an advance healthcare directive and then tucking it in a box with your will under the table and nobody knows you have actually got one. How do we actually access that is something that we need to look at.

CHAIR: A database is being developed in Queensland Health now. You would be familiar with The Viewer. You can access that and see exactly where the care plans are.

Dr Dhupelia: Yes.

CHAIR: Dr Moy, how long have you been practising in South Australia?

Dr Moy: I have been practising since 1991.

CHAIR: In the palliative care space?

Dr Moy: I am a general practitioner but I have been in aged care since about 1994. I actually did some palliative care when I was a resident.

CHAIR: Treating people in the palliative care space?

Dr Moy: In aged care, but I have also worked a lot with palliative care services to make the link with general practitioners. I am the chair of the operations committee of the GP Palliative Care Shared Care Program which is a program that actually links specialist palliative care services with GPs in the community and provides education to GPs about matters that we have discussed.

CHAIR: We have to accept that there are divergent views from all health practitioners. I do not know if you are aware, and I raised it this morning with the two groups here, Dr Will Cairns in Townsville set up the palliative care system there which was replicated on the Sunshine Coast one.

They are very good models. Ultimately this is a question for us to articulate in the report. It is about providing choice. For someone who has practised in palliative care for 40 years, he actually said in the Townsville public hearing that he thought people should be given a choice. There are gaps despite the best palliative care. I put to you the same question I put to other doctors and feel free to answer it. In your treatment of these patients have you had patients saying, 'Please just end it. Take away the pain.' ?

Dr Moy: I personally have not ever got to that point. I foresaw that you might ask this question because it is always in that situation, particularly in neurodegenerative conditions. It is that very small percentage that we are talking about. I would contend that if you can get good palliative care, which is not just the medical side of things—it is medical partly, but it is actually the social side of things and the psychological side of things because a lot of these issues are psychosocial in these situations which are massive—you can alleviate a lot of the symptoms if you get enough in there. There is obviously the terminal sedation in the end stage which may be a factor as well. I will say to you that the question I have is even for individuals that you have talked to, their world is looking at this through the eyes of the individuals that they have to treat and they are the ones you are going to hear from. I understand that you are going to hear that, but the question is, is there a system in the world that can absolutely 100 per cent alleviate 100 per cent of all suffering? We can hopefully alleviate it, but can we always remove all of it? The question then is by shifting the needle, and I get back to that shifting the needle, they are not looking at it from the wider perspective then. That is what you brought up before: does this change the needle. What you are doing, in effect, is for the first time actually opening up to one sector of the community, us doctors, the ability to end the life of others.

CHAIR: If I can bring you back to when you give that terminal sedation, when you give that cocktail of narcotics the end result is the death of the patient. I know it is the doctrine of double effect, but making sure that it is a compassionate way of removing pain and suffering.

Dr Moy: Until the patient dies.

CHAIR: Yes. So the end result is death.

Dr Moy: But the intention is not. That is the big difference. That is the opening up of the value system about what people can do in terms of decision-making in other situations.

CHAIR: The question for us is we are putting a legal framework around it. We all discussed this morning personal interactions with health. I had it with a death in the family earlier this year where they came in and went, 'We can give this if there is any suffering. Just let us know.' It happens anyway. There is a point there where that care and compassion has that double effect of being able to treat and results in the death of the patient.

Dr Moy: My question is why was the medication dosage not titrated up in that situation?

CHAIR: I guess it is an individual case. It is a really fine line. The end result is you are removing pain and suffering.

Dr Moy: You are relieving the symptoms.

CHAIR: Yes.

Dr Moy: It has a secondary effect, that is the double effect, but again the intention is still the same and it does make a big difference.

Dr Dhupelia: My answer to that is the titration part. In the sedation, if we are giving morphine, for example, we start at 10 milligrams and see what the response is. If it is no, not good enough, we go to 20, go to 30, go to 40, go to 50. If I want to actually kill that person then why would I not just go straight for 100 milligrams because I know that will actually do that? There is a difference between titrating the dose to put them into a comfortable state and actually giving a lethal dose. The intention here is to actually put them into terminal sedation, the intention is not to actually give them a dose that will actually knock them off.

CHAIR: But the side effects of the titrated increase with morphine is bradycardia, respiratory depression, hypotension?

Dr Dhupelia: Absolutely, but the primary intention is to make sure that—

Dr Moy: But it might not be. Again the intention is you are playing the ball, not the—

Mr McARDLE: Can I make the point that with voluntary assisted dying the intent is to end the life of the patient—that is the primary intention. With sedation the intention is to alleviate pain or suffering, which may lead to death, but the intentions are quite distinct and morally they are quite different and legally they are different as well in this state; is that correct?

Dr Dhupelia: Absolutely.

CHAIR: Well articulated. At the end of the day the patient is going to die from either the titrated effect in either circumstances.

Dr Moy: But we are all going to die and it is a question of when.

CHAIR: That is something none of us can avoid.

Dr Moy: It is an important issue because I think sometimes you start to miss the point of what this is. I remember a famous statement Philip Neitzke made once that made me realise he had forgotten what it was about. He was trying to reverse the legislation in the Northern Territory. He was referring to a particular woman and he came on TV and said, 'We have to finish this now because if we don't she could die before it comes in.' It is really easy to get lost in the thinking about what this is. It is concentrated on the symptoms and that is a big difference between me making a specific intention.

CHAIR: For us it is about providing people with choice at the end of life. That is the question before us.

Dr Moy: The question is where the choice opens up something else.

CHAIR: Thank you so much, both of you, for the work you are doing and for your contribution here this afternoon. We appreciate it.

Dr Dhupelia: Thank you for having us.

CASEY, Adjunct Associate Professor Veronica, Health Practitioner, Nursing and Midwifery Board of Australia

O'DEMPSEY, Mr Jim, National Director, Compliance, Australian Health Practitioner Regulation Agency

O'DWYER, Dr Susan, Practitioner Member, Medical Board of Australia, Queensland

CHAIR: Good afternoon. Thank you for being here. Would you like to make an opening statement?

Mr O'Dempsey: We thank you for the invitation to appear before you today. It is an opportunity for us to talk to you about how voluntary assisted dying relates to regulated health practitioners and the national registration accreditation scheme. We will keep our statement brief so we can spend our time answering your questions, if you have any. The common feature, from our perspective, of voluntary assisted dying schemes is that they provide for a third-party, commonly a medical practitioner or a nurse practitioner, to assist a person in ending their life. That raises issues and questions about professional ethics and professional conduct and, as you are aware, all regulated health practitioners in Australia have a code of conduct to which they are obligated to practise under. This may be relevant to your consideration of a voluntary assisted dying scheme in Queensland. I am going to hand over to Susan and then Veronica to give examples from their professions.

Dr O'Dwyer: The Medical Board of Australia's *Good medical practice: A code of conduct for doctors in Australia*, describes what is expected of all doctors registered to practise medicine in Australia. It sets out the principles that characterise good medical practise and makes explicit the standards of ethical and professional conduct expected of doctors by their professional peers and the community. Section 2.4.6 of the code sets out the requirements for registered medical practitioners regarding decisions about access to medical care. It provides that good medical practice involves registered medical practitioners being aware of their right to not provide or directly participate in treatments to which they conscientiously object, informing their patients and, if relevant, their colleagues of their objection, but also not using their objection to impede access to treatments that are legal.

Prof. Casey: Similarly to other registered health professionals, the Nursing and Midwifery Board of Australia's codes of conduct for nurses set out the legal requirements, professional behaviour and conduct expectations of all nurses in all practice settings within Australia. The code describes the principles of professional behaviour that guides safe practice and clearly outlines the conduct expected of nurses by their colleagues and the broader community. Section 3.6 of the code sets out the requirements of registered nurses in providing culturally appropriate end-of-life care and this also incorporates to accept that the person has the right to refuse treatment or to request withdrawal of treatment while ensuring the person receives relief from distress. It also facilitates advance care planning and the provision of end-of-life care where relevant and in accordance with local policy and legislation and it takes reasonable steps to ensure support is provided to people and their families even when it is not possible to deliver the outcome they desire.

Mr O'Dempsey: In conclusion, should Queensland elect to pursue legislation in support of voluntary assisted dying arrangements we would encourage members to continue to consult with the national scheme to ensure that appropriate regulatory mechanisms are in place to support both the implementation and then ongoing operation of such arrangements. We welcome questions from the committee.

CHAIR: Thank you very much. I would imagine each body that you represent would have had some dialogue in the Victorian bill. I am not sure if you are aware of the ministerial expert panel on voluntary assisted dying in Western Australia, but it is about exactly the issues you raise about making sure that there is regulation around health practitioners, be it nurses or doctors. Can you speak to any of the experiences either with Victoria or WA? Have you had any dialogue? I understand we need to put some framework around protecting health workers and health practitioners. This is not the first time this has been raised in this country in terms of voluntary assisted dying. I want to explore a little any interactions you may have had with either WA or Victoria.

Mr O'Dempsey: I do not have any personal knowledge of particular interactions. I can comment on some of the impacts of the Victorian legislation, if that is appropriate.

CHAIR: Yes.

Mr O'Dempsey: The Victorian legislation establishes both AHPRA and through AHPRA and the national scheme the Medical Board as a decision-maker on whether a medical practitioner has breached the requirements laid down in that legislation in a sense that makes the Medical Board an enforcer of the legislation rather than making judgements about whether professional standards have been met or not met. That is the only characterisation or comment—

CHAIR: That is probably more on the health complaints section. In Victoria there is a review board for voluntary assisted dying and recommendations in the Western Australian document are very similar—that is, a review board is the first cab off the rank, so to speak, in terms of someone partaking in the legislation of voluntary assisted dying. You would have to be working with those particular bodies, I would imagine.

Mr O'Dempsey: That is why in terms of the form of the legislation, if you move to a scheme of voluntary assisted dying, it is important to have the conversation so that we can have input into what the provisions would require of AHPRA in supporting implementation and operation and what the impact on the regulatory decision-makers—being the boards—would be.

CHAIR: Did either of you two want to comment?

Dr O'Dwyer: I think probably the particular part in the Victorian legislation is about health practitioners not initiating discussions with patients.

CHAIR: Interestingly, Western Australia is different.

Dr O'Dwyer: Setting that aside, yes. Their legislation explicitly says that that contravention is regarded as unprofessional conduct. The Medical Board of Australia operates across all jurisdictions and we will have practitioners potentially subject to different models of care or manners in which they will be able to deliver care under voluntary assisted dying legislation depending on what state or jurisdiction they are practising in—that is, the requirement for them to be cognisant of that and the requirement for them to be cognisant that they will be in breach of the national law and be found guilty of unprofessional conduct. You see that you will have practitioners in Victoria who will not be able to initiate those conversations. If they do, that is unprofessional conduct and will result in a notification. In Western Australia if they are allowed to initiate those conversations it will not result in unprofessional conduct.

Prof. Casey: That would be the same of nursing obviously for all professionals.

CHAIR: Thank you all very much.

Mr HUNT: I am interested in legislation with the requirement that requires a doctor with a conscientious objection to refer to another doctor. The Victorian legislation has only just commenced, but I imagine that there are doctors who vehemently object to participating in voluntary assisted dying to the point where if somebody made a request they might say, 'I object. I don't participate in that. There are others that do and I'm not going to participate to the point where I refer you to someone who will.' What would the consequences be for a doctor in that situation under the current Victorian legislation?

Dr O'Dwyer: The Victorian legislation, as I understand it, is silent on the requirement to on-refer a patient if you have a conscientious objection.

Mr HUNT: It is. Okay.

Dr O'Dwyer: Yes, so it is silent in that respect. Our code of conduct, as I said at the beginning, specifically allows for practitioners to have a conscientious objection and not to participate in the provision of care, but it also requires them not to impede access to care for those patients as well.

Mr HUNT: By merely saying, 'I don't participate in it. You'll have to go elsewhere,' would that be seen as impeding, do you think?

Dr O'Dwyer: It has not been tested in my experience in the national board whether impeding is not on-referring or actively discouraging. Do you know what I mean?

Mr HUNT: Yes.

Dr O'Dwyer: In terms of defining what impeding access is has not come to my attention in the national board where we have had a situation where we have had to tease that apart.

Mr HUNT: I imagine that some of these things are going to come up in the future with people complaining that they did not get the information that they needed et cetera from a doctor.

Dr O'Dwyer: Yes. I think in the Victorian situation though that, given that health practitioners are explicitly not able to initiate a discussion in that respect, it will not come from that side but obviously patients inquiring about it. Given that the law in Victoria does not say they must on-refer, we will yet have to see how that goes.

Mr HUNT: My mistake. I thought it did. Thank you.

Ms PEASE: Thank you very much for coming in. I am just trying to get some clarity around what role you have in oversight of the aged-care sector. Do you have any regulation or—

Dr O'Dwyer: Our oversight is in relation to individual registered health practitioners.

Ms PEASE: Practitioners, so if they worked within the aged-care sector you would?

Dr O'Dwyer: If they are registered, yes. If a notification was received regarding them, then their performance, conduct or health would be referred to us.

Ms PEASE: The practitioner could be a medical practitioner or a palliative care nurse?

Dr O'Dwyer: Yes.

Ms PEASE: What if they are unregistered?

Prof. Casey: If they are unregulated they are outside of our scope.

Dr O'Dwyer: They come under the Office of the Health Ombudsman.

Ms PEASE: Thank you. In terms of education, I know that that is a role that you undertake. Just going on with the conversations that you were having before about a scope of practice, how are you going to train your practitioners in Victoria around voluntary assisted dying and what their requirements and their expectations are given that it is a national body—that is, what you do—and my understanding is that it is going to be a different regulation of what happens in WA than what happens in Victoria? What oversight do you have in terms of if you have a practitioner who had been practising in Victoria which had one rule but then had to move to WA? Does it fit within your role that you make sure they are up to date?

Dr O'Dwyer: No. We do not provide education. We accredit education providers at the undergraduate and postgraduate level, but we do not provide individualised education. That would be up to the practitioner through their continuing professional development and also up to whomever their employer is or the state in which they are working in to make sure that the information was available to them to understand the legislative framework in which they are working.

Ms PEASE: I have to think that answer through, sorry.

Prof. Casey: Might I just add that in all of the standards and codes that we do there is always the thread that says that you must comply with the law and that law will be state law as well as federal law. It is up to the practitioner to particularly understand as you register. I work in Queensland and I must be aware, and I will use drugs and poisons just as an example. That is a clear one that has multiple different pieces of legislation or variations throughout Australia, so you must comply with that law but then fit it in with your different codes and standards. That is up to the practitioner, but it is very clear under the regulator's information and education when people register every year.

Mr O'Dempsey: It is an important point but, to come back to your question around education, our obligation would be to educate the regulatory decision-makers about the different laws in different jurisdictions. For example, we could have a national committee making the decision on the professional conduct of a practitioner in South Australia, so they would have to know what the law is that applies in South Australia. That is where the complexity comes for us and the decision-making complexity for the individual practitioner of course is where there is regular or irregular cross-border practice, and we know that that happens on the borders at all times.

Ms PEASE: Thank you. I am not sure if you were in the room when Dr Moy was speaking particularly about the current Queensland legislation and how difficult it is for practitioners to interpret that legislation. Were you here for that?

Mr O'Dempsey: Yes.

Ms PEASE: Can you give any comment on the Queensland legislation? Is it difficult to interpret and apply, and it was particularly around the fact that the patient may decide to withhold treatment and then another doctor can come in and override that?

Dr O'Dwyer: From a regulator's perspective with the Medical Board of Australia and on the Queensland board, it has not come to my attention that there have been any practitioners who have had any issues in relation to the administration of the Guardianship and Administration Act. That is not a feature of any notifications or complaints that we have seen.

CHAIR: Perhaps it is an interpretation from Dr Moy on our legislation in Queensland.

Dr O'Dwyer: Yes. From the regulator's perspective, that is really the only comment I could make.

Ms PEASE: Thank you.

Mr McARDLE: Thank you for being here today. Taking you to your letter of 18 April, you say at the base that it would be important to start negotiations early rather than later in relation to regulations to ensure a smooth transition. The Victorian bill or act was delayed about 12 months, I think, to put in place what you are talking about—that is, relevant regulations—to ensure a smooth transition. Would you advocate that being the case here as well—that is, that the act not start immediately but there be ongoing negotiations or at least understandings?

Mr O'Dempsey: I think in good practice it is always best practice to have a preparatory period in order to communicate and educate practitioners about the new obligations within the jurisdiction and for us across our decision-makers. Our particular point in the letter was not in making the regulations but in consulting on actually drafting the legislation to ensure that they do not have unintended consequences and that it is clear that, if we could be receiving notifications about practitioners in this sphere, what position we would need to take and what further information the regulatory decision-makers would require.

Mr McARDLE: What time period would you suggest that the committee consider if we go down that track?

Mr O'Dempsey: I do not have a particular time period that I could say is best practice but a sufficient lead time to enable there to be training and communication.

CHAIR: Yes, training. Deputy Chair, I can probably refer to this document here. The Western Australian Ministerial Expert Panel on Voluntary Assisted Dying has recommended 18 months—I could not find the recommendation—and 12 months to train health practitioners.

Mr McARDLE: You would not disagree with that 18 months?

Mr O'Dempsey: No.

Mr McARDLE: You highlighted that the state jurisdictions may well be quite distinct. In fact, Victoria will be distinct from the proposed WA model if it goes through the parliament. Would you recommend harmonisation? Forget about the issue of the content or what the impact is but for certainty of practitioners moving from jurisdiction to jurisdiction. An innocent practitioner may undertake a course of action that is illegal in the state they move to but legal in the state they moved from, so is harmonisation an important element going forward?

Dr O'Dwyer: I would say yes. In terms of the experience with the national law, I think most recently if I reflect—and we do not want to get into the mandatory reporting laws here—obviously the mandatory reporting laws is one that is different across a few jurisdictions and that sort of thing. Harmonisation makes it easier to administer the law. It makes it easier to understand practitioners' obligations. It also makes it easier to communicate those obligations through your registration standards and your codes of conduct as well. Obviously it is also easier for practitioners, because we do have a lot of practitioners who work across borders as well.

Mr McARDLE: There is also the question potentially, too, of residents in one jurisdiction to another jurisdiction.

Dr O'Dwyer: That is right.

Mr McARDLE: In one you may have to reside full stop and for how long that is as opposed to 12 months is quite a moot question in relation to how a doctor reacts in those circumstances. Working out those issues that can be quite a problem for a medical practitioner, or any practitioner, is important going forward.

Prof. Casey: Yes. The other element is with the law as a regulator we are here to protect the public. I would never presume to speak for the public, but without consistency and harmonisation it would be difficult to understand why it is different in different places.

Dr O'Dwyer: As a patient.

Prof. Casey: Yes, as a patient.

Mr McARDLE: As a patient, exactly right. They trumpet the Victorian legislation as having 62 or 68 protections for the client, or the patient. Have you looked at the protections offered to practitioners within that legislation? Do you have an opinion on whether or not those protections are satisfactory?

Dr O'Dwyer: No, I do not have detailed knowledge of the protections within the Victorian legislation.

Mr McARDLE: Do you have knowledge of the protections of patients contained in that legislation? Are you familiar with that at all?

Dr O'Dwyer: In relation to patient characteristics and those sorts of things?

Mr McARDLE: Patients being protected from an outcome that is directed by something outside their will?

Dr O'Dwyer: Not the specific detail on those.

Mr McARDLE: What involvement did any of your organisations have in the regulation of the Victorian bill before it became enacted and subsequently in place?

Dr O'Dwyer: I am not aware that the Medical Board of Australia had any direct involvement in drafting or consulting on that legislation.

Mr O'Dempsey: I would make the same comment from AHPRA's perspective.

Mr McARDLE: None? They did not come to you to seek your advice about the protections of patients?

Dr O'Dwyer: Not that I am aware of.

Mr McARDLE: Is there an equivalent OHO in Victoria? It may not be called OHO.

Dr O'Dwyer: No.

Mr McARDLE: Office of Health Ombudsman?

Dr O'Dwyer: No.

Mr McARDLE: To your knowledge was there any thought given to an external body looking at the bill in Victoria to assess the protections in that bill for a patient?

Mr O'Dempsey: I could say I have no personal knowledge of it. However, in Victoria they have an analogous body called the health complaints commission or health rights commission established under legislation that deals with complaints from consumers about their care. We have a similar relationship with them in terms of the OHO or the Ombudsman in terms of consulting on who will best deal with the matter, noting that the Ombudsman deals with the most serious matters in Queensland, so there is a legislative body.

Mr O'ROURKE: I am trying to think through the process. Where a person with a disability is receiving funding and support through the NDIS are any issues being raised that we should be aware of where people are transitioning through into aged care or palliative care—people with severe disabilities, for example?

Dr O'Dwyer: There are none that have come to my attention at all through the Medical Board in that process.

Prof. Casey: There are none through the Nursing and Midwifery Board.

Mr O'Dempsey: There are nil through AHPRA.

Mr McARDLE: In relation to voluntary assisted dying, unlike termination or abortion, the conversation is more likely to start in the aged-care facility or in the hospital with a nurse—probably more so than a doctor because you have that bond between the two: the patient and the nurse or the patient and the PCW, as the case may be. It is important that the protections are in place for them. Are PCWs covered by the term 'medical'? They are not a 'medical practitioner'?

Prof. Casey: No.

Mr McARDLE: It is only those who are registered as a nurse?

Prof. Casey: Yes.

Mr McARDLE: No-one else, such as an EN or an AIN, is—

Prof. Casey: An EN can.

Mr McARDLE: But an AIN is not?

Prof. Casey: No.

Mr McARDLE: And a PCW is not as well?

Prof. Casey: No.

CHAIR: I thank each of you for your contributions today in this important space. We will have a break until two o'clock and then we will start with the next witnesses.

Proceedings suspended from 1.48 pm to 2.01 pm.

CHALMERS, Ms Lucille, General Manager Commissioned Programs, Brisbane South Primary Health Network

GOOD, Associate Professor Phillip, Director of Palliative Care, St Vincent's Health Australia

HALL, Mr Toby, Group Chief Executive Officer, St Vincent's Health Australia

JOHNSON, Ms Susan, Program Officer, Paediatric Palliative Care Service

PEDERSEN, Ms Lee-anne, Nurse Practitioner, Paediatric Palliative Care Service

CHAIR: I welcome to the table Lucille Chalmers from Brisbane South Primary Health Network; Associate Professor Phillip Good from St Vincent's; Toby Hall, Group Chief Executive Officer from St Vincent's; Lee-anne Pedersen, a nurse practitioner—it is on the public record that they are some of my favourite people I have met; they are fantastic—from the Paediatric Palliative Care Service; and Susan Johnson, Program Officer from the Paediatric Palliative Care Service. Welcome everyone and thank you for your time this afternoon in providing the health committee with the views of your organisations and how we can better deliver aged, palliative and end-of-life care. It is entirely up to you if you want to make a contribution in the voluntary assisted dying space. Would you like to make some opening remarks and then we will move to questions.

Ms Chalmers: Thank you for the opportunity to appear before the public hearing for the inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying. PHNs play a key role in coordinating primary health care to improve whole-of-life health and wellbeing across our region. We work with a wide range of primary healthcare services and health professionals to improve access to and delivery of services for patients with an emphasis on those most vulnerable people at risk of poor health outcomes.

Aged care has been identified as a priority for PHNs across Australia. Brisbane South PHN, together with Metro South Hospital and Health Service, has recently developed a strategy for older persons' health and wellness to guide our collaborative efforts in planning and service delivery for our region. Through our interactions with GPs, other health and aged-care providers, consumers, their carers and families, we have identified a range of gaps in aged and palliative care services that will be broadly grouped into three areas—workforce, system navigation and service access.

A key workforce enabler is appropriate staff availability and quality in aged care, residential care, community care and palliative care. The appropriate skill mix includes personal carers, enrolled nurses, registered nurses, clinical nurse practitioners, allied health, general practitioners with timely access to palliative care consultants, geriatricians, psychiatrists and other medical specialties. Models of care that engage multidisciplinary teams and address the psychosocial support needs of patients and carers will result in a more holistic and effective approach to aged and palliative care.

Navigating the complex aged-care system to gain access to assessment and then the relevant home support, home care packages or residential aged-care services via the federal government's My Aged Care portal can be particularly difficult for older people without family advocates and for those with limited computer literacy or who do not speak English well but who are experiencing homelessness. Addressing the lack of coordination and creating a seamless interface across the state and federal aged-care systems will improve consumer experience and provide for timely support to be established in the home.

Access to the appropriate services for aged and palliative care is a challenge for many. Palliative care services in the home are limited, meaning that many who would prefer to die in their own home are unable to do so. There are currently no hospice facilities within the Brisbane South PHN region for older people. For those requiring home care packages, a long wait can mean the prolonging of an unsafe home situation, requiring more hospitalisation and premature entry into residential aged care. This lack of services will only be exacerbated as the ageing population increases.

In summary, we recognise the many challenges across state and federal health and aged-care systems in meeting the needs of older people of Queensland. We welcome an integrated and strength based planning approach that places the person at the centre and recognises the need for improved integration between health and the broader care needs of older people and those needing the support of palliative care services.

CHAIR: We will come back to some questions, but just to prompt you I asked another PHN how you can better integrate with the Queensland Health model to deliver those gaps that you have identified. I will let you think about that as we move to St Vincent's.

Mr Hall: I would like to thank the inquiry for inviting St Vincent's Health Australia to participate in this discussion today, particularly how to deliver world-class quality and respect for aged and palliative care to all Queenslanders. I would like to acknowledge the Turrbal people, the traditional owners of the land on which we gather, and pay my respects to elders past, present and emerging.

St Vincent's is the largest non-profit health and aged-care provider in Australia. We have been providing health and aged-care services in Australia for over 175 years. We operate two public health district networks, 10 private hospitals and 18 aged-care facilities, and run three research institutes. We believe that we are well placed with our experience in delivering high-quality acute and palliative care and aged-care services to help provide input to the inquiry.

Several committee members and members of the public in the room today will obviously know of Mount Olivet, a 40-bed specialist unit which is now called St Vincent's Private Hospital, which provides shared public and private services in the field of palliative care. I am very pleased that Professor Phillip Good, our director of palliative care services, is with us today. Many members of the community fondly remember being with family members when they have had their last days with St Vincent's. It is an iconic part of the health network in this city. The hospital also provides multidisciplinary community specialist palliative care service for patients within the Brisbane local government area which includes allowing support for home visits and home palliation services. That service operates support 24 hours a day seven days a week.

We believe that the inquiry provides an opportunity for Queensland to develop a whole-of-the-state, world-class end-of-life strategy. We advocate firstly for a master plan to coordinate care and support Queenslanders who are approaching the end of their life based on the following reforms: firstly, an opportunity to identify and address the many bureaucratic contractual, technological and funding issues and inconsistencies across aged-care and palliative care systems. This requires an all-of-government response to start working better to deliver an holistic integrated end-of-life care system for all Queenslanders.

Secondly, we need to look at the demand for aged-care and palliative care services and end-of-life support which will only increase over time given the population growth and the ageing within Queensland. Palliative care in the state needs better resourcing from GPs through to hospitals to aged care and community care. Far more comprehensive training needs to be put in place to upskill our health and aged-care workers in the fundamental support of people travelling towards the end of their life.

We absolutely need better and wider public education about end of life. We need to empower the community to understand what options are available to them and how they should individually approach the end of their life in a destigmatised way which is supported throughout the community. We also need to grow and support the capacity of our end-of-life care system to focus on and build services to meet population changes of the future whilst also specifically referring to quite complex cultural and geographical issues which are faced by Queensland.

As in other areas of health, Aboriginal and Torres Strait Islanders are extremely disadvantaged in comparison to the wider population when it comes to access to palliative care services and end-of-life services. That is even more challenging in the most remote areas of Queensland. For the benefit of the members, we have put in our submission the details of the work that we are doing in terms of the provision of palliative care in the northern peninsula of Cape York. Finally, in a decentralised state like Queensland we need to make much better use of technology to deliver advice, support and services into regional and remote areas to support clinicians and service providers who are delivering end-of-life care within regional and remote areas.

It is probably worth the committee being aware of the fact that St Vincent's obviously operates in Victoria and has an extensive understanding of the voluntary assisted dying system in Victoria. Not surprisingly, St Vincent's is not supportive of voluntary assisted dying. We do not believe that that is part of an integrated healthcare system. We believe that voluntary assisted dying has the potential to undermine palliative care which is actually the most important thing to most people in the community. In Queensland where people's access to quality care is not guaranteed at end of life, particularly in the regional and remote areas, we believe the government should first invest in a world-class palliative care system for considering voluntary assisted dying. No-one should feel that ending their life is the only choice that they have.

In Victoria we made it clear to the government that we would opt out from providing voluntary assisted dying in our facilities as is absolutely permitted under the law through conscientious objection, but we realise that we do not operate in a vacuum. Along with the rest of Victoria, we have put significant effort into understanding how we will support people who are looking at voluntary assisted dying as part of their end-of-life options and how we can ensure they have access to those services through other facilities in Victoria. We have also specifically visited equivalent services in Canada to understand how they operate in a real world environment from that perspective.

We have assured Victorians that we are not shut down to those conversations and that we will support them to make the choices that are right for them and for their families, and we will continue to do that as St Vincent's has done for a significant amount of time. We will, however, ensure a process where if in the odd case we have to transfer care we will do that with full compassion, attention and support to the families and those who are going through a choice to access assisted dying.

The issues that underpin the VAD debate in Queensland and elsewhere highlight the importance of, and we think the lack of today, a well-resourced end-of-life system that should be in place for patients so that they, their loved ones and their community can access benefits of palliative care and end-of-life services early with confidence. We should all have the right to approach end of life understanding what will happen and what access to services we can have and to ensure that that process can be as good as possible for each and every member of the Queensland community.

CHAIR: Thank you very much for your opening statement. We will come back to questions. I want to acknowledge the work St Vincent's does. It has been around for a long time. We heard in Cairns and Mossman about the work up in the cape with the NPA, although I think the funding runs out at some point.

Mr Hall: Yes, it does.

CHAIR: Having come from regional Queensland, from Townsville, and we have been out to Mount Isa, Palm Island and a few other places, I want to prompt you to talk about what other options there are for delivering palliative care in regional or remote Indigenous communities be it telehealth—we heard a little bit about that this week in Longreach—or other things. Does your organisation have a helpline? I would love to see St Vincent's in regional Queensland. A lot of it seems to be based in the south-east area or in other states. We will come back to that. I welcome Lee-anne Pedersen and Susan Johnson from the Paediatric Palliative Care Service.

Ms Pedersen: Thank you very much for this opportunity. As the paediatric representative, we recognise that this can be an emotive concept that we are bringing the paediatric group into the discussion around palliative care. The Paediatric Palliative Care Service is a service across Queensland, despite my computer sitting here in Brisbane. We do service across all of the state. We look after families who have a child with a life-limiting condition not expected to survive childhood, so that definition can be a little different to the grown-up presentation of palliative care. We meet the families while they are still pregnant with a child or we meet their neonate, their child or their young person at any point during their illness. Sometimes we know the families for years, sometimes for months or for weeks and sadly sometimes only for hours.

We know that to achieve the best outcome for these families in the long term it is about them having choice of location of care, particularly at end of life. This could be their home, regardless of what geography that is, the children's hospice perhaps, a tertiary hospital or their local hospital. This service certainly supports the families, the healthcare providers and the communities across the whole state to care for the child with palliative care needs, particularly at end of life, in that location of choice. This holistic approach with the local teams and communities results in the best preparation for the family's long bereavement road ahead of them. All of our combined care helps the families live with the loss of their child going forward. Ideally, it helps the families to continue to be productive members of the community with good physical health, good mental health and cultural and economic safety. We are certainly all responsible for the care of these community members.

CHAIR: Thank you so much. Thank you for the work you do in what is a very difficult space—the paediatric space. Quite often in this inquiry before us we have seen that palliative care is generally associated with adults and end-of-life care. The committee went to Hummingbird House. We certainly commend the work they do there. I have already had organisations contact me as the local member and say that we should be able to replicate that in regional Queensland. It is an incredibly difficult place for staff or anyone associated with it. The death of a child is incredibly challenging. I want to put on record my thanks for the work you and the staff do. I will probably ask a little bit more about how that is delivered and how we can better deliver that as we go forward.

I am going to go back to Lucille. How can the PHN, being federal government funded, work closer? We heard some contributions this morning about how accessing more funds across-the-board—because of the shared funding arrangement in health—could better provide services in aged care, palliative care and end-of-life care. We will look at aged care straight up, and it is probably an area you do not want to go into. We have heard time and time again of people waiting for home care packages for up to 12 or 18 months. Quite often they have been diagnosed with an illness and they do not actually get the funding as they die before that. That is one aspect. From a PHN perspective—and you identified some gaps—what are the solutions in terms of that going forward?

Ms Chalmers: Thanks for the question. Your description of some of the challenges is absolutely what we are hearing on a daily basis. In terms of addressing some of those, the role of the PHN is around, firstly, understanding the needs of the community and looking to work with those who have the capacity to address them or address them in our own right if that is available to us. In terms of aged care, our role is more as a connector of the system rather than necessarily having a significant amount of money to inject into service delivery per se. Our focus is more closely aligned around planning and strategy. As I mentioned, we have been working with Metro South Health in a joint plan to identify what our joint priorities are and how we can address those over the next three to five years to deliver on that. From a strategic perspective, that is what our PHN is doing, and many others are doing the same.

In terms of an on-the-ground example of that, one of the areas that we know is challenging is around providing strong and consistent palliative care services in the home. We are working with Metro South Health, who deliver a number of those services from the tertiary facility, to connect with those primary care providers who are willing and able to deliver services in the community; we are building workforce capacity to do that work.

In terms of the broader issue you were referring to around access to services, one of the other activities that we are involved in at Brisbane South PHN is a federally funded initiative around aged-care navigation. We are working with COTA Australia around a trial around a number of navigation models to enable people to get into the system. It does not then address the issues that are currently experienced within the system, but at least it is addressing some of those issues, particularly for those groups I spoke about who do not have family members to assist them into the system as it stands.

CHAIR: At risk of duplicating, we heard about nurse practitioners and nurse navigators and trying to navigate the aged-care system. It is incredibly complex sometimes. There have been some good outcomes already from what we are seeing in that model. In terms of your role as general manager—and I know it is a commissioned program, so you get a bucket of money allocated to see these programs through. I congratulate you on working with Metro South Health in trying to alleviate some of the burden on the public health system. How do you feed back the issues that you are hearing and that we are hearing? What is the process in terms of an annual report identifying gaps in waiting times and things like that and getting access to the funds to stay at home or to get care? How do you report up?

Ms Chalmers: In terms of the cycle or the way that PHNs work, it is very much based on a needs analysis for the community. We do a set big piece every three years and that is renewed on an annual basis. Those types of issues are identified in that core document, and all PHNs will have one of those. Then, as I said, we have had our supplementary deep dive, if you like, into issues around older people's health and there is further information about that. We have a role in making that information publicly available, so the knowledge is there. We do not have a significant amount of funding to invest in services for older people, though, in terms of the way our funding streams work.

CHAIR: I will come back to explore some of that later. Thank you very much. I turn to St Vincent's. I did touch on how we can better deliver palliative care in regional Queensland around telehealth or services you provide.

Mr Hall: I am absolutely happy to discuss that. We actually run a statewide 24/7 service in Victoria to regional and rural areas to support providers, families and clinicians in those communities, so we have very good experience in that field.

Firstly, there is a need to understand, particularly for GP practice support and nursing support, that telehealth can be done in isolation. We absolutely need to provide training to GPs, nurses and allied health specialists in terms of how to support people through end of life. In fact, at St Vincent's private, or Mount Olivet as it used to be called, we used to run a training program for GPs precisely for that purpose. I think that needs to be part of it. That said, in regional areas, there is absolutely that capacity to provide clinician-to-clinician 24/7 coverage to support people who are in the field who have an emergency at some point in time to understand how to treat someone in the home. That is absolutely key because a number of family members and clinicians are absolutely able to support family members in the home in regional areas. However, there is this fear and doubt of, 'What happens when something goes wrong? What do I do?'

In a clinician-to-clinician peer model we actually provide support to those clinicians from a palliative care expert 24/7. They can call at three in the morning and say, 'Oh my goodness, this is happening. Can you tell me what to do?', and we will step them through, either via telephone or videoconferencing, exactly what to do. That kind of service is absolutely replicable across Australia—in fact, it should be in place across Australia. We have the technology to do that quite easily. However, it needs to come with the training programs for those practitioners so they know how to respond in general and then when they have very complex issues, they can access us.

Interestingly enough, what we found through that is when that is in place, the capacity in that local community and the confidence to deliver in-home services go up very, very quickly because the fear is taken away. What it is replicated with is an understanding and knowledge that 'if there is a problem I can always get an answer'. When people know that, family members and providers are much more confident and it works much better.

CHAIR: Do you have anything to add to that?

Prof. Good: I completely agree obviously with what Toby is saying. In addition to that—and I think Toby was talking about Victoria—I have worked in New South Wales and they have a similar hub-and-spoke approach. One of the other aspects of that is the importance of actually identifying with those people, so actually doing visits to those areas. It is interesting that places like Victoria and New South Wales have those in place whereas Queensland, being the most decentralised state in Australia, does not really have that as such. In those states it has often been a connection between an urban centre and a rural centre, and that has not quite happened in Queensland. A number of years ago there was a central number at Mount Olivet that people could call which petered out over time. The importance of that is not only the telehealth but the ability of the specialist to visit those areas on a regular basis.

In Queensland Dr Peter Whan was doing a lot of visits around the place, but he is looking at retirement. That was just one person and it is not really sustainable to do that. We would all think a better model would be to have a connection between a more rural and regional area and a tertiary or a city facility. One of the barriers to that in Queensland is structural with HHSs. It does not seem as if anyone is too keen to challenge to go across HHSs. St Vincent's particularly has that challenge in their services in Brisbane, let alone outside of those areas. As Toby said, I think everyone from a clinical point of view—certainly all the doctors—are very aware of the challenges in the community. We still get quite a lot of GPs coming down to St Vincent's through the PEPA program, which is a program where people can come down for about four days and go back to those areas, and they have that connection through that.

I think what we are really talking about here is having a more standardised, integrated system where there are much stronger connections. It is okay to have a loose visit and not have any follow-up, but if you have a constant connection, as Toby was saying, it leads to having much more ability to ring when people are in trouble and much more confidence in the local area. To be honest, my experience in New South Wales when I worked there—and I worked in Newcastle—is that the people in the rural areas were amazing in how they would look after people.

CHAIR: We saw that again yesterday in Longreach. It is incredible.

Prof. Good: Yes. They have much greater ability—

CHAIR: They find a way.

Prof. Good:—to be patient centred in their care as opposed to worrying about barriers. That is the really important thing I think. Anything we can do to assist with that is really important. People can find it challenging to go from a city area where they are getting a lot of their treatment back to a rural area. They often worry about confidence. Anything we can do to put things in place to address that would be a bonus.

CHAIR: Thank you very much for that. I do not know if anyone can talk to the crossover between a patient transitioning from aged care to palliative care. We have seen various models already in our site visits where HHSs are incorporated within the Blue Care model that I keep talking about at Wynnum. How better can we replicate that? What are the solutions in taking the burden off public hospitals, hospices or whatever to make sure we are providing care at the community level, be it a residential aged-care facility or whatever?

Mr Hall: In Melbourne we are actually building Australia's first fully integrated palliation and aged-care facility, which will allow residents access onsite to full palliation services but will also provide external palliation services onsite for end-of-life care. I absolutely believe that this is a funding issue. It is dealing with the bureaucracy between the different levels of government to allow access to funding to deliver palliation in aged-care facilities. The reality is that most of our aged-care facilities today are actually bordering on subacute hospitals. They are quite capable and have the staffing structure in place—if the staff are trained and there is enough highly qualified staff—to deliver most palliation within the facility. One of the saddest things we see at St Vincent's is when people are basically taken out of an aged-care facility—and we try to deliver as much as we can in aged care—and taken across to a hospice. That is the last thing they want and it is the last thing their families want.

With the right training and the support programs that we talked about with Phillip, we should absolutely be able to provide palliation within the aged-care facility. We just need to have the funding models and the bureaucracy broken through. Phillip has talked about that. There are a lot of things which seemingly might have been logical at one point in the past such as where a particular district looks after the issues. It needs to be something which is done on a statewide basis. It needs to work with the feds in terms of the funding models to make sure that the funding for GPs and nurses is all put in place but then you can do it in aged care, which is actually what everyone wants. No-one wants to have to go somewhere else. It is much easier for people to stay. I would say the vast majority can be dealt with in the aged-care facility. A very small number may need to go somewhere like St Vincent's private. I actually think that is at the margins. If we provided the services properly in aged care, we could deliver that. There is no reason that that cannot be structured and delivered.

CHAIR: I might come back to that if we have time.

Prof. Good: You were asking about models. For example, in Canberra they have done some research on regular nurse practitioner ward rounds in aged-care facilities, and that is one of our suggestions. Most people would think it is a good suggestion to have a regular palliative care presence in aged-care facilities working in conjunction with the aged-care facility and the general practitioner. That is about just thinking from a palliative care point of view in aged care, trying to recognise early and to look at things like advance care planning and what do people actually want. It is about people being able to raise in their own voice what they actually want and that being delivered. A lot of the times people end up going back to hospital not necessarily because they want to but because various options have not been raised.

Certainly, some people need to go back to hospital and that is fine. In Canberra, the first study that they published showed that having the regular nurse practitioner ward round in aged-care facilities it did not necessarily decrease the number of admissions to hospital, but it decreased the length of stay of those patients in hospitals. That meant that they were in there for a shorter period and able to get home quicker. That is something that we certainly advocate.

Of course, the challenge is that, if you go into an aged-care facility, that position would probably be funded under state government funding as opposed to an aged-care facility, which is funded federally. There would be issues around that. Having said that, the cost saving would come out of state hospitals not having as many people. We have certainly proposed this to private health funds as an option as well. It has not been taken up yet by them. Other models that we have had have been taken up. We certainly think that it is a way forward—to have that regular recognition and early involvement.

CHAIR: Thank you very much. What do paediatric palliative care services look like in Queensland? Where does your funding come from? How does it operate? If you have a sick child in Coen, or Thursday Island, what services are offered there? Hummingbird House does fantastic work. The numbers that were provided to us show that it takes about 130 children a year. How do we support paediatric palliative care in regional and remote places?

Ms Pedersen: Currently, we offer a 24-hour toll-free phone line. Apparently, it works from Fiji. This morning, we had a call from a young fellow in Fiji who was visiting. That is very accessible regardless of geography. We also have now currently some federal money that is funding what we call a QuoCCA project. It is a collaborative project that works across all the other six national paediatric palliative care specialist services to reach out. Regardless of the child's geographic position, we can make sure that we are providing some education to some of these away centres. South Australia and Queensland are servicing the Northern Territory. Melbourne is servicing Tasmania. That is federal money.

It is a collaborative project. Part of that is scheduled education—so rolling that out as required at request and as we see the need. The second part of it, which has changed our practice totally, is this pop-up model. We recognise that a very ill child in a regional or remote location—or anywhere—is luckily a very infrequent occurrence. If the child is in the tertiary centre with us and they are wanting to go home to Thursday Island, we work very closely with our local teams as to what resources they have, what additional support they need to receive this young person.

Recently, we sent an Indigenous baby back to Dalby, because that was very important. They needed to be home to country. Dalby would never take on such a sick baby. However, that comes with a package of support. The team from the specialist palliative care team work with the family and the retrieval service, because sometimes we need their help when children are just so sick they require ventilation and support to get them back to where they want to be in the best condition they can be. We make decisions about the destination—do they want to be in the hospital, at home, or outback? We were under the tree with the mob—that is how it played out—and it was picture perfect.

For the long-term health of that family, that was the best scenario. We role modelled behaviour to the local staff so that they could see clinically how to manage the child's condition so that he was very comfortable, he was not distressed. We set that up for the best outcome. That local community is suffering a terrible loss. However, going forward, they are going to be in the best order they can be because it was all on their terms—on their territory, spiritually safe; great. That funding model that we have currently to provide that is just absolute gold. That is changing the landscape a lot.

We are working alongside a lot of care providers who are not paediatric orientated at all. As soon as you leave the south-east corner, you often do not get a paediatrician. You certainly do not get anybody with paediatric palliative care experience—unless they have seen us before. To then support an away team means that the expertise from here goes alongside with role models and teachers in time. We know that the literature tells us that in-time training, on the spot, related to a case is the best way for health professionals to learn.

They may not see another case like this for a year, or two years. Our last case on Thursday Island was probably a good two years ago. The health professionals rotate, so you are not going to see the same cluster of health professionals you saw at the last visit. You are having to do that all over again. I think our current model where we are a pop-up, federally funded model gets away a little bit from the jurisdiction stuff. As much as we are paid by the state government, the flights and the additional costs are paid by the federal grant. That is giving us a bit more licence.

We have to be invited to these away centres. We do not just turn up randomly. This is changing the family's outcome for the long term. It is huge. It also supports the on-site, local providers, whether it is a school that needs some follow-up support to look after the rest of the siblings. The ripple effect of an ill child is huge. We want our whole community to be able to better support bereaved families through the loss of a child in any circumstance.

CHAIR: Thank you. That is a really well-articulated case. How long have you been established?

Ms Pedersen: We have been about 13 years now.

CHAIR: That recurrent funding is locked in? It is not going to go away?

Ms Pedersen: We are putting our new proposal in now. This will be our third round. For this round, we have had an invitation to the funding, which is very lovely. We are hoping that it is a bit more of a given than previously, where we were in the pot with everybody else. We are desperate for that funding to continue as a national body, because it has just really improved our services.

Paediatric palliative care is a very specialised subspecialty. The impact on our community members is huge. The loss of a child is just so significant and it will roll into further implications in adult care. We feel the pressure much of getting it right, because we only get one go. We want to make this terrible experience for this family the best it can be, so using all of these models has proven to be absolutely worthwhile.

CHAIR: I put on record the great work that you do for Queensland. Thank you for that and I wish you well with that funding application.

Ms Pedersen: Thank you.

Mr HUNT: I will direct my first question to paediatrics. If I read the statistics right—and correct me if I am wrong—the number of children per 100,000 requiring palliative care is increasing.

Ms Pedersen: Yes.

Mr HUNT: Could you expand on that?

Ms Pedersen: The complexity of who we are seeing is changing a lot. In childhood cancer, a standard leukaemia patient now has about a 95 per cent chance of survival long term, which is very different from when we started this specialty a number of years back, which is amazing. However, we are seeing in the neonatal nursery and in children's ICU a lot more interventions, both surgically and in medical management. Medication management is improving no end. A lot of children, or neonates under 28 days, may well have succumbed to these conditions or rare scary events much earlier in their lives. Now, there are a lot more surgical techniques for heart—cardiac. We know that, say, a hypoplastic left heart baby—a baby born with a very poor pumping side of their heart—can go forward now and have three-stage surgery with fewer and fewer complications as time goes on with surgical improvements. We know that those children still will not survive to adulthood. It is a palliative procedure. Those kids are becoming a whole cohort. They are not eligible for a heart transplant still owing to the nature of their condition. We are seeing really changing, more complex cases.

We now have the challenge that some of these kids have survived so well in childhood that they are needing a transition to adult services. That is a whole gap in itself. What do we do with these extremely complex paediatric patients who are ageing out of our team and needing to join the adult services and they are not ready to meet these kids yet? This is the whole dilemma that we face now.

CHAIR: Is some of that attributed to advances in in medicine?

Ms Pedersen: Absolutely, in both surgical and pharmacology—across-the-board. A lot of these tiny infants who would have otherwise succumbed to some dreadful birth defect or something are not. We are meeting them as palliative care patients.

Mr HUNT: The irony is that the statistic on its own looks like it is bad news, but it is actually an extension of life in a lot of respects.

Ms Pedersen: Yes, and these kids live with extremely complex medical conditions and benefit from a palliative approach. The families may be very clear that they do not want any more suffering for the child, but want them to live the best they can be. That is where the palliative care remit fits in. They still remain with their primary teams—their oncology, or cardiac teams—but we are adding value and helping them be in their away centres a bit longer. That is where we are fitting in with these kids as well. Every time it is 'No, he's too complicated for us, we'll send him out on a helicopter,' by calling in the service we can often work with them. We are not the acute people. If he has some sort of dreadful acute condition, yes, it is appropriate for him to come on a helicopter to the tertiary centre, but a lot of families are extremely resourceful and can manage these kids. They know them intimately. Having a helpline where they can talk things through is just saving presentations absolutely.

Mr HUNT: Professor Good, before I ask you a couple of questions, can you put your experience in palliative care on the record for us?

Prof. Good: I have worked in palliative care for 19 years. I am a director of palliative care at St Vincent's and I am a palliative care specialist at the Mater Hospital. I am a professor of palliative care at the University of Technology Sydney and an associate of professor of palliative care at the University of Queensland. I trained in Brisbane, Newcastle and Melbourne. I have worked in Newcastle for about seven years. I was acting director there for a year at the Hunter-New England area health service before coming to Brisbane.

Mr HUNT: In those 19 years, is it fair to say that palliative medicine has come a long way?

Prof. Good: Yes, I think there have been lots of changes in palliative care.

Mr HUNT: Has it hit a plateau? Medical science seems to be skyrocketing in a lot of fields. Is palliative care one of those fields where we are still making advancements in how we care for people, or has it hit a peak?

Prof. Good: No, I think there are lots of advancements happening and they are ongoing. In health care, there are two different interesting ways of looking at advancements. One is this idea of new medicines and new things. We are certainly involved in different trials of different medications to try to improve symptom control. The other area is this idea of processes, or reliability of care, and models of care. I think that is where the most value is going to come over the next 10 to 15 years. A lot of money is put into new drugs, which are exceedingly expensive, that will help some people but, if we are looking at a population base, it is about how can we improve processes, how can we improve reliability, how can we try to make each person's experience as good as possible, which is a thing that we try to do every day in medicine.

Mr HUNT: Over those 19 years, you would have seen a lot of people in the dying process in distress and families in distress. There is now the call for voluntary assisted dying. To what extent is dying physical suffering as opposed to existential, or psychological suffering, even from the point of view of families watching somebody suffer and their perception of what is going on or what the reality is? We are hearing a lot of stories through this process of people who watch family members die in what they considered to be a lot of distress and pain. Can that be a perception and not always? Can you comment on that?

Prof. Good: Dying is a really tough time for everyone. It is tough for the person dying, obviously; it is tough for the family around. The story that always sticks in my mind is earlier in my career I was looking after a man who had a particular type of cancer which meant he was short of breath. He was really fearful about dying from suffocating. Interestingly, a lot of people who are dying of cancers or other illnesses that cause shortness of breath will not say to you that they are fearful of suffocating but if you ask them almost everyone says it, but it is almost that sort of real fear. He said to me that his dad actually had the same illness and he said, ‘I am really worried. My dad had a terrible death. He died short of breath and I am really fearful this is going to happen to me.’ Obviously everyone could understand that if you had seen your dad die that way.

Interestingly, I spent time with him—he was there with his sister—and afterwards his sister said to me, ‘You know what. I was at the same death and to me it was a peaceful death.’ On TV sometimes you see people die and people think dying is a sort of romantic, peaceful event. I do not think it really has ever been like that as such. I think there are a lot of reflex breathing things that happen at the end of life that, if you are not aware they are going to happen, can be very scary. We do not think that a lot of those reflex breathing events at the end of life are actually painful or suffering to the person, but if you are not used to seeing it or if you are not aware it is going to happen or even if you do hear different noises it can be very hard.

I will give you another example. I have seen lots of people die and one of the things that can happen sometimes, not to everyone but to some people at the end of life, is they get what is called the death rattle figuratively in society, but what is now called respiratory secretions at the end of life. The vast majority of people in that situation are unconscious and we do not think, although obviously it is very hard to know, that there is any suffering involved with that, but I still find that disconcerting hearing that when I see someone and I have seen literally more than a thousand people dying. I still find that experience disconcerting. I still think from the point of view of the person that they in most cases are unconscious and are not suffering at that time from that, but I am suffering when I hear it and family members. Interestingly, some people are not worried about it one little bit and other people are very distressed by it. I think it is fair to say that there is a really variable experience and response of how dying affects us all.

Mr HUNT: A very important part of palliative care is communication with the family and with the person themselves about what to expect and what things mean and what they might be going through.

Prof. Good: I think it is the most important thing. I think it is the most important thing to explain what is happening. I think a lot of people want reassurance that what is happening is not suffering for that person. I think one of the most important things is to say we think this actually seems to be causing some distress and this is why we give medication for it, we think this experience or some reflex breathing patterns are reflex and are not causing distress and does not mean suffering. I think that is a big part of what we do in an inpatient palliative care unit or looking after people at home.

I think the other thing to say about dying is how much courage people who are dying have, how much courage and how much great community effort people have in looking after people who are dying. I think we really need to acknowledge just how hard work it is for people to do it and how lucky people are to have people around them who do do it so they can die in the place they want to die.

Mr HUNT: I acknowledge a lot of nodding going on there, Lee-anne, and I will invite a comment from you as well, but I imagine with children particularly there would be a lot of love and family around them which might be different for older people.

Ms Pederson: I think that is true. I think it would be a rare event for us to be involved with a young person perhaps or a child who does not have love of some description surrounding them. I think the expression of suffering has a heavy cultural inference as well. I think it is all about people’s life experiences. The meaning in the death of a child is very different to the meaning of 98-year-old grandma, but if 98-year-old grandma was the matriarch of a huge Greek family then it has a very different meaning. I think it is really hard to tease all of that out. I think the best part of working in this field is that each family and each patient you meet, regardless of age or scenario, is very different, which is where I think the laws and legislations need to be really sound because I think each case is very much an individual case.

Mr O’ROURKE: Firstly, thank you for being available this afternoon. My question is to the representative of St Vincent’s, given the large aged-care provider you are. How many of the people who come into aged care actually have an advance healthcare directive in place?

Mr Hall: Off the top of my head I cannot answer that. I would be happy to give the committee a report back.

Mr O'ROURKE: Would there be quite a few who do?

Mr Hall: Certainly the last study I saw across our facilities is around 10 to 15 per cent have clear directives. In some of the aged-care facilities it is higher than that, but it is not as much as you want it to be.

Mr O'ROURKE: It does appear to be an issue across the state. The AMA spoke earlier about Fifty over Fifty. Their target is 50 per cent of people over the age of 50 having an advance healthcare directive in place. How do you think it would be best to promote that to get more people to put that in place?

Mr Hall: I think firstly it is like any other public awareness issue. I think there needs to be significant effort put into the concept of dying as a whole in our community and part of the reason we are having these inquiries right across the country is because we are confronted by the concept of dying. Secondly, I think we need to actually make sure the right people are talking to people in aged-care facilities and hospitals about the concept of advance care planning or advance care directives. That is not necessarily a clinician. One of the things we put into our submission is this concept of wellness hubs to help people through the concept of how do I plan for dying. The reality is one of the sure things in life is that it is going to happen to all of us. Most of us do not actually want to go through a planning process and talk about it.

When it comes down to it, I cannot see any reason you would not be saying in aged-care environments that there should be a mandatory requirement for advance care planning for all people who have come into aged care where they have a considered and supported process either with social work trained individuals or people who have specialist end-of-life training to assist them through the process because you need to understand some of the issues which are going to face you. One of the complexities, and we look at advance care planning as quite a simple process, is that the reality is what I feel today about the end of life may be very different from what I feel two weeks away from the end of my life. It is a continual process. Whilst you can have some form of directive, it is very important to ensure that that can be adapted and people can talk through that with their clinicians and care providers right throughout the process. Queensland I think, particularly because you have electronic medical records rolling out right across the state, is in a good position to actually make sure those can be provided into aged-care facilities as well to ensure that people have got up-to-date, good information based on where their health is at that particular point in time. I would certainly encourage looking at that.

One of the failings of VAD around the world has actually been because of advance care planning where people have written a directive before a disease has had an onset and then they have had the onset and then actually they do not necessarily want to follow through with the advance care directive they set and so it does need to be a continuous process. I would support, particularly I think in the aged-care environment, that there needs to be a larger effort to get people involved in it. We believe a model of wellness hubs to help people talk through end-of-life is a powerful thing.

CHAIR: Earlier you spoke on connecting with the US health system in relation to the model that you are building in Melbourne. I do not know what that looks like. Were there learnings from there in regard to health navigation that you took on board to land on this model?

Mr Hall: I think definitely there are some good learnings. Atul Gawande has written really well on the concept of dying and I would recommend anyone who is looking at this issue to read his work.

CHAIR: Who is that?

Mr Hall: He is an American clinician and one of the most interesting things is he has looked at the concept of death and people's response to it. Where that is playing out in America, which I think is really good, is firstly the concept of training clinicians on a wider basis than they have been trained to date. A lot of clinicians—I apologise if I offend any clinicians, but we assume clinicians all know about end of life and dying. The reality is that a large number do not. In fact, palliative care experts do, but there are plenty of clinicians in hospitals who do not have vast experience in that field. Making sure clinicians understand the issue is important. The second thing is actually getting clinicians, and America is doing some really good work around this, to look at the concept of what is a good end of life for someone. We have seen I think a trajectory in the last 15 years of massive investment in drugs, very expensive drugs, which sometimes extend life for very short periods of time rather than actually talking about an investment in end of life and good end of life.

The reality is where palliative care is going today is not only about the last three or four days of life, which is what everybody thinks, but it is actually the last four, five years of life; saying how do I have a good end of life. What each of us want individually is different. I might want to have a good six months with my kids and die, some other people might want to fight on through every process, every drug, every treatment and then die. Having honesty in that process and training clinicians to have those discussions with people is, one, what patient centred care should be about, but, two, actually avoids massive expenditure in the health system on highly costly drugs which actually are not treating what the person wanted. Having a process to train clinicians to talk to their patients is important.

Where they have approached this in America, which I think is really exciting, is around this concept of wellness hubs and actually in-hospital health coaches who can come alongside people and talk them through what is going to happen from where they are today towards the end of their life and actually talk about their aspirations and hopes. When you talk about palliative care, a classic example I had is that a man in one of our facilities was really struggling, in massive pain through his palliation, and the clinicians were doing everything they should be doing to stop pain, to manage his illness and it was not until someone who is a health coach and a social worker sat down and said to him, 'Can you talk through what your aspirations are.', they found out that the only thing he wanted before he died was actually to reconcile with his son. Once he had had this discussion they actually went through a process to reconcile him with his son. From that point onwards literally his pain dissipated, his treatment was far easier and he ended up with a very gentle death because someone had talked through what he hoped for and what his aspirations were.

Having a model with health coaches, which they are really pushing now in America I think and Canada, is something which can help people make good decisions about their own health care and the right way for them individually to die because it is a personal choice. It is actually low cost, can avoid really complex medical interventions at times and it is something most of our clinicians are not trained in. Firstly training clinicians a little bit about end of life and how to give people choice, but actually then putting people alongside patients to help them through the journey I think is a powerful thing.

CHAIR: It is almost like the nurse navigator.

Mr Hall: Very similar.

CHAIR: Define what a health coach is? I have not heard of that before. Is it a medical based position?

Mr Hall: Interestingly enough, and this is confronting for me in my role, a number of people doing that work are not actually medically trained. What they are trained in is helping people talk through the issues which are important to them towards the end of their life and they work with the clinical team then to define the right treatment protocols for that individual. Most people coming into our healthcare environments do not understand treatment particularly well and it is almost someone who is translating between the patient and the clinical team the aspirations of that person.

CHAIR: The health literacy side of things.

Mr Hall: Yes.

Ms PEASE: Thank you everyone for coming in. I really appreciate you giving up your time not only in being here but also the wonderful submissions that you have made. I just wanted to ask Lucille about the project that you are working on with COTA and what that actually looks like?

Ms Chalmers: Happy to. We are one of 60-plus trial sites that are trialling three different models of these aged-care navigator roles. As you alluded to before, the term 'navigator' is being used widely but meaning all sorts of different things. In this particular trial there is a focus on working with established and trusted community groups to provide advice to people who are seeking it to enter into the system. Our particular model is working in two areas, mainly in Logan and Redlands, and we are working with community centres that are the hub of those communities with all sorts of activities et cetera. We have trained up a couple of their volunteers and they then act and provide advice about what the aged-care system is, what My Aged Care is and there is an opportunity for one-on-one advice on how to fill out the forms, for example, and to get into the system. More broadly than that, we are also providing, again, general advice going to libraries and other places where older people gather to give them some of that first line information about how My Aged Care works.

Ms PEASE: That is live? That is actually happening?

Ms Chalmers: That is live now. It kicked off in January. There is an 18-month trial. I should just say the third plank of that that we are also implementing is a specialist support worker. For those people with particularly complex needs—that may be language that is not English, it may be a homelessness issue or something that really makes it particularly challenging—we have more of a clinical role to support them through a one-on-one approach to move them into the system.

Ms PEASE: One of the experiences that I have had personally—and it was some years ago, so things may have changed—was navigating the services that were available to people who need assistance in the community. With regard to my parents, my father was ill and dying and we needed to get some advice about where we could access some support and we went to his GP, who was a longstanding GP in the area, and he said, 'There's nothing available.' Just because my father had three tenacious daughters, we knew that that was not going to be the case and we found out there was. Is there training made available to the GPs out there to let them know what services are available in the community?

Ms Chalmers: That will differ in different areas. As part of our work we are doing exactly that. It is really challenging for GPs because they are so often the first port of call and there is an expectation that they would know. As any GP will tell you, they are expected to know about absolutely everything in the same level of detail. One of our roles as a PHN is to try and make that information as accessible as possible for them.

Ms PEASE: For the GP?

Ms Chalmers: For the GPs. The other tool we have available to us—again, this is across the state—or our version of it is a health pathway. There is an online pathway where a GP can literally hop online and say, 'I've got a patient with condition X. What do I do next?' That is also the case for aged care.

Ms PEASE: Are you aware if GPs are taking up access to that information? Are they making use of it?

Ms Chalmers: We have had a very strong response to the training that we have made available and it is necessary for that training to be delivered in a whole range of different ways. GPs cannot always make themselves available to attend that sort of training, so making the system more accessible for GPs and other front-line primary care people is something that is a gap and can continue to be addressed by My Aged Care itself.

Ms PEASE: Finally, with regard to the training and the education that you provide to GPs through the PHN, is that time allocated as part of their professional development or can they claim it on Medicare? Is there any incentive for them to undertake it?

Ms Chalmers: It depends. The way that is delivered depends on how the information is structured. In this particular example it is not, but for a more sustainable approach it would absolutely need to be.

Ms PEASE: Thank you very much.

Mr McARDLE: I thank all of you for being here today. I start with the staff-patient ratio issue that has been raised on several occasions before this committee. There is at the moment a nurse-patient ratio in Queensland Health hospitals, but it is important to understand the background to that. They only apply to surgical or medical wards and only in designated hospitals, so you would not find the hospital at Aramac having a nurse-patient ratio for obvious reasons. Queensland Health also have data going back a very long period of time, so they can historically indicate almost day by day what their cohort will be and work that through. Here it seems to me that the staff-patient ratio does not have any parameters on the facility type or the number of patients or residents within it.

The other point is this: if I have a 60-bed aged-care facility but next to it I have a 60-bed facility—10 hostel beds, 15 dementia beds and 35 aged-care beds—should that ratio be the same? If it is going to be the same or not the same, who sets that standard? Clearly the surgical and medical wards can be looked at historically, but I would have thought it is very difficult to compare apples with apples with the two cohorts I have described. Can somebody comment upon how we get around that—that is, not nurse-patient ratio but staff-patient ratio? I will then ask you other questions as well.

Mr Hall: I can certainly refer to that from an aged-care point of view and I will let Phillip talk about it from a palliative care point of view. We are doing a lot of research on this at the moment and what we have found in the aged-care environment as standard is that the quality of staff is far more important than the volume of staff and it is actually having staff who understand at one level about caring for people, because aged care is called that for a reason. It is about caring for individuals. It is about providing a loving and empathetic environment. Looking at staff who have that characteristic as part of their make-up is absolutely vital and we are going through a process to determine that. We have a testing tool to assess essentially for empathy because a staff with empathy is far more important than 20 staff with no empathy. That is one issue.

In the highly complex dementia space I think there is some merit in mandating both quality of qualification and volume of staff in dementia fields, but even in that environment it is difficult because we often assume that dementia is this kind of blanket illness that is the same every day. A dementia patient can be fine one day and really bad the next day, so the treatment and model of care needed on Monday is very different from Tuesday. That said, broadly speaking you could certainly say that you could go through a process to identify staff ratios in that environment, a bit like we have done in the acute elective environments and we were doing with mental health patients. In standard aged care I think it is all about having highly qualified staff who understand the concept of care. From the medical practitioner's point of view, I do not think it needs to be a certain number per bed. It needs to be based on the facility and the complexity that the facility says it is going to take. I will let Phillip talk on palliative care because he understands that much better than I do.

Prof. Good: I am not sure I understand a great deal better, but you are talking about nurse-to-patient ratio in palliative care?

Mr McARDLE: No, not nurse to patient but staff to patient.

Prof. Good: Staff to patient.

Mr McARDLE: It may well be that RNs may be one, two or three, but the issue I have is two facilities where the bed numbers are identical but the mix of patients is quite significantly different. How do you come to a ratio? More importantly, who sets the ratio?

Prof. Good: I think at the moment in facilities the facilities set the ratio as far as I am aware of that point of view. I do not think I have much expertise in terms of working out what it should be or how you set it, except I think what Toby said about the quality of the staff is really important and I would think that that is one of the most important things. I think it is a really good question to work that out. I am not sure if I have expertise in answering it though.

Mr McARDLE: Thank you. Lucille?

Ms Chalmers: Yes, I would support all of those comments particularly about the quality of staff. Recruiting for attitudes, mindsets and compassion is absolutely something that is vital. In terms of the number of staffing, it is set by the facilities as I understand it and there is no guidance through what is currently the assessment tool for the residential aged-care facilities, the ACFI, but there is work being done around that funding model at the moment and I am not sure whether that will lead to some indications of staffing models that reflect complexity within the facilities. There is no doubt, as someone mentioned earlier, about the level of complexity of residents. That is increasing, so in terms of the mix—that does include RNs plus a range of other health professionals—it is important to have that mix right and to have it reflect the actual needs and to have flexibility in the way the facility is run to be able to mix and match as the residents move in and out of the facility.

Ms Pedersen: I agree with everybody else's comments. I think trying to get the staff care ratio in any facility, even in our children's hospice, correct is a very big challenge when there is not an overall governance to that in any shape or form, so I am looking forward to some reforms. I am looking at my parents needing some care, so I am hoping some reforms are seen soon. I do not have the answer to that, I am afraid.

Mr McARDLE: The question I have in my mind is that we can certainly agree on a principle, but how that devolves down to Longreach or Caloundra, where I come from, is very difficult to assess and it may well be that our desire for a particular outcome will differ by way of what we put in place from place to place as well. The other point is this: if we have a standard staff-patient ratio—not nurse-patient ratio—it has always been very difficult to get people to move from the south-east corner into western and remote Queensland because it is just not the person themselves. It is their partner or their spouse. They have to give up their job, as it might well be, move to a new area and hopefully find a job. The two children go with them for a certain period of time. With doctors in years gone by, when the children get to grade 7 they go back from where they came from because they perceive—incorrectly—better education facilities. Even if we put in place a regime to establish a ratio, how do we incentivise staff of all levels such as RN, AIN and EN, let alone palliative care medical physicians, because you will not get them in Longreach? How do we incentivise people to go out there and stay there given the trouble we have had in the past of trying to retain doctors in Queensland Health in regional Queensland?

Prof. Good: There have been a number of different ways of looking at that. The first thing obviously is intake into medical schools. If you come from a rural area, you are much more likely to go back to a rural area. That is the first thing. If you are looking at an area like palliative medicine, it is not attractive to go to a single site as a single doctor in a specialty area and then either you are on call 24 hours a day or you are never on call because you decide you are never going to do that. Some places around Australia have looked at this. Obviously the population is growing in most areas and I do not think there should be any single palliative medicine specialist anywhere in any place. They should all be a part of a team and there should be more than one person because it is not really feasible.

One way to look at it is that you need to look upon it as you should not have single people and you should have it set up as two people, either part time or full time, and that is from a retention point of view. I think you will find that almost all of the places around Queensland where the single people have been there for a while it is very hard to keep people there for a very long time because it becomes unsustainable. Where you have more people in a team it is much more sustainable, but the downside to that is it costs more money. Rather than seeing rural areas getting less money because they have fewer people, it should be seen as it is more expensive—sometimes—to do health in those areas and that should be the way it should be funded. You should accept that from that point of view if you are going to provide a service to those people. The alternative is to not give people as good a service as they get elsewhere in the state.

Mr McARDLE: Which happens now.

Prof. Good: Okay.

Mr McARDLE: I am from the Sunshine Coast with a $1.8 billion hospital. There is a palliative care unit at Caloundra with 14 beds going to 18, and that is one of the primary palliative care units. In Longreach you would not get that level.

Prof. Good: A good example is the Sunshine Coast and the settings of that. My understanding of the palliative care unit there as a stand-alone facility is that they had to employ more junior doctors to enable the facility to operate 24 hours a day and they took that on board to do that whereas other places obviously choose not to do that. It can be done and at a specialist level subspecialties generally need to be supported with more than one person.

Mr McARDLE: Are there any other comments about the issue about how you incentivise not just physicians et cetera but also nursing staff et cetera to go out to these areas?

Mr Hall: I lived in rural New Zealand, so I know exactly the situation you are talking about. It is very complex. In relation to aged care, and even in some of the work needed in palliative care, the reality is that the concept of empathy and compassion is the base of what is needed to deliver good services. A number of communities have people who have that capacity but need the training and support to develop. We are going through this with Indigenous staff across our health systems now. Everybody said it would be impossible to find people, but when you find people with the right attitude you can give them the training in their community to stay in their community. There is absolutely no reason you cannot take someone in as a personal care worker, move them up to an AIN—some of them to ENs and RNs—in their community. That needs training and investment, the right attitude and the right leadership.

We are certainly putting that focus in our community. We want people from the local community. We do not want people to come in from outside all the time, because we know they are going to go. To be honest, it is the same in Sydney and Melbourne. They are going to come in and then they are going to clear off. If we are going to invest, let us invest in people who have the right attitude and who want to stay in the community because they love the place. We can give them the skills. I think there is absolutely an emphasis that can be put on that.

We have brought the universities in. In Victoria, I think we are using the Queensland university to train people in our hospitals to be an EN from an AIN so they do not have to go somewhere else. They do not have to go to university; they do it in their work time in our facility. They are staying with us because they like us and they know we care, and I think that can be put into place in regional areas. Certainly in New Zealand we put a lot of focus into that.

Mr McARDLE: We can certainly look at a real generalist model and moving forward with that to incorporate nurse practitioners, RNs and the like.

Mr Hall: Absolutely.

Mr McARDLE: Over time that would be a way to develop a local cohort who stay in the local area. Would you agree with that, Lee-anne or Susan?

Ms Pedersen: Travelling all over the state these days, I have encountered some amazing rural and remote centres that are doing a fantastic job with very limited resources. To invest in those folk who are invested in that community and care for their cohort of community members, I cannot get that in the city anywhere, so that is amazing. You really want to tap into that and utilise that better. When you create new positions you create a shared model so that one of you can tap in and out, because it is very hard to be on call for an exceptional amount of time. Maybe look at the funding model for a GP or a doctor to get education. How do they come away from a busy clinic to see you for 40 minutes if they do not get funding for that? That is definitely a challenge. For nurses, some of it is built into the award, which I think is really helpful, but getting people to backfill for those positions in Augathella, for example, is all but impossible. I am not sure of the answer to that, but some of that built into the award of the different health professionals is very helpful.

Mr McARDLE: Would you agree that a lot of work has to be done to massage the outcome in relation to staff-to-patient ratios? Simply putting it out there like that and saying, 'It's got to happen' could create a lot of problems going forward.

Ms Pedersen: I think so.

Mr McARDLE: One of the things that struck me early in this inquiry was the future use of technology in aged-care services, palliative care services and the like. I am not talking about tomorrow morning, but as time rolls by AI and the like will have a larger say in relation to how aged care and the like operate. Can you comment on the future of technology in this space across the spectrum?

Ms Pedersen: Currently, we are using technology to the best of our ability from the city sites to the away sites. A lot of the away sites are very tech savvy within the limitations of the availability of internet services. Some of them are still very isolated in that technology space. That is real. Out in remote Australia connections are still pretty ordinary. We have a lot of work to do with that. I get a lot of great internet service here in my apartment, but out there locally that is not true. We still have some work to do across the nation in relation to that. These days everybody has a phone. Everybody FaceTimes everybody about everything, so I think building that into some of our care profiles is going to happen by default.

Mr Hall: There is some interesting technology coming into the market, particularly for aged care, and it is happening in the health industry. The interesting thing is that, if you look at a country like Japan, which has a massive ageing population and not a good younger workforce, they are dealing with some of the complexity around staff ratios with some really quite interesting technology. Some of it is a bit frightening. For example, using robotics to help move and carry people is something which is absolutely feasible, and they are already doing it now in Japan because they do not have enough people to help with transfers. The use of technology to enable a caring staff workforce to do the work with fewer people is something which is probably inevitable as part of our system in the long term. I would caution though, particularly in aged care, that the heart of aged care, in our view, is outcaring for people, and that is the one-on-one interaction with people.

There is some really good technology in terms of comfort for people with dementia. We are already using robotics in some cases to help people be calm. There is great technology in terms of spaces people can walk into to change behavioural attitudes. That is technology. That is moving and will become part of the future. We do the most advanced robotics work in Australia in the medical system. The heart of it, though, is about caring for people and the technology is only ever an enabler. It will come. There is some brilliant work around videoconferencing, but I echo the points made here. We are doing work in very remote areas and it is very difficult. Everyone said that teleconferencing is the answer and it is nirvana. The reality is that when you are in the middle of nowhere with really bad technology it does not make any difference at all. What does make a difference is when someone like Phillip contacts a local clinician who has had some training in palliative care to say, 'This is what you need to do following the training we did.'

Ms Pedersen: Or a pop-up. The goal is that you have a face-to-face at least once on returning the patient to their local site, and then they will engage with follow-up by phone. They say face-to-face in the first instance, but we are still humans at the bottom of all of this, so promoting that in-time response. How do we do that across different jurisdictions and HHSs with the politics of that, bringing the speciality that you need at that time in a timely response to your remote areas? We will keep working on that.

Ms Chalmers: From a primary care perspective, one of the challenges for general practitioners to be involved in what is fairly simple telehealth medicine is the funding model. There is still a reluctance to be involved. Perhaps the level of logistical support in terms of implementing that model means it is not really being used to its fullest potential at the moment, but I think there is potential for that to happen. The other area where technology desperately needs to be supported—it exists, it is just not implemented—is in terms of information sharing. We still have this difficulty where the primary care physician or the GP has a certain amount of information, the hospital has another lot and the facility has another bunch of information. None of it is integrated at the moment. That technology exists; it is just not being implemented. There are barriers to that.

Mr McARDLE: The advance health directive has been spoken of by several people here today, including the AMA and yourselves. It seems to me that the public are not taking that up in great numbers, which would alleviate a lot of concerns going forward in relation to their medical care as they come towards the end of their lives. Would you agree that a strong education program needs to flow as part of the recommendations from this committee to ensure that we get that out to the public and they understand what can be done? Secondly, should there be a central database outside of Queensland Health? Because private hospitals and aged-care facilities all have reason to access a document of that nature at different times.

Mr Hall: The answer to the first question is yes, you absolutely need an education platform. I do not think you could answer otherwise. The concept of having centralised information along the lines of My Health Record is important, because the reality is that people access a whole range of different facilities. Being able to understand that there is a centralised portal to access their advance care directive would be a helpful thing across the health system, there is no doubt about it.

Prof. Good: Queensland actually leads in advance care planning in terms of they would have the most advance care plans. An advance health directive is just one document on the whole advance care planning platform. What we have learned is that documents do not always work—planning does. Whilst it is easy to get a document like an advance health directive and say, ‘This is how many are done,’ what is really important is to have had a conversation and to have some advance care planning done. Even if you are just telling your spouse or someone else, ‘This is what I would like’, that is a real step forward. I do not know the numbers. I know the advance care planning people have presented to the committee. Queensland, as far as I am aware, has the most number of advance care plans on a central database in Australia, including statement of choices and advance health directives. The reality is that there is no uniform advance care planning legislation around Australia. That has been proposed for a long time, but the states and federal government do not seem to have got together on that. The advance health directive is a very legalistic document and the statement of choices is certainly much more taken up by people.

Victoria has moved towards a similar sort of thing which is much more value based about what is important to you. Around that, that is much more important. As Toby was saying, it is hard to navigate those documents on your own if you are just given them and told, ‘Fill this out.’ If you are older and you are not sure what this is—even if you are younger and you are not sure what this is—the value of all this is having someone just spend some time with you. There was a study done in Victoria many years ago now which showed that just by offering to have a conversation on advance care planning with everyone over 65 who came into hospital there was a very large increase in the number who took hold of that conversation. A lot more of those people died where they wanted to die. A lot more of those people died outside of intensive care. Interestingly, one of the things that came out of that was that people’s rating of their experience in hospital was much higher just by having someone talk to them about advance care planning. It is just an offer. I think it is a multifaceted approach in relation to people who are most likely to need one, which is people who come into hospital and leave, and then the community in general along the way.

Mr McARDLE: My final question is to Mr Hall. Earlier you referred to different models of care. Do you have a document that we could look at which outlines what you are talking about, how they apply the potential staff ratio et cetera?

Mr Hall: Yes, we can definitely provide some information on the model of care work we are doing.

Mr McARDLE: Could you do that within 48 hours? I do not know whether you have a document or whether you are talking about collating documents together.

Mr Hall: We will do our best to give you something in 48 hours.

CHAIR: We will take it on notice and we will give you five days. Thank you all for the work that you do and for your significant contributions in better informing the committee in our important work going forward in all aspects of this inquiry into aged care, palliative care and end-of-life care. It has been great to have you here.

Proceedings suspended from 3.27 pm to 3.41 pm.

GREENWOOD, Ms Suzanne, Chief Executive Officer, Catholic Health Australia

HART, Mr Michael, Chief Mission and Identity, Southern Cross Care

McINTOSH, Reverend Dr Adam, Associate Director of Mission, Uniting Church, representing the Queensland Synod of Uniting Church Queensland

McWILLIAM, Reverend Linda, Anglicare Southern Queensland

PRICE, Mr Francis, Director, Southern Cross Care

WEBBY, Ms Glenys, Director, Industry Service Reform & Innovation, UnitingCare Queensland, Uniting Church in Australia Queensland

WOOD, Ms Leanne, Research, Social Policy and Advocacy Advisor, Anglicare Southern Queensland

CHAIR: Welcome to all of you. It has been a massive day and it continues right into the evening. I welcome the next group of witnesses. I will start by asking you to each make an opening statement before we move into general questions. Reverend Linda, would you like to start?

Rev. McWilliam: Thank you for the opportunity to be here to speak on behalf of Anglicare Southern Queensland. I just want to note that I am not a healthcare practitioner; I am a spiritual care practitioner and will be speaking from that perspective. I would like to acknowledge the traditional owners of the land on which we stand, elders past and present and those emerging, and give thanks for their care of this land.

You may have noticed that there was a strong thread that ran through our submission about the power of narrative, both positive and negative. We talked about the story society tells our older people about being a burden on society and a problem to be fixed. There is a story about how death is to be resisted with all the clinical expertise we can throw at it regardless of whether that is what people actually want at heart. There is the flip side of those stories that recognises the value of people’s life stories and what it means to people in their final weeks or days of life to have the opportunity to share their story with people who have the time to listen. These are the things that contribute to a good death where we can look after people physically, socially, psychologically, culturally and spiritually. Everyone has the right to this—of every age, location, sexual preference and cultural background.

Our submission calls for individuals and their families, during this final, most challenging phase of life, to be placed right at the heart of end-of-life and palliative care services so that every Queenslander can have the good death they deserve. I could go on and say a lot more, but I am hoping that you will ask me some questions at pertinent times and I might be able to fill you in. I was very interested in some of the questions in the last session and I could have contributed to some of those. Are you happy with that short opening statement?

CHAIR: Yes, thank you very much.

Rev. Dr McIntosh: Thanks for the opportunity to be able to share with you and thank you for the important work that you are doing as a committee. It is a big task and looking at your schedule today as an example I think you have a lot to think about. We appreciate the work that you are doing.

The Uniting Church Synod of Queensland has significant involvement in health, aged care, end-of-life and palliative care services across Queensland through UnitingCare and Wesley Mission Queensland. The Queensland synod is committed to witness to the God-given dignity and worth of every person in every circumstance of life. After consultations with our communities, in May this year the Queensland synod made a decision to not support the legalisation of voluntary assisted dying in Queensland. If legalised, our health and community service agencies, UnitingCare Queensland and Wesley Mission Queensland, will not provide this as a service and our staff, in the course of their employment, will not participate in medical acts intended to end a life through voluntary assisted dying.

We recognise that in some situations the experience of end of life can cause significant distress for the person dying, their family as well as care staff. While we do not support voluntary assisted dying, if it is legalised, the church is committed to offering compassionate and pastoral support to people and families who choose this path. This support does not include medically participating in acts intended to end a life through a voluntary assisted dying process.

We want to highlight the following areas from our submission. If voluntary assisted dying is legalised, we strongly believe that conscientious objection provisions for organisations and individuals need to be included in any legislation. It is important that organisations have legal clarity to conscientiously object to acts that are contrary to their stated mission, values and beliefs. We also argue strongly for multiple safeguards in any voluntary assisted dying scheme, including a compulsory counselling service, a psychiatric assessment or other relevant specialist assessment to verify a person's decision-making capacity and ensure that their choice is truly voluntary, and a period of at least two weeks between completing the application process to access voluntary assisted dying and the final administering or prescribing of a relevant substance.

Even if voluntary assisted dying is legalised, the majority of Queenslanders will still need and have a right to access high-quality palliative care. The Uniting Church Synod of Queensland affirms the critical importance of high-quality, well-resourced and accessible palliative and end-of-life care that responds to the physical, the psychosocial and the spiritual needs of people at the end of life. People can and do have good deaths in Queensland and more often than not, this is facilitated by access to high-quality palliative care. By working with people early, relief and prevention of suffering is possible through assessment and treatment of pain and other physical symptoms.

Psychosocial and spiritual concerns also need to be worked through and addressed. This is especially important for end-of-life and palliative care in enabling people to work through issues of meaning of life, legacy, restoring relationships and preparing emotionally and spiritually to be at peace with dying. Excellent palliative care needs to be delivered by multidisciplinary teams of medical, nursing, allied health and pastoral care staff who are able to work flexibly with people in the setting of their choice.

All of our agencies' palliative and end-of-life care services are struggling to meet demand, and models for community based palliative care are often changing, underresourced or non-existent. Our health, aids and community care systems need to be appropriately resourced and flexible so people are placed at the centre of care and are able to get support in the setting of their choice.

We welcome the Queensland government's announcement last week of increased funding for NGOs delivering palliative care in the community. More work needs to be done, however, supported by adequate ongoing funding to create a fully integrated and sustainable palliative care system that can support the community into the future. Actions to progress this are discussed in our submission.

With regard to aged care, the needs of older people are best served by a health and aged-care system that is person centred and integrated. Older Queenslanders are entitled to access the same services from the general healthcare system as the rest of the population. However, they frequently miss out due to assumptions that aged-care funding can effectively provide a full range of health services. Aged care is not funded to provide acute health services, and this inequity for older people must be addressed as a matter of urgency.

We believe the Queensland government has an opportunity to lead an innovative response to gaps at the health and aged-care interface and does not need to wade into the findings of the royal commission to act. In our submission we recommend that the Queensland government partner with the aged-care sector to develop and implement a strategy to improve the interface between hospitals and aged care to meet the health needs of older people. We also welcome and congratulate the government on the inclusion of community nursing in the 2019-20 Queensland budget. This is an important step in recognising and meeting people's health needs in community settings. Ultimately, if properly resourced and supported with supplementary funding and capability by the broader healthcare system, aged care services have the skills, capacity and opportunity to reduce costly hospital admissions through both avoidance of hospital admissions and shortened length of stay.

In conclusion, the Uniting Church is committed to continuing to advocate for a well-resourced and flexible system in end-of-life and palliative care that consistently meets people's needs and preferences for care. We are also committed to continuing to provide high-quality and accessible palliative care, responsive to the physical, psychosocial and spiritual needs of people as central to our mission as the church. Our focus is on witnessing the intrinsic value of all people at every stage of life in every circumstance of life.

CHAIR: Thank you very much for your opening statement. I might go to a quick question before we move on—it is a large panel and I might forget. You just heard from St Vincent's who were here before you. I think they hold a very similar position in Victoria where they did not allow for voluntary assisted dying to happen within their service, but they made arrangements to assist people who make that choice to go to another service. Would the Uniting Church in Queensland have a position on that going forward if, in fact, voluntary assisted dying is legalised in Queensland?

Rev. Dr McIntosh: This was a really important point in our overall consultation process. If it is legalised, essentially there are four core principles to which our agency would develop a policy and practice response, obviously in light of the legislation. The first one is that we are opposed to voluntary assisted dying. The second one is that we will not provide it as a service; we are quite clear about that. Our staff will not directly participate. However, it was really important as we consulted right across the synod that we offer compassionate pastoral care to people. We are leaving open the possibility of it happening in our facilities. It depends on the legislation and the legal complexities of that, but that is a possibility. We do not want to disrupt people; we want to minimise the physical pain of people as much as possible. However, at the same time our priority is really around bearing witness to the intrinsic dignity and value of all people at every stage of life in every circumstance of life. We want to uphold that, but at the same time we need to respect people's choice. We will honour that and we will do so in a compassionate way while maintaining opposition to it.

CHAIR: You have just answered my question. It is about choice, and I think you are advocating for people to allow them to have choice in this space.

Rev. Dr McIntosh: Yes, but at the same time we are holding that we will not provide it as a service—

CHAIR: Yes, and I understand the provision of it. I respect the Uniting Church Queensland's position there. You would have interest in this in running several aged-care facilities throughout Queensland. Do you have any idea of the bed numbers you have in your facilities?

Ms Webby: There are just over 3½ thousand aged-care residential beds.

CHAIR: Did you provide a submission to the royal commission with regard to their inquiry?

Ms Webby: Absolutely.

CHAIR: Obviously we are particularly interested in, as you would have heard, the issues around the staff mix and patient ratios. I do not know if we have been to any of the Uniting Church—

Ms PEASE: That is Blue Care.

CHAIR: Blue Care? That is an excellent facility because of the model of having the Queensland Health palliative care facility within it.

Ms Webby: That is right. That is a special—it is separate to the aged care—palliative care unit that is a shared project with Queensland Health that you saw that day.

CHAIR: Yes, that is right. You were there?

Ms Webby: I was there.

CHAIR: It is all coming back to me. Queensland Health funds that?

Ms Webby: That is right.

CHAIR: It allows people to stay within that aged-care facility?

Ms Webby: That is right. People sometimes go into the facility after the intensive time in the unit, but they sometimes go back home as well. They are able to go to that local space rather than going into one of the hospitals—Redlands, PA or somewhere else.

CHAIR: I will probably come back to some questions. Thank you very much. Thank you for the work you do.

Mr Price: Thanks for allowing the organisation the time to present to you today. Southern Cross Care is a not-for-profit charitable organisation registered under the Corporations Act and the Australian Charities and Not-for-profits Commission as an approved provider for aged care. We have been providing aged care in Queensland for 40 years in a number of rural, remote and metropolitan locations. We are committed to providing a safe environment for consumers where we can offer the best care in our facilities and in the community. Aged care is clearly a Commonwealth responsibility and as a provider, it is interesting that the state government is choosing to hold an inquiry at the same time that the Commonwealth has instituted a royal commission into aged care.

The community is struggling to identify the most appropriate way to deliver services and support and respect older members of Queensland. The Queensland parliament may have had this in mind when they set up this inquiry. Providers are also managing a raft of ongoing Commonwealth driven changes to standards and funding. If the intent of this committee is to make genuine recommendations around how to improve the provision of support for older people across Queensland, you can start by removing the barriers between state and Commonwealth that segregate responsibility for primary, acute and aged care, do nothing to improve the delivery and in many cases and circumstances result in negative outcomes and a significant waste of resources.

We recognise the need for excellent end-of-life care for all consumers, and our facilities are in communities within the Catholic framework and ethos from which we work. As a Catholic organisation, founded on the central principle of valuing and respecting human life, part of the way we demonstrate that is by providing services in smaller communities to enable equitable access in areas that would otherwise have no service.

In Catholic health care there is a long tradition of palliative and hospice care for the sickest and most vulnerable. It is disappointing that part of the disconnect between state and Commonwealth health systems means that the delivery of these services is significantly underfunded. The Catholic tradition also means that Southern Cross Care Queensland believe that it is never permissible to purposefully end an individual's life through euthanasia or assisted suicide. We will continue to support people in terms of their aged care within whatever the legislative framework may come to be, but we ask that this support be done in a government system that not only respects the individual but respects the values of those who provide the services.

CHAIR: You have had 40 years of delivering care to Queenslanders. How many facilities and how many beds do you have?

Mr Price: We have 11 aged-care facilities. We also have five retirement villages. We have 632 beds in those aged-care facilities. We have five of those facilities east of the Great Divide and six west of the Great Divide in areas such as Taroom in the South Burnett and also Allora.

CHAIR: You mentioned the funding model. You have been established for 40 years. This committee is tasked with providing some recommendations on how to better deliver care in aged care and palliative care. I have not gone into the palliative care side of it at the moment. If there is frustration with the barriers, as you have identified—and we have heard, as has the royal commission, of people waiting over 18 months to access home care packages which do not include funding for nursing care or to get into a residential aged-care facility. You have been providing care for 40 years. Surely you have had some opportunities in the past to provide messaging to the Commonwealth about making it easier to get funding for the people you look after. Obviously we will make recommendations to try to remove those barriers, but this is not your first rodeo.

Mr Price: It is not a new exercise. Susan may be able to answer the question better in terms of the number of inquiries, but there has been an inquiry into aged care probably going on consistently for the last 40 years. In terms of where we struggle, people's condition is very dynamic and can change day to day. To catch up with the funding associated with that is a very onerous task and is a lagging task, but the expectation, rightly, within our communities and our facilities is that we do provide the care that people need, but there is no recognition in the funding in terms of where that funding is provided and the changing circumstances of people in that environment. There is a very bureaucratic process that is put in place that does not meet the changing needs of people within those communities or those facilities.

CHAIR: That is certainly something we want to reflect. We are working closely with the royal commission in passing on information. They report a year later than we do, but they are taking a national snapshot. What we have seen in that aged-care funding is deplorable—people waiting and dying before they receive care or acquire a bed. It is complex. There is a lot of red tape. You are right. We need to break down the barriers.

Mr Price: I just make the other comment in terms of palliative care that within an aged-care environment there is no special funding for palliative care. From an aged-care provider perspective—and the comment was made by the previous panel—it would be far better for the individual, for their families and for our staff quite frankly to have that service continue within our facilities. Quite often the resources are not available within our facilities. People are transferred to hospital just purely through lack of resources and not through—

CHAIR: This is where the burden on the public health system becomes an issue causing bed block, so to speak, with people trying to get into hospital when care could be better delivered in an aged-care facility. We will use your facility as an example, and that is working with Queensland Health.

Ms Webby: Yes, and it is a pilot.

CHAIR: It is a pilot, yes.

Ms Webby: It is useful.

CHAIR: We are about finding solutions and making recommendations. That is an excellent example that we keep putting up as a pilot. When does that run out?

Ms Webby: That is a good question. I am not sure. I think we are about halfway through it.

CHAIR: Are there any other solutions that you could provide the committee in terms of smashing the barriers, so to speak, and getting funding? If I am an aged-care resident in one of the Southern Cross facilities and I sell my house to get in—I know there are funding models where the Commonwealth co-contributes funding to residential aged-care facilities—and then I get sick, as in diagnosed with a terminal illness, you are essentially saying that I will have to go to a hospital.

Mr Price: We will support people for as long as we practically can. In terms of the level of support we can provide, that is limited by the resources that we have available. There is currently no way to bring in those resources to provide them in our facilities.

CHAIR: I do not know if you were here this morning to hear the nurse practitioners and the nursing representatives from different bodies. They talked about increasing staff to patient ratios and levels of expertise in aged-care facilities to better provide palliative care. Do you have a view on that? I imagine that Southern Cross would have also given data on their skills mix. I do not know what your particular model is in terms of whether a registered nurse is there 24 hours a day or what the ratio is. Perhaps you could provide that to us on notice for those facilities. It would give us a view of the public system versus the private system and how we can make recommendations to get the best model possible where you are not sending someone to a public hospital.

Mr Price: Ratios are a different and difficult issues. I find it ironic that on the one hand we are focusing increasingly on the individual but we are using a sledgehammer to solve an overall systemic issue. I can have an individual who is in a facility who needs far less care than another individual. As an organisation we will never skimp in terms of the resources we have available to provide the appropriate care, but that changes in terms of the acuity of people within our facility and the number and type of people within our facility.

CHAIR: We would still like to get a view though if we can from each of them. We will endeavour to get to a Southern Cross facility in our travels going forward to have a look at one. I think it is wise for us to have the current staff to patient ratios. We did ask that question at Wynnum. It gives us a view, and then we need to back that in with how to get better expertise, whether that is more registered nurses or better integration between GPs and the facilities. I imagine that you would all have good working relationships with your local GPs. If you can provide any data for your existing 11 aged-care facilities and five retirement villages to give us an idea of what the staffing level is—

Mr Price: We do not have staff in retirement villages looking after health though.

CHAIR: They are a semi—

Mr Price: It is a retirement village. There is no—

CHAIR: Perhaps then provide staffing levels for the 11 aged-care facilities, if you could. That would be beneficial for us. Perhaps the Uniting Church and Anglicare could do that as well. It just gives us an idea.

Mr Price: I will point out that literally there will be a day-to-day variation.

CHAIR: Is that based on the level of care that is needed, whether you have dementia patients, acute care—

Mr Price: Yes, and with sickness—

CHAIR: You can ramp up and dial down as needed in terms of staff numbers?

Mr Price: Yes.

Ms Webby: Yes.

CHAIR: We will take that into consideration. It would certainly give us an idea of where things are at particularly in the faith based areas who are looking after so many Queenslanders—literally thousands. I will stop there for a moment. We will continue with opening statements and then we will move to questions.

Ms Greenwood: Thank you for the invitation to be here today. I will would like to echo the comments of my colleagues in their acknowledgement of country. I think it is very poignant that we are recognising our Indigenous elders past, present and emerging when aged care is something that we are looking so closely at. We probably have a lot that we can learn from our Indigenous brothers and sisters.

My name is Suzanne Greenwood. I am the CEO of Catholic Health Australia. Catholic Health Australia is Australia's largest non-government provider grouping of health, aged-care and community care services. In Queensland our members do include Southern Cross Care and also St Vincent's—

and we heard earlier from Toby Hall. We also obviously have the Mater Group with all of their public and private facilities here in the south-east of the state. We also have St Vincent's aged care as well as their hospitals in Toowoomba, on the north side and at Kangaroo Point.

Mercy Health and Aged Care Central Queensland also have a number of hospitals in Central Queensland. We have hospitals in Bundaberg, Rockhampton, Mackay and Townsville—all the way up the coast. We have Canossa Private Hospital here in Oxley. We have Ozcare aged care all across the state. Mercy Health has aged care in Cairns as well. The Queensland Hibernian Friendly Society has the beautiful BallyCara on the north side of Brisbane. We have a number of smaller facilities around the state.

You asked about bed numbers before. We have 320 public hospital beds, 1,600 private hospital beds and 5,800-odd residential aged-care beds and independent living units, and more than 10,000 home care packages in Queensland. They are the Queensland statistics. Across Australia it is 80 hospitals and 25,000 aged-care beds.

Our members do offer a wealth of clinical expertise and experience in the areas of aged care, end-of-life care and palliative care—services which Catholic Health providers have a very long and proud tradition of providing. CHA members have always valued the delivery of person centred care that is founded in a respect for human dignity and life. Catholic Health Australia's view is that it is never permissible to purposefully end an individual's life through euthanasia or assisted suicide because we believe it compromises the inherent value of the person and erodes trust in the medical profession who must care for those individuals at all points in their journey.

Based on our experience, Catholic Health Australia believes that high-quality aged care, palliative care and end-of-life care are the best options to allow freedom of choice, dignity, comfort and respect as a person nears the end of life. That is not just for the individual but also for their families, carers and the community that surrounds them.

We support the approach that has been recommended by the Productivity Commission back in 2017 that state and territory governments do need to increase the availability of palliative care services across their jurisdictions. We strongly believe that the provision of good palliative care does not include the provision of methods that would assist individuals to take that own lives. If any form of euthanasia or voluntary assisted dying was to be legalised in Queensland, Catholic Health Australia member facilities would not be providing such services.

Turning to each in turn, with respect to aged care, Catholic Health Australia supports the inquiry that the Australian government is doing with the Royal Commission into Aged Care Quality and Safety so that the future of care for Australia's elderly can be properly and independently addressed. I commend to the panel our witness statement which was by Catholic Health Australia's Director of Aged Care, Mr Nick Mersiades, as was provided to the royal commission.

CHA also supports progressing though the significant reforms to improve aged-care systems that are already underway and which have been recommended in recent reports which Francis referred to earlier. These reforms stem mainly from recently the Tune report and the Carnell-Paterson report and focus on improving the quality regulations and the control of services and securing the resourcing for the ever-burgeoning need for aged-care services in this country.

Currently the prospects for elderly Australians needing quality aged-care services are uncertain because there is no federal funding plan that is going to cater for the projected two million Australians who are going to be over the age of 85 by the year 2055. On Tuesday this week, Catholic Health Australia held an aged-care forum in Canberra. We had a number of representatives from the Department of Health speaking. They said that at the moment the waitlist for a person to receive a level 4 package is more than two years after they become qualified and entitled to access it. This is two years for people who have high-level care needs and are waiting to get the care they deserve.

That is shocking because the life expectancy for many of these individuals needing a level 4 package will be less than two years. What is the reality of that list? Is it six years? Is it 10 years? It is just shocking. Accordingly, Catholic Health Australia recommends that the key focus of this inquiry really should be to explore and recommend options for ensuring aged-care residents have timely access to medical services when needed and that it also explores and recommends options for expanding the availability of specialist palliative care services for Queensland's aged-care homes.

Turning now to end-of-life care and palliative care specifically, in February this year we released a report on palliative care which outlines barriers and enablers to the provision of palliative care services. What that showed us is that Catholic Health Australia members actually provide 13 per cent of all palliative care hospitalisations in Australia. This was six per cent of the public hospitalisations and more than 50 per cent of all of the private palliative care provision of inpatient care services.

CHAIR: Can you repeat those numbers?

Ms Greenwood: Yes. Thirteen per cent of all palliative care hospitalisations, so if you looked generally across, but if you break it down to the public and private we are six per cent of the public and the exact figure I think is about 53 per cent of private palliative care in-patient beds. Unfortunately, we submit that the palliative care services in Queensland do not meet the needs of Queenslanders. As proud as we are of the volume we provide, my hand is on my heart to say we need to do more as well. I am not pointing a figure at anyone. We all need to do more. The demand for services far exceeds the services available, particularly for community based palliative care services. We did hear in the earlier session that nobody wants to die in a hospital and so to give people that choice to be in the care setting of their choosing, it is home or it may be their residential aged-care facility which for those people is home, and so having those inreach services coming in is very important. Concerns also remain regarding the equity of access to care for those who are in aged-care facilities from Aboriginal or Torres Strait Islander communities or culturally and linguistically diverse communities and those who have non-malignant diseases.

The CHA report into palliative care describes a number of barriers, the most significant of which are inadequate funding and restrictive funding models, fragmentation of care, nursing workforce shortages, workforce and community awareness of palliative care and a lack of research investment. These barriers must be fixed before the community can have discussions about the need for assisted dying. As a society, the term assisted suicide as a preference before caring for the sick and dying is a broken society. Barriers urgently need to be addressed in order to ensure people experience the good death they expect and are entitled to, yet these barriers are even more acute in regional, rural and remote Queensland.

I had the joy a couple of weeks ago of visiting Townsville. The services up there are remarkable, but there are struggles to get the workforce. There are a very unique set of challenges that we need to address as we move outside the south-east corner of the state.

CHAIR: Can I interrupt you for a minute before I lose track, you mentioned the CHA report. We would dearly like that to be provided to the committee.

Ms Greenwood: Absolutely. We did have a link in our submission, but I am also happy to provide some hard copies. Also it is available as a free download off our website as well.

CHAIR: Thank you very much. You mentioned the recent conference. Do you have any learnings from that? Those numbers you spoke of are deplorable. We have people dying waiting for funding. How we better send that message to the Commonwealth to get that funding quicker to get people the beds and the care they need would be very helpful in terms of us making our recommendations in a few months time. I do not think there is a committee member here whose blood does not boil that there are people in these situations.

Ms Greenwood: I think we are very fortunate that the royal commission is going on at the moment. It really is opening that conversation up of what is the aged care we want for our older Australians, what is the model to deliver that care and how do we sustainably fund it into the future.

CHAIR: We have an opportunity to make recommendations a year before and we are taking on board what you are saying that that barrier needs to be absolutely broken down because I would imagine all of you will take those people on anyway, regardless.

Ms Greenwood: Absolutely. Francis might be better to state this, but in Australia at the moment something like 45 per cent of aged-care facilities in the country are running at a loss. That is because they will take everyone on. They will care for everybody, but it is not sustainable. In that submission that I mentioned it actually does also list our eight recommendations for improvement to palliative care services that are actually in that report as well. In the interests of time I might just move on to voluntary assisted dying.

Catholic Health Australia members are committed to providing the best possible evidence based, compassionate care to all members of society. We do not consider that the prescription of a lethal substance to a person to help them end their own life, nor the administration of a lethal substance to a person by a health practitioner to end their life, are part of end-of-life care. We also remain concerned about the risk of an inaccurate prognosis and the difficulties of defining an individual as being at the end of life, the risk of undermining mental health prevention and treatment, the risk of celebrating suicide as an answer which fundamentally undermines years of preventative work by the mental health profession and acts against the fundamental values of dignity and respect for life that have been the pillars of Australian communities, the risk of legalising lethal drugs and the risk of much needed funding for palliative care being diverted to assisted suicide.

Legalising voluntary assisted dying advances the misguided belief that the elderly, sick and vulnerable constitute a burden to society. We urge the Queensland government to consider the type of community it wants to create and not act to create a community that does not value and respect the sanctity of human life.

I would like to echo the views of my colleagues from the Uniting Church that an essential aspect of any proposed legislation for assisted suicide must be the ability of health professionals and healthcare organisations to be able to conscientiously object to providing a medical treatment that goes against their ethical beliefs and values. This is a basic human right that should be respected and protected at all costs and not doing so leaves healthcare facilities and their staff exposed to statutory uncertainty and jeopardises their ability to provide quality care. Protections must be guaranteed by law to prevent additional pain and suffering to health professionals and community members. This is something we feel very strongly about.

In talking to our colleagues in Canada, as Mr Toby Hall mentioned earlier, one of the struggles they are facing is how we care for the carers now. People who are exposed to many of these situations that are arising due to assisted dying are experiencing things that are very challenging to their own beliefs and yet what we are seeing in Australia in Victoria is that the legislation offers conscientious objection to individuals but it has done very little to marry that back to the professional codes of conduct and standards amongst the various practitioner bodies and those sorts of organisations. There are still situations that have been identified in Victoria where people will potentially be exposed for being negligent if they try to exercise their right of conscientious objection. That is a difficulty. I understand the navigator service that is being brought in in Victoria is going to help to alleviate some of that concern, but it is a terrific concern and I think it is one that our lawyers who are considering the legislation need to look at.

CHAIR: Could you provide evidence of that actually occurring?

Ms Greenwood: Yes, certainly. I possibly should have said at the outset that I am an admitted solicitor to the Queensland Law Society and have been an admitted solicitor here for over 25 years. Therefore, one of the things we have done is we have looked very, very closely at the interplay between the practitioner codes and the legislation in Victoria. We have also written to the health minister there requesting that the regulations be amended to address this, but they have referred very much on *Hansard*, saying that at places like this it was assured that organisational conscientious objection would be respected.

CHAIR: We had the organisational bodies here before, the Medical Board of Australia, AHPRA and the nursing board as well. None of them mentioned this as an issue.

Ms Greenwood: I am happy to provide some further detail.

CHAIR: I am surprised to hear that.

Ms Greenwood: Obviously until things start to play out a little bit more in Victoria—it was only 19 June that it commenced there—we are really yet to see how the various bodies might consider they need to police and action their own codes

CHAIR: Conscientious objection.

Ms Greenwood: Yes. Sorry, I am monopolising time here. Obviously, we believe very strongly that it is premature to consider voluntary assisted dying when inadequate and inequitable palliative care is being provided across the state. We thank you very much for the opportunity to appear today.

CHAIR: Thank you for your contribution as well. I want to clarify the position that CHA has. Thank you for the work you do. You obviously have a massive footprint across Queensland particularly.

Ms Greenwood: Yes.

CHAIR: You kind of hit a middle road. I think you said you were against having voluntary assisted dying occurring within the facilities, but again similar to the question I asked of Mr McIntosh, would you then therefore refer people on in terms of choice?

Ms Greenwood: We have a slightly different perspective. As Mr Toby Hall said before, we will transfer a patient who is wanting to access a service. We will very strongly operate from a position of nonabandonment of our patients and nonjudgement of our patients, but we will not be providing the service within our facilities, we will not be allowing third parties to come into our facilities to undertake assessments of the individuals and we will not be referring them to a specific service in that we feel that we will not be in a position to know really where the appropriate place is for people to access these services or who the practitioners might be who have undertaken the training and that sort of thing, but we will certainly not resist any person who wants to access those services.

CHAIR: Thank you for clarifying that. We have your clear stance on conscientious objection for the providers working in your facilities. You mentioned people coming in with lethal doses. All of you in the residential aged-care space would have seen people depart—die—over time, some perhaps in the palliative care space with GPs providing forms of palliative care. We had the doctors here this morning—I am sorry you were not here for that. There was a discussion about the clinical interaction of giving, as they said, a cocktail of drugs, be they sedatives, morphine, narcotics, that is providing compassionate care to relieve pain, but the end result is there will be a death. They are providing an injection now of standard medications.

Ms Greenwood: I do think there is a lot of misinformation out there about this. There is quite a difference between palliative sedation and terminal sedation. We probably should have teased this out a little bit better with Professor Good before. It is never the intention to end a person’s life in managing the level of pain medication that would be required.

CHAIR: The end result is they die.

Mr HUNT: It is intent. We have covered this a lot today.

CHAIR: We have.

Mr HUNT: It is pretty clear to me.

Ms Greenwood: We are all going to die. It may have an impact of hastening death, but we are not talking about someone who has a month to live all of a sudden has a week, we are talking about somebody who probably has two to three days left to live who may live for two to 2½ days. When it is managed properly—and I think that is one of the things I tried to highlight. Some of the barriers to palliative care are that we do not have enough trained palliative care specialists out there; we do not have enough understanding. It would be lovely to be able to have multidisciplinary teams, bringing the geriatricians together with the cardiac experts with the palliative care teams around a person, but the reality is, although that is the ideal palliative care, it is not what many of us can access.

CHAIR: We have heard from palliative care specialists with decades of experience who have their own views on voluntary assisted dying and they have provided that to the committee. With respect to members, yes, we have had a discussion on this this morning but the end result is you are providing medications that will potentially, as they say, hasten death. It is removing suffering.

Ms Greenwood: If given in the right dosage they will not have that consequence, but that is one of the challenges—how do we educate the medical professions to understand the levels that are appropriate. Something else I would not mind touching on briefly, in case you are not going to ask questions, only because this is another thing I learnt myself earlier this week in meetings we have had with Victoria, is that telehealth is something that has been focused on and I think with the length and breadth of Queensland it is something that is critically important. What has come out with Victoria is that the legislative regime is such that telehealth will not be able to be used with respect to voluntary assisted dying because the laws are such that they state that you cannot incite suicide using IT. It is seen that voluntary assisted dying is assisted suicide and they will not be able to use telehealth with voluntary assisted dying. That is already proving a challenge in the state of Victoria. I understand that people in Bendigo are seeking to access VAD, but those who have done the training are not going to Bendigo to provide the assessments.

CHAIR: Are you familiar with that particular document?

Ms Greenwood: Yes, I am, but it is very big. Please do not ask me a question that is too specific.

CHAIR: They talked to us. It was a ministerial expert panel on voluntary assisted dying. It is not law in Western Australia, but they made several recommendations. Reading that document yesterday, they talk about the difficulties of geography in Western Australia. Queensland is the same. This is why they have ended up with a model of not two doctors but a nurse practitioner. Do not ask me whereabouts it is in there, but it is in there about the difficulties of the tyranny of distance and using telehealth.

Ms Greenwood: I think Western Australia is also concerned that they feel the regime in Victoria is quite conservative and a bit restrictive. It came in two weeks ago. I think that is a scary conversation to have at this stage. I understand we do have that challenge of distance in Australia, but that is nothing new. We have addressed that with all sorts of health issues over the years. I think that, as was raised this morning, we need to make sure there are safeguards.

Mr HUNT: Certainly our churches have a proud history of care in this country, particularly for our most vulnerable. You talk about operating at a loss to care for people, so congratulations to you all on the services you provide. I want to clarify one thing with you first, Reverend Dr McIntosh. I think the chair drew you to a point where he concluded that you support choice. I want to draw that out a little bit. Can you clarify that it is the position of the Uniting Church in Australia and Queensland that you do not support voluntary assisted dying legislation?

Rev. Dr McIntosh: That is right. Just to clarify, we support people who choose and we will compassionately accompany people while maintaining a clear stance that we oppose voluntary assisted dying. In other words, we will do all that we can to ensure that they are comfortable, to minimise pain and suffering, to offer physical, psychosocial and spiritual support while at the same time maintaining a position in opposition to voluntary assisted dying. We support the person who chooses rather than the idea of choice.

CHAIR: That was my interpretation, member for Nicklin. That is absolutely fine. It is good practice for estimates.

Mr McARDLE: Let the member for Nicklin continue with the question.

CHAIR: Thanks, Deputy Chair.

Mr HUNT: You have a policy of nonabandonment and nonjudgement but not necessarily supporting the choice itself.

Rev. Dr McIntosh: That is right, yes.

Mr HUNT: Reverend McWilliam, you mentioned earlier that you were listening to the last panel and you thought you could provide some input in relation to some of our questions. Can you expand on that? I will give you the opportunity now to make a submission on some of those previous questions.

Rev. McWilliam: I could probably expand on the question about hastening death with a cocktail. I worked in palliative care for 15 years as a chaplain. From my perspective of working in that setting, I found the whole debate about whether it hastened death, shortened life and all of those questions really interesting. For me, the important thing spiritually and theologically has always been that there has never been any intention by the practitioner to end their life at that point in time. The intention has always been to alleviate suffering, knowing that the person only has a few weeks to live. I have seen some beautiful cases where people who were hysterically frightened about the dying process and could not manage that anxiety were given enough medication to be in a completely relaxed state, and they trusted that physician to keep them in that state without hastening the end of their life. From what I have seen in many settings, I have no issues. I believe that it has not been the intention with any of those practitioners to shorten life. Theologically, we should seek to alleviate pain but not intentionally end life.

The Anglican Church really takes discussion on these matters seriously, and we will not just launch suddenly into ‘this is what we believe at this point.’ Philosophically we would say that we do not support terminating life but we would alleviate suffering. We are really pleased to be having this discussion about palliative care, because from my perspective and Anglicare’s perspective there is not enough funding and support for palliative care here in this state, whether that is in the community or aged-care settings. We look forward to changes being made, so therefore we are not really entering deeply into the debate on assisted dying.

CHAIR: Did you note—sorry, member for Nicklin.

Mr HUNT: Are you jumping in again?

CHAIR: Sorry, member for Nicklin. Seventeen million dollars was allocated in the budget towards that—

Mr McARDLE: Mr Chair, everyone has been respectful to you when you have asked questions and not overstepped the mark by interrupting you. Can I please ask you to let the member speak and ask the question and then move on. I understand that you want to make a statement, but courtesy cuts both ways.

CHAIR: It certainly does. Let us move on to the member for Nicklin.

Mr HUNT: Please continue.

Rev. McWilliam: One of the things that I was thinking about when you were talking about advance health directives is what Anglicare has been doing recently. We identified that a lot of people, particularly in parish and community, do not even know how to access funding and what is available.

They have no idea about enduring powers of attorney, advance health directives or wills. We have been offering information sessions to any of the parishes or communities who would like to hear about those things. We have found that they have been so successful for people to have an understanding and ask lots of questions. That is something I can contribute to the conversation about advance health directives, enduring powers of attorneys and wills.

In relation to health coaches, I believe that is what our spiritual and pastoral care practitioners do in the work that they do sitting with people and talking about their life journey, looking at what the difficulties are. It is not a religious service. It can be a religious service if someone wants it to be, but most of the work that our spiritual and pastoral care providers do in the community and aged-care settings is the sort of work those coaches are doing. We would find it really helpful in community settings if we had some funding for that spiritual care component, because we seek to qualify them and train them professionally in all areas of palliative care, dementia and community care services. We really feel strongly that those spiritual practitioners can do some really good work in those circumstances.

Mr HUNT: I want to ask everyone broadly: as we talk about voluntary assisted dying I have heard the word ‘burden’ a lot. Certainly as people get older they may feel that they do not want to be a burden. To what extent do the services you provide attempt to alleviate that and deal with how people value themselves? I guess that comes into what you were speaking about with health coaches, but maybe the Catholic group can comment on that.

Mr Hart: At Southern Cross Care we have a pastoral care service as well that is similar to what was spoken about before. We believe that holistic care is not just about the physical wellbeing but also the spiritual and emotional wellbeing, so making sure that we take care of that person as a whole person. It is really important for the services that we provide in our facilities, and I know across all of the Catholic health services that is an integral part of what we are trying to do. We are not just a physical being; we are social and we are spiritual and we have all those other dimensions. Particularly at the end of life and as people are coming to terms with whatever their belief might be after that, there are often really important questions that arise. Spiritual care and pastoral care can be there to assist in that process. I think they are really important things to be considered. I take on board the idea of the provision of resources and funding around that. Whilst we do it because we believe it is integral to our faith tradition, it has a broader worth as well. That is something to be considered.

Ms Webby: I would support the notion of the need for funding for the broader spiritual and pastoral care work that we do. The other thing that we do at Blue Care is we have a service model called Tailor Made, which is really about supporting people to be all they can be irrelevant of what stage of life they are at, so to recognise the valued roles and see people as people. That goes from an early intervention stage right through to end-of-life care. I think it is really important that we are able to use a model of care like that that helps all of our staff, not just the spiritual and pastoral carers providing that role, but all of our staff to work with people as individuals and support them through that journey and continue to help them have valued roles and contribute in whatever way they can to life.

Mr Price: Can I just make another comment in terms of that, not so much about the spiritual but the practical. We already confront that concept occasionally—very occasionally—in terms of people paying and contributing to their own care when that can impact in terms of the amount of money that is left for families and relatives. I guarantee that one of the things that is going to go forward is people are going to be asked to contribute more to their care, not less. The government is not going to continue to fund to the level they are now. As that requirement to fund more increases, the pressure on individuals will increase also. In terms of this discussion, one of the outcomes is going to be that people will be encouraged to end their life sooner.

Mr HUNT: Yes, it is a concern.

Rev. McWilliam: The other danger is that some family members will seek to encourage the elderly to end their life sooner.

Mr HUNT: That can be quite subtle too, can’t it?

Rev. McWilliam: It is very subtle, absolutely. That is one of my great concerns, yes.

Ms PEASE: I know that in my area of Wynnum we have Lota House, so thank you. Anglicare does a wonderful job there; Blue Care in Sibley Road does a great job. I am really impressed with the palliative care services that are operated there. I wanted to ask either Francis or Michael about Southern Cross Care. I know that we do not talk about high care and low care anymore, but in terms of those levels of care that you provide the reality is that you have different levels of care. People require different services. For those people who have much more complex needs—and they would come with a package and you are funded for that—what happens at the end? You said that you try to provide services until it gets to such a point where you cannot maintain it. Do you just send them off to the hospital?

Mr Price: The level of acuity in most aged-care facilities is increasing. We are one facility that, when it was built, people went in when they were 50 and some have been in there for 20 or 30 years.

Ms PEASE: We have visited similar places.

Mr Price: Now in most locations the level of acuity for people going in is increasing, so the length of stay is shortening. The concept that we ferry them off is unfortunate in terms of a term—

Ms PEASE: Sorry, I did not mean it to sound—

Mr Price:—but the reality is that we do not have the resources to provide 24-hour care at bedside for someone in our facilities. The fact is that acute care, which in a lot of cases is a requirement around palliative care, is not something that aged care has been or is funded to, albeit that we would love to be able to provide that. The irony is that we go from an environment where we provide care to an environment in a state government hospital where you are paying anything up to $5,000 a day to do something we do for considerably less.

Ms PEASE: I guess that is my point. There are aged-care facilities that do provide that where there are staff on board and they keep them and they keep their residents—

Mr Price: We will keep residents for as long as we can. In some of our locations there is not necessarily the opportunity to transfer them to a hospital. Are we providing the level of care that we would like to to their end of life? In some cases probably not, purely from a physical resourcing point of view, whether that is expertise in terms of staff, whether that is adequacy in terms of medication or whether that is adequacy in terms of access to GPs to provide the support that they need.

Ms PEASE: Within Southern Cross, are there requirements for registered nurses to be on staff?

Mr Price: Yes.

Ms PEASE: What does that normally look like? I guess it would depend on different facilities?

Mr Price: What it normally looks like is what we need. Having said that, we have facilities where we struggle. In a place like Taroom we struggle to get registered nurses. We work very hard to get them, but the reality is that in an environment such as that we cannot keep them. We also have environments like Chinchilla that are subject to economic changes. We have gone up and down in terms of staff, because it was hit with the cost increases associated with coal seam gas. It became impossible for a number of our workers to continue to live in that environment and pay the rents, or they were being offered jobs with the gas companies paying three times the amount of money. That came off the boil; it is starting to increase again. Currently, we have some low-cost beds in that environment. We are having to use those low-cost beds to house staff, because they cannot afford to live in town. They are the sorts of issues that we have to struggle with in terms of getting staff. While it might be an easy discussion to have about what nurses and staff do we have, we have a desire to have staff; but in a lot of cases we really struggle for the same reasons that every other industry struggles in those sorts of environments. It is just that ours is one that is caring for people, and it hurts us in terms of not being able to provide that staff when we want to in those locations.

Ms PEASE: I suppose that would be the same for the other providers? Are you all experiencing the same issue?

Rev. McWilliam: For us in Hervey Bay and Bundaberg, it is difficult to get nursing staff and the quality of nursing staff that we require. I heard the word ‘empathy’ in the last session. We need staff with empathy and with good clinical practice. We in Hervey Bay and Bundaberg do struggle. It is a repeated cycle of trying to get the right staff to manage the facility as well as the registered nurses to be the clinical nurse. We do not have such a struggle in other areas.

Ms PEASE: And Uniting Care?

Ms Webby: Absolutely. From our perspective, we have services from the tip of Torres Strait to out west. It absolutely is a challenge to look at staffing. We look at other models such as how we can use technology, so using remote clinical monitoring. For example, as a support to services, we might not be able to get the number of RNs we need. We might have RN coverage all the time but are there other ways that we can supplement that to provide services using technology in a different way? We are starting to look at different models that do support the fact that we have the challenge with staffing. Earlier, I heard someone talking about growing our own staff. We are absolutely committed to providing a pathway for our staff to skill up. On Thursday Island we have people who have started as part-time people in the kitchen who have gone on to do Certificate IIIs and up to nursing now. There is a person who is looking at a service management role. That is over a long period of time where we have accessed a lot of work, effort and special funding around training to put in there. It is those kinds of strategies that we need to look at in terms of building our workforce. I support what my colleague said around staffing ratios in that we run multidisciplinary teams. It is not just nursing: it is allied health staffing. It is our unregulated workforce as well. We need to give consideration to their training and how to provide meaningful work opportunities and good value propositions.

Ms PEASE: We heard earlier questions that I asked about that unregulated workforce and about claiming for those. I return to that point. I did correct myself in terms of using the word 'ferry' as I used another word after that. I apologise, because I knew it was a poor choice of words. I did actually correct myself. Having said that, one thing I would like to understand concerns your facilities and if you do not have access to a registered nurse at any time during the day—

Mr Price: We always have access to a registered nurse.

Ms PEASE: That is what I was trying to clarify.

Mr Price: The reason for someone going to hospital is never about not having a registered nurse.

Ms PEASE: I am trying to understand access to appropriate staff, for example, to administer medication as required.

Mr Price: But quite often a GP is required to certify that that medication can be administered. Often the condition of the patient will change in a short period of time and we cannot then get a GP in to change medication or re-prescribe medication; therefore, the site is unable to provide the care that the individual needs.

Ms Webby: The other point I make on access is that, if we do not have our own staff, we use agency staff. Sometimes we fly them in and fly them out. The ACFI funding instrument that has been referred to in other sessions today does not significantly take into consideration some of the issues that come around cost in providing a service. That is another challenge should we go down any sort of staff ratio track. There is a whole range of strategies that we use, but they do not come without a collection of barriers as well that we need to find ways around.

Ms PEASE: Finally, we were talking about spiritual and pastoral carers. Reverend Linda, you said that your spiritual and pastoral carers provide similar work to health coaches?

Rev. McWilliam: It sounds like it from the description that Toby gave.

Ms PEASE: In terms of health coaches, I imagine that they provide very different information from a spiritual and pastoral carer. Do your spiritual and pastoral carers have medical training? I know that previously you were a nurse?

Rev. McWilliam: No, I was not. I worked as a chaplain in palliative care.

Ms PEASE: What advice might a spiritual and pastoral carer give in the health space?

Rev. McWilliam: They do not give advice. A coach does not usually give advice, either. For a coach or a counsellor, advice is not what you are supposed to be giving. You are supposed to be helping the person talk about the issues they face. It might be that you provide them with resources and information, but it is about helping that person along that trajectory, whatever it is, to know what they want, what issues they face, what resources they might need and what healthcare services can be provided. I am a trained coach as well. It is not about advice giving. I am a trained counsellor. It is not about advice giving. Spiritual carers are not about advice giving. All of those are about helping to empower people to find what it is that will help to find the peace, freedom, information and the resources that they need. That is what our spiritual and pastoral care providers do in that sense. There is a fine line among all of those types of services.

The main thing is that practitioners are really well trained and skilled in whichever area they are working in. If someone says that they want the spiritual and pastoral carer to read the Bible, to pray with them, to do their funeral, all those sorts of things, absolutely that is part of what they will do. Essentially, that is not why they are there. Essentially, we believe that all people are entitled to spiritual care, that all people are spiritual beings and that that involves a whole range of issues. It was just the way it was described that a number of people said to me, 'That is actually what spiritual and pastoral carers do.' Does that explain it a little bit?

Ms PEASE: Certainly. Basically, you have made clear your position on voluntary assisted dying. Where does that take you if the person speaking to you says, 'I would like to get some assistance to end my life'? At what point do you use the church's position on that? If that happened to be the case, how would that impact on interfering with the legislative requirement?

Rev. McWilliam: For example, in the hospital setting, of course, people would ask that or their relatives would say, 'Look at my husband, he is suffering. If he were a dog or a cat, he would be put down.' For me and for the doctors, it was about having those conversations with them, listening to them, saying, 'Yes, it is really hard. When you are looking at your husband, it is really hard because you feel like he is suffering.' It was about those long conversations, listening and not minimising their feelings. Most people got to a place where they could see that things were going along okay. We would never use our religious tradition in those settings—I can speak only from that hospital perspective—and how our spiritual and pastoral care coordinators would work with those people in listening. If there were something that needed addressing, they would be referred on to someone else who had more expertise in that area. It is the listening—not minimising—and validating what they feel to try to help them get to a place where they can actually perceive and understand things differently. As long as good care is put in place, we always need the good care in place. Does that help?

Ms PEASE: Sure. Thank you very much.

Mr McARDLE: Thank you for being here this afternoon. I want to clarify for the record that palliative sedation does not have an intent of ending a life. Palliative sedation has the intent of alleviating pain or distress. On occasions, it may lead to the patient's passing. To try and link the end result to palliative sedation is the wrong way to consider what is the intention from day one; is that correct?

Ms Greenwood: Yes.

Mr McARDLE: The issue of conscientious objection has been raised on a couple of occasions. In Queensland we now have the Termination of Pregnancy Act in force. In those circumstances, if a practitioner and I have that objection, I can refuse to provide that service, but by law I must refer that woman or lady to an organisation or a doctor who will provide the service. If the law in this state on voluntary assisted dying goes through and a similar clause exists, that is a church based organisation can refuse but the law then requires a referral on to an organisation that would perform, would you object to that?

Ms Greenwood: Absolutely. We would not refer.

Mr McARDLE: That would be based upon the conscientious objection stays in place, because you would argue that I will not do it, therefore it must be wrong for me to refer on to somebody who will do it. The principle applies. Is that uniform?

Rev. Dr McIntosh: I think it is a really good example and it is a really good question, but to me the critical difference around termination and conscientious objection and voluntary assisted dying is in voluntary assisted dying you are not faced with a medical emergency that needs immediate treatment where there would be harm caused if I do not refer on that person.

CHAIR: Can you repeat that?

Rev. Dr McIntosh: The key difference between voluntary assisted dying and termination of pregnancy is that we are not faced with a medical emergency where if we do not act there will be a consequence of that act in terms of the person before you. In voluntary assisted dying, we do not have that situation. Generally, people will undertake the process earlier, and there are other mechanisms we can use such as the navigator model or a point-of-contact model where people are not placed in that ethical quandary of, 'I need to refer a person on despite that being against my conscience.' That would be our position around that.

Mr McARDLE: You would refer on?

Rev. Dr McIntosh: We argue that you should not be forced to refer on.

Mr McARDLE: You would then not refer on?

Rev. Dr McIntosh: It does not mean that you would not refer on, but you should not be forced to refer on.

Mr McARDLE: What if the law says you must? If the law says you must, would you refer on? The Catholic Church says no. Do you say if the law says you will not perform it but then clause B says that if you will not you must refer on, would you do so?

Rev. Dr McIntosh: It depends what the law says.

Mr McARDLE: Just say it says that.

Rev. Dr McIntosh: In terms of our position, we will develop a policy and practice approach according to what the legislation says.

Ms Greenwood: Sorry, but I should probably clarify: in states where that is the abortion law, we do refer because it is about acting in the interests of the patient and in the scope the law is protecting. To add to what Adam is saying, they are very different situations. When you are talking about an abortion, the number of weeks into the pregnancy is what is really important. If there is delay with the person not getting to another service, there is strong concern whether they will still be able to access that service, but that is not the case—

Mr McARDLE: Are you changing your opinion?

Ms Greenwood: No. What I suppose I was trying to say before was we will argue until we are blue in the face that it is entirely inappropriate that there would be a positive obligation to refer to be put into assisted suicide legislation.

Mr McARDLE: If it did exist, would you refer on? That is a simple question.

Ms Greenwood: It is not a simple question because it is not something that is a reality. We are talking in hypotheticals, so it is not something that has been teased out on our side. I would say that we very definitely would see it as we are facilitating if we have to refer and it would really compromise our ethics and values.

Mr McARDLE: It would be a major moral dilemma for the church?

Ms Greenwood: Yes, absolutely a moral dilemma.

Mr McARDLE: Southern Cross?

Mr Price: One of the things that is a significant issue is when someone is in an aged-care facility it is not like being in a hospital. They are there and it is their home and they have tenure. We are very clear that we are not going to allow assisted suicide in our facilities, but you are in an environment where a person has a right to stay in that facility. If push comes to shove, we will exit the industry.

Ms PEASE: Sorry?

Mr Price: We will exit the industry. We will pull out of aged-care facilities.

Mr McARDLE: Exit the industry? If you were pushed into the point to make that—

Mr Price: We would cease to operate in aged-care facilities.

Mr McARDLE: That is a fairly important step and one that would have ramifications right across the industry. I get the moral point that you are raising—

Mr Price: And I would be surprised if that approach would not be taken up across the industry.

CHAIR: Have you exited the industry in Victoria?

Ms Greenwood: It is not mandatory in Victoria to refer, so it is not relevant.

CHAIR: Thank you.

Mr McARDLE: Anglicare?

Rev. McWilliam: We do not have a policy on this at this point in time, but I can say for myself if I was in that situation, regardless of where I was, if it was not against policy and it was the law and pastorally it was the right thing to do to help that person to find the resources and access what they needed, it would be very difficult for me as a person to not provide them with the information that they needed. Anglicare does not have a policy at this point in time on any of those issues, so I am only speaking from my own point of view.

Mr McARDLE: Not on behalf of the church?

Rev. McWilliam: No, not at all.

Mr McARDLE: Okay. If I asked you if you could describe Queensland's palliative care model, how would you describe that?

Mr Price: In a relative term, close to non-existent. With regard to the capacity of the general population of, say, four million in Queensland in terms of the percentage of those people who could access reasonable palliative care, if it is more than 10 per cent I would be surprised.

Mr McARDLE: Other comments disagreeing with that or agreeing or another point of view?

Ms Greenwood: Yes. The number of trained palliative care specialists across the country is shockingly small. That is the sad reality—that is, that most people cannot access it, even if they wanted to. One thing that I was wanting to touch on, because I think we are kind of hearing a bit of the doom and gloom here, is that there are some really bright sparks. When you just asked for someone to describe it in Queensland, there are some excellent things happening in Queensland. I am not sure whether you have heard any presentations from the ELDAC project, the End of Life Directions for Aged Care project.

Mr McARDLE: No.

Ms Greenwood: That is a $17 million federally funded initiative that is a consortium between some universities and also the aged-care peaks—so ourselves, ACSA and LASA—and also Palliative Care Australia and the Australian Healthcare and Hospitals Association. ELDAC is about providing support and resources for the staff of aged-care facilities so that they are better tooled up to address palliative care needs. The reason I am raising it is that the lead partner in the consortium is QUT university here in Brisbane. Professor Patsy Yates is the chair of the ELDAC consortium working group. One of the other things they have done is they have a fabulous website with a lot of toolkits to support staff and even toolkits on the legal issues. They also have phone helplines so that staff of an aged-care facility can ring at any time and say, 'This situation's happening. What do I do? Where do I go?' They also have a dashboard that they are piloting at the moment across a number of aged-care facilities across Australia and I have had the privilege of playing with the dashboard. One of the things it does is it allows the aged-care facilities to map who has an advance care plan, whose maybe needs to be updated and when it was last updated. In terms of a lot of that data that we were struggling to capture in the past around the take-up of advance care plans and aged-care directives, if this pilot is successful and is rolled out more broadly it will certainly be a tool that will give us that data moving forward.

Mr McARDLE: Other comments in relation to that point?

Ms Webby: The comment I was going to make is more around community. For people who choose to die at home, it is very difficult for them to get any support. Predominantly there are some services available that are more centre centric perhaps, so hospitals or places such as Hummingbird House, which is palliative care for children which I know you visited because it is one of our services. For those people who choose to stay at home, getting access to funded palliative care is even more difficult. We do run a palliative care service. It is supported by the specialist services run out of Queensland Health, but we get up to one hour of nursing per day in some geographical locations for a very short period of time and many people need more support than that. It is really difficult for people to have a choice about the place that they might choose to die in, even if it is coming out of hospital and going home for a short period of time. I think that is a really important thing for us to consider as a community.

Mr McARDLE: Thank you.

Rev. McWilliam: Many other countries have a hospice community. In the UK, Canada and New Zealand there are lots of community hospices. We have a few in Queensland, but it seems to be very difficult to maintain them funding wise. There is never enough funding that comes apart from community funding and volunteers. I did go over to work for two weeks in St Christopher's Hospice, which was one of the original hospices, and I think that we need more funding, we need more places and we need different types of care for people, particularly in the aged-care homes. I think at Anglicare we are doing quite well in managing those people who are coming in now more end of life in the last three months, but we have certainly got a long way to go educating our staff and having the staff ratios that we would like to have to do that well, because I think aged-care homes are going to become palliative care in the very near future. They are moving towards that. We have a long way to go in lots of spaces, but we do have lots of good things happening.

Mr McARDLE: Mr Price, you raised perhaps the elephant in the room—that is, the state-fed divide in relation to funding models and funding and also the rollout of services. The feds have the money but no expertise, mainly. The states have no money and the expertise, as I see it. How would you resolve that issue, because to me the heart of your problem is that because of that massive grey area between the two people fall through the cracks?

Mr Price: It is probably two different approaches. The system will survive in metropolitan areas. In spite of all its inadequacies and inefficiencies, the system will survive in one way or another. In small communities you have federal funding, and take an example for us like Taroom where we have a small facility and there is a hospital. The state funds the hospital. The federal government funds us to an extent. There is limited GP support in that environment. Because of that separation, it just is totally inefficient and we struggle to get RNs in those environments. For a while that hospital struggled to maintain a specialist doctor in that environment who was the only doctor in town. I think we all need to have a discussion about how you provide an integrated service in those sorts of environments and that starts by saying, ‘Forget about where the money’s coming from to start with. How do we start talking about providing aged care in those sorts of environments?’, and that is just one. That is replicated hundreds of times across the state.

I think we need to have something that involves the community and also involves the state in terms of the health facilities they provide and also involves the federal government in terms of the dollars they provide both in terms of what goes through the primary health networks and also some of the funding for GPs. There has been discussion about whether you need nurse practitioners in some sorts of environments. One of the difficulties with that is to make sure that they get access to the Medicare numbers so they can charge for the service that they are providing which is not always an automatic thing that happens. I am sure there are models out there that can do it, but it needs to be able to free up some of the regulation that prevents people from getting funding, involves the community in terms of a genuine open discussion about the best way to provide those services, involves the state in saying, ‘We’re going to ignore the stuff that happens outside the doors of our hospitals,’ and involves the funding that comes into environments like us in aged care so that we can integrate our services but share resources in those sorts of environments.

Mr McARDLE: It may well be an issue more for the royal commission given its breadth of terms of reference and funding than perhaps this body can look at in detail, but it is certainly worthwhile considering new models in relation to funding from federal to state and utilisation into new models of care, not unlike the HHSs here in Queensland when prime minister Rudd moved into a new model of funding for state hospitals. It could be looked at in that sense. Mr Price, in talking to ratios you said that ratios are a difficult issue and use a sledgehammer to solve a problem. I want to make a comparative statement between trying to put ratios in relation to aged care and hospitals here in Queensland. As you know, we do have ratios in hospitals. The profile of the resident of an aged-care facility is radically different to that of a patient in a hospital surgical or medical ward, to a large extent, and to try and impose one umbrella over all aged-care facilities, in my opinion, is a very difficult exercise because they are uniquely separate one from the other. All of you may have aged-care facilities that you could point to and say, ‘This one here is different to that one there,’ because of demographics and the like. To my way of thinking, simply to make a statement of a staff-patient ratio, not a nurse-patient ratio, is a simplistic statement that does not take into account how you implement that and, more importantly, who the guiding light is who says that Catholic Health have to do X, Southern Cross Y et cetera. Is that an accurate statement?

Mr Price: I will not call myself an aged-care expert—I am just on a board—but to me there are three fundamental things that happen in an aged-care facility. You provide medical care for the people in that facility. You provide their environment—that is, where they live, with food, with a clean environment. You also provide a social environment for them to live in. There is very clearly a need to have people with medical expertise to be able to provide that medical support. In terms of the environment and having a safe environment, having a clean environment, having appropriate food and those sorts of things, there is a requirement to provide that. The individual requirements and demands in terms of those other things are separate.

While you speak about a homogeneous group in an aged-care environment, they are not. There are as many different people and requirements in an aged-care environment as there are people. To cite an example, we have facilities where there will be individuals who are quite happy being almost detached from the rest of the people in that facility. You have other people who are very keen to be very social and talk to the other people in that environment. You have other people who you need to actively engage with in terms of making sure they are not lonely even though they might be in an environment with another 100 people. With regard to saying that there should be a fixed ratio over an environment, and accepting you need that medical clinical care, in terms of those other things the needs of every individual will be different and so it is very difficult to come up with a number.

Ms Webby: The other thing that we are dealing with more and more is consumer direction and consumer choice—their wishes about their lifestyle. Sometimes the way they want their health care delivered is different and to have a ratio mandated in that sense frustrates that principle that is a policy position we have taken across the aged-care sector as well.

Mr McARDLE: I think Michael or you, Susan, discussed the issue of a meeting in Canberra with the Department of Health and they mentioned a two-year waiting list for a level 4 package. Did they explain why that was the case or was it simply a statement without an explanation to it?

Ms Greenwood: It was really made as a statement because it was to a room of people working in the aged-care sector. We all know the reality is that there are big waiting list and really funding is probably the underlying issue there. That was really my point before in saying with the royal commission it is an opportunity for talking about what is the aged care we want in this country. We are tending here to be talking about aged-care homes are not self-contained health services. Are we talking about turning aged-care facilities—I am hypothesising—into sub-acute healthcare facilities and really that is not what most of them are designed to be. We have almost created the situation because the kind of care and the home packages are absolutely brilliant and they achieve the great aim of keeping people in their homes longer. It was Francis's point before that then people are moving into aged care with much higher needs, much higher acuities, much more significant comorbidities and so they are also moving into aged care in a state where they may be not as connected with who they were in their younger life.

I have also often heard of frustrations from staff who 20 years ago in aged care they really got to know their residents, they got to know the hobbies of the residents and what they were into and were really able to support their individual interests and needs, but now with that older demographic with the increased comorbidities they may be coming into aged care at a time when maybe dementia has quite severely taken hold of them and so they are not able to really even express who they were as far as their passions in life and their interests and so the staff are saying it is not as engaging a profession even for them to be in anymore. There are all sorts of challenges that are existing for the workforce.

There seems to be an awful lot of talk today about ratios, but I must admit I fully agree with Francis that I think ratios by themselves are a blunt instrument. We know the Oakden case in South Australia had the highest ratio of nurse to resident of any aged-care facility in the country and yet look what happened. It had it because it was a wing of a hospital that had been converted to aged care so it was operating on hospital ratios.

Mr McARDLE: I want to ask one final question. It comes from your comment about what we want aged-care facilities to be: as we knew them or a health service in some manner. Isn't our society demanding that they become a health service? For example, in Queensland Health facilities you could give birth in the Caloundra Hospital 30, 40 years ago; you cannot do that now. Isn't our society now demanding a new model? Isn't our society saying that worked well 30 or 40-odd years ago, but with increasing age, increasing comorbidities, isn't it incumbent upon aged-care facilities to move forward into the modern sense of what they should be?

Ms Greenwood: Absolutely, and that is why I am saying it is such an important discussion that the royal commission is bringing up, because if that is the aged care we want then we need to work out what the model is to deliver it and how we sustainably fund it. At the moment we do not seem to be able to sustainably fund the model we have and yet we are talking about moving into something that will be much more an intense drain on the workforce and requirements, but absolutely it is probably where we need to go because we are living longer.

CHAIR: We have gone over time. We will reduce our break to five minutes for the last session if the deputy chair is happy with that.

Mr McARDLE: I am delighted at the prospect.

CHAIR: You would have seen $17 million announced in the state budget in the palliative care space. If you had a wand, I want to get on record what you think the funding should be in terms of improving palliative care. Has anyone given any thought to what it would look like? Palliative Care Queensland will be in the next session and they certainly have their views on it, but would anyone like to comment?

Rev. McWilliam: Certainly more funding in packages for palliative care, more funding for different aspects of that—for example, spiritual care in that space.

Ms Webby: I think I would do two things: I would look at how we could build a sustainable system from a community perspective which is supported by the specialist services from Queensland Health to help more people stay at home which relieves the health system of those admissions and then I would seek to top up the bucket, so to speak, from the hospital avoidance. The second thing I would do is that there is some very good work that is happening in pockets, our Wynnum example is one, and there is other good work that is being done in Queensland Health with community and it is very different in each health and hospital network, which for an organisation like ours is a little frustrating because we are doing different things in different places, but if we could take the best of those projects and take them to scale rather than operating them in one single place we would create a different model based on evidence and change the place incrementally, I think. For me it is about trying to help people stay at home and avoid hospital and then recreate some of the good work that is happening.

CHAIR: I look forward to the outcomes of your pilot at Wynnum. I think that the committee should seriously consider taking forward integrating state HHS assistance within the aged-care facility. Any other comments?

Mr HUNT: I have a supplementary question. I am only jumping in because it is probably the most concerning thing I have heard in the inquiry so far and it was your comment, Mr Price, that only 10 per cent of people get access to good quality palliative care. Is that based on a best guess?

Mr Price: A finger in the air, but having lived in Queensland, and all parts of Queensland, and been to all parts of Queensland, if you go outside the south-east corner, aside from a few other pockets, I suggest that the majority of the area of Queensland does not have access to palliative care.

Mr HUNT: I am sure we will cover it a bit more in the next session, but it was a concerning anecdotal figure from one of the large providers of care.

Mr Price: It is not based on any research.

Mr HUNT: It is still concerning when we are talking about voluntary assisted dying.

Mr Price: It was not necessarily related to palliative care, but it was interesting, having seen things happen for so long, some really great pilots happen, but very few continue. We had some very positive results where we had a geriatrician linking with one of our sites via telehealth. When the funding finished that finished. While it was yielding great results there was no easy way to continue that sort of thing. I am sure everyone has seen trials that work that are positive and when the money runs out, trying to get back into the system to get more money is nigh on impossible and so all that you learn and all that benefit disappears.

CHAIR: I want to clarify a final thing. The deputy chair mentioned—I will have to check *Hansard*—in his opening questions no-one here has any clinical background, am I correct in that? You offered opinions about end-of-life and palliative care. The deputy chair went on to say that giving terminal sedation or palliative care at end of life is not to hasten death—and we have had a number of palliative care specialists in front of us—but it may cause the death of the patient. That is reliant upon a number of things, not just opinion but evidence based research. We have had geriatricians, oncologists and palliative care specialists talk about providing drugs to reduce pain and suffering, their initial purpose is to reduce pain and suffering but the reality is some people will die as a result of that medication being titrated and volumed up. I wanted to clarify that it is evidence based research that the medical fraternity looks at but there is none there to actually guide us. People are just providing an opinion on what their views are at that time. [redacted]

Ms Greenwood: That is not palliative care.

CHAIR: No, it is not.

Ms Greenwood: That is not palliative care. This is was my point before.

CHAIR: What is it bringing on though?

Ms Greenwood: Sorry?

CHAIR: What is that last injection bringing on?

Ms Greenwood: [redacted] I do not get how your point is that that relates to good palliative care.

CHAIR: No, it is not palliative care.

Ms Greenwood: No, it is not.

CHAIR: What it is doing is bringing on death.

Ms Greenwood: That is not what any of us are advocating for.

Mr McARDLE: It is a deliberate action to bring on death.

Ms Greenwood: Yes, it is a deliberate action to bring on death.

Mr McARDLE: If that is the case it cannot be palliative care and it cannot be palliative sedation. A deliberate act to cause death is an offence in this state.

CHAIR: I do not think it was a deliberate act, it was to reduce pain and suffering.

Mr McARDLE: Well, that is palliative care, palliative sedation.

CHAIR: We can debate this. We have had the medical fraternity talk of it.

Ms Greenwood: One of the resources that we rely very heavily on is our code of ethical standards for Catholic hospitals and aged-care facilities. There are volumes and volumes of ethical arguments about this point, and intent, from a legal perspective and an ethical perspective, is a very important element of this.

CHAIR: I think from the medical fraternity what I took, particularly from this morning's session, is that it is a fine line at that end of life of reducing pain and suffering, that is their first intent, but it may, in fact, cause—

Ms Greenwood: Really I think what you have highlighted is where we need to care for the health practitioners in this because that fine line is something that they are probably trying to draw comfort from when they are feeling pressured by the family to do something beyond—

Mr Price: Sorry, Mr Chair, I am just struggling with your point in that there is that margin around the end where people die, and I consider I am blessed, I watched both my parents die. When you talk about voluntary assisted dying, that is not something that would suddenly be signed off in a three-minute exercise at the end of life. You are talking about something premeditated, well out from that point. To suggest that what you are saying, whether you think it is palliative care or someone intervening to end their life I would suggest what they are doing is providing palliation to ease their suffering, is the same as saying we want to give someone a law that says you can choose to commit suicide are two different things.

CHAIR: But they both result in death, unfortunately.

Mr Price: Getting hit by a car results in death.

Mr HUNT: You cannot draw people into agreeing that they are already contributing to voluntary assisted dying, which is what you are trying to do.

CHAIR: I am pointing out the obvious. No, certainly not.

Mr HUNT: It is not obvious.

Mr McARDLE: It is not the obvious.

Mr HUNT: The intent is the obvious thing.

Mr McARDLE: You are drawing the conclusion therefore it must be intentional. That is my concern. It is not intentional.

CHAIR: We can debate this.

Mr McARDLE: We will debate this until the cows come home.

CHAIR: No doubt, in another room in this parliament going forward. Who knows. We have a report to produce. We are going into our final session. We invite you to stay to listen. I thank you all for the work that you do in providing care throughout Queensland in the various organisations and for your contributions today.

ADAMS, Ms Marg, Member, Palliative Care Nurse Practitioner and Program Manager, Palliative Care Queensland

HOPE, Ms Carol, State Council Member, Palliative Care Queensland

CHAIR: I welcome Palliative Care Queensland. We know the great work that Palliative Care Queensland does in this space. We welcome your contribution here this afternoon. Do you want to make an opening statement?

Ms Hope: Yes, I would please. We would like to start by acknowledging the traditional owners of the land where we are meeting today and pay our respects to elders, past, present and emerging. Palliative Care Queensland, PCQ, has a practice of following traditional owners' acknowledgement with a reminder. That reminder is that the way we care for our dying is a significant indicator of the society that we are.

We would like to thank the committee for the invitation to attend this hearing today. My name is Carol Hope and I am a member of the PCQ State Council. I am also a registered nurse with 20 years of palliative care experience, 15 of which were here in Queensland. I am currently employed at West Moreton Hospital and Health Service, but I am here today appearing in a private capacity representing PCQ.

I would like to introduce you to my colleague Marg Adams. Marg is a palliative care nurse practitioner. In fact, Marg was the first community nurse practitioner in Queensland. Margaret is also an employed team member at PCQ, and a very valuable team member at that. Shyla Mills has asked me to pass on her apologies. She is taking a well-earned couple of days break with her family.

By way of a brief reminder, PCQ is the collective voice for palliative care in Queensland. We have over 400 members. These are made up of individuals and organisations with an interest or an experience in palliative care. They include service providers from across the health and social care spectrum.

Palliative care, as I am sure you have heard already, cuts across all age groups, all disease types, all levels of treatment, all cultures and all geographical locations. PCQ acknowledges the complexity in creating equitable policy, and planning and delivering quality palliative care services across a state like Queensland. However, we believe that systemic reform in palliative care is needed to prepare for future growth in demand and ensure quality care for all at the end of life. PCQ's written submission to this inquiry presented five priorities for palliative care. These priorities were identified in the Palliative Care in Queensland Annual Summit, which was held in December last year. The summit was attended by over 200 people who work in palliative care. This is what they had to say.

The first priority in Queensland is to increase funding. The demand for palliative care is increasing and the funding is not keeping up with that demand. Furthermore, most of the funding is provided to hospital and health services through service agreements for subacute services. Much of this is hidden as well; it is not particularly transparent. However, PCQ contends that whilst most palliative care could happen in the community, the funding models are incongruent with supporting home based palliative care. PCQ has provided a number of recommendations about funding including making funding easier to access home based care including aged care.

The second priority is increasing access to palliative care services. Our community expects equity of palliative care across service delivery regardless of age, diagnosis, cultural background or geographical location. However, our data shows that there are many gaps in access to palliative care across Queensland, and I am sure you have seen many of those on your travels. One example is that whilst approximately 30 per cent of deaths in Queensland are caused by a malignancy, over 78 per cent of the people accessing a secondary or tertiary palliative care service have a malignant diagnosis. The question is: what does this mean for the 70 per cent of people dying with a diagnosis other than cancer? PCQ acknowledges the excellent work going on in our state to improve access, but more needs to be done—for example, increasing the trained palliative care workforce, sustainable funding models in regional and remote areas, and collaborative connected service delivery models.

Our third priority is around activating the community to be more involved in palliative care. We know that our professional care is struggling and we do believe that by using a public health approach to palliative care, we can assist with that professional care through supportive networks in our community.

The fourth priority for palliative care is a focus on advance care planning. The evidence tells us—and I am sure you have heard this as well—that completion of an advance care plan translates to more people being cared for in their place of choice and, more importantly, fewer transfers for death and at the end of the life from home to hospital care. We want to see that continue.

The fifth and final priority for palliative care in Queensland is to develop the health workforce. The need for palliative and end-of-life care has grown significantly over the last 20 years and will continue to grow well into the future. We need to have a whole-of-system approach to palliative care that includes the whole health and social care workforce. Not everybody needs specialist palliative care support. However, specialist services are reporting more and more referrals for care in the last few days. Palliative care is everybody's business and most people should be able to experience quality palliative care anywhere within our health system.

Finally, I am sure you have been bombarded with a raft of statistics and numbers during the course of this inquiry. However, PCQ asks you to remember just one: one out of every one Queenslander will be affected by death, dying, grief, loss or ageing during the course of their life. How often are any of us able to say we have been part of a process that has the potential to influence quality of life and death for every Queenslander? The work of the committee in this inquiry is incredibly important and PCQ thanks you for the work you are doing.

Mr HUNT: We have heard a couple of times today—and you just mentioned it then—about funding models, boundaries and HHSs and how that impacts service delivery. One of the palliative care specialists earlier indicated a hub-and-spoke approach. Would you advocate something like that, almost a mobile palliative care workforce?

Ms Hope: I think what we would advocate for is looking at a local level what those models might look like. In some areas a hub and spoke would work really well, as long as you do not then end up putting that pressure on to the palliative specialist service, for example, in the remote areas. Particularly in North Queensland we really have only one substantive service in Townsville that would be servicing the whole of North Queensland. Hub and spoke is really important and it is a proven model, but there will be some areas where we might have to be a bit more creative.

Mr HUNT: Were you here for the last session when—

Ms Hope: Part of it, yes.

Mr HUNT:—we heard the statistic—it was a best guess; it was not a statistic borne by any evidence that was presented to us—that only 10 per cent of people get access to good-quality palliative care. Can you comment on that or give us your best guess?

Ms Hope: The best way to put that is probably we do not know. I know that is not what you want to hear me come out with; you want facts and figures. The reality is that we do not know. We know that there are about 31,000 deaths in Queensland each year and that is increasing by about a thousand a year at the moment. We can look at how many people are being seen by palliative care services through our PCOC data and we know we can look at separations. The separations from hospitals and health services tell us that there have been around 11,000, so a third of all deaths have been—not deaths particularly. You can kind of work the two out. The best guess, the best case scenario, is that we are seeing a third. My sense—and I think PCQ's sense from our experience—is that it is a lot less than that. I think it would be somewhere between 10 and 20 per cent. It is really difficult because how do you collect that data? Who defines what a palliative care patient is? In actual fact, depending on where you go in our state there are different criteria as to how we define a palliative care patient because it is all linked to how patients are funded.

Mr HUNT: Is it the case that there are people requesting services who are not getting them?

Ms Hope: I think, yes, in some places there are, absolutely—where people are asking for access to services and they are having to wait, because the services that are available are full and they cannot get on to a list. I think that, largely, in the metropolitan areas, because we have more services here, we do not necessarily have that issue, but certainly out in rural and remote areas people are having to wait, often in hospitals, to be able to either go home or back to their residential facility.

Mr HUNT: In your submission on voluntary assisted dying, or euthanasia, you do not take a position, acknowledging that members have divergent views, but you made the point, 'the following possible assumptions be addressed,' and the first one is, 'Not assume everyone who requests to explore VAD will already be receiving Specialist Palliative Care.'

Ms Hope: Absolutely. Between Marg and me we probably have 50 years of palliative care nursing experience behind us. We have spent a lot of time around dying people. I can honestly say that we do not get those requests very often through palliative care. I am not saying that they come when they do not have access to it but, for us, we cannot make the assumption that all of these people are going to go through palliative care and we cannot make the assumption that they are not.

Mr HUNT: The second point is not to assume that specialist palliative care will be the main provider of voluntary assisted dying.

Ms Hope: Absolutely. Our position at the moment is that voluntary assisted dying and palliative care are not congruent particularly. We do not own dying. Palliative care does not own death and dying. We provide an expert body of knowledge and skills to people who have specific needs at the end of life. That is specialist palliative care, but when we talk about palliative care more generally, again, nobody owns death and dying. We should never make the assumption that this is going to fall in a place for palliative care services to deliver.

Mr HUNT: I think earlier somebody said that palliative care provides dying with dignity, but that seems to be hijacked by voluntary assisted dying.

Ms Adams: In terms of clinical experience and also some recent experiences in working on a project that we are supporting through the North Queensland PHNs—the HHSs around Mackay, Townsville and Cairns—and also having compassionate community service conversations throughout Queensland and being able to hear the voices of clinicians, workers and carers, we recognise that we talk a lot about specialist palliative care but there are services that are being provided by general practitioners day to day that are supporting people with multiple complexities and comorbidities that may be malignant or non-malignant conditions where people are being supported very well to live and, when they die, we will see good outcomes.

When you talk about the outcome measures across hospitals—and I have worked across all avenues of care in my 35 years of nursing—you will see different approaches to collecting information that can give you an indication of the value of the service and the experience for the person. We believe that the important thing to remember with Palliative Care Queensland is that, central to whatever we are doing, there is a human being who has a support network around them, or they may not if we are talking about the homeless and the marginalised.

Mr O'ROURKE: You touched on the difficulty with services in rural and remote areas. Do you think that there is a better way of delivering those services such as using the Royal Flying Doctor Service, for example? Do you have any suggestions on how we can improve the delivery?

Ms Hope: Absolutely. We have just done a heap of work with the department around rural and remote areas and what people are thinking, what the communities want and what clinicians need. I think there is a lot that we can do. We have to be really clear that we are not suggesting for one moment that we need specialist services in every township across Queensland. That is absolutely unrealistic and is not needed at all. What we do need, though, is support structures at the system level around whoever is providing that care, whether that be community services, or whether that be the small hospitals in those areas. We need to be able to put the support systems around that.

One of those is the hub and spoke that we talked about earlier. One other is where you have things like a 24-hour line where people can make contact—having specialist doctors potentially from the south-east corner on call for the state to support those places in their need. I think we also probably need to understand that there are certain things that people need at the end of life if they are going to die at home. Those things include equipment. We need to be able to provide that to those people regardless of how difficult it is. At the moment, we hear stories—and I think you will probably read one in our submission—of having to call the local gardener who happens to have a trailer to come and pick up a spare bed at the hospital to take it to a patient. We need to get on top of that kind of thing. We cannot have an ad hoc system depending on who they happen to get in contact with. We need to have a system around that. It might be expensive and we have to accept that. We are not expecting there to be a gold plated specialist in every town, but there are certain necessities that we should be expecting.

Ms Adams: Thank you for asking the question. In thinking about different models of care in terms of advance practice nursing—and I have had something to do with that given my experience as a nurse practitioner—my endorsement was in 2007, so I have seen a lot of change in legislation and the applicability of the advance practice model in communities. In terms of experience, I can say that there is great capacity for growth and extension of nurse-led models in communities. When we look at the continuity of acute care in communities and supporting and value-adding to services that exist currently, through research they have been demonstrated to be effective.

The other thing is looking at the capacity of communities. That is one of the biggest things. Why I feel very excited to represent Palliative Care Queensland is to say thank you for listening to Queensland. That is what we are being told when we go out and about—that there is not a lot of opportunity for people to be able to tell their stories. That is at clinician level and community level. If we listen well we can find out that, in terms of capacity, the community can do quite a lot. I grew up in a country town, so I can imagine neighbours caring for neighbours. What is a compassionate community? We talk about that and we look at strengths within communities.

When we talk about specialist palliative care, and having worked in specialist palliative care services, they are there to support and value-add to the general practitioners who are providing palliative care every day. When you look at capacity and you look at communities, you see that sometimes rural communities can have a very good structure. I think where it gets tricky is around looking after people, particularly those who are younger than 65 years of age—when you have the man or the woman who are in their 40s or 50s dealing with a neurodegenerative disorder, such as motor neurone disease or multiple sclerosis, or you have early onset dementia or Alzheimer's. You have people who are not able to connect as community members. Palliative care is not all about the symptoms and burden of disease; it is about being able to connect as a human being and being part of a society and living well until you die. Communities have a big part to play in that.

Yes, we have gaps for specialist palliative care services. We could work smarter in terms of workforce capability and confidence, particularly in residential aged care. We have been working very closely with North Queensland and have a body of work around that. In terms of looking at building the capacity of communities to support individuals who are dying, we could invest a lot into communities.

Mr O'ROURKE: Thank you for that.

Ms PEASE: I just wanted to make a comment. I acknowledge the great work that you do. Palliative care workers are invaluable. Thank you very much for your dedication and the work that you do for the people in our communities and the support that you give to families and carers. It is very much appreciated.

Ms Adams: Thank you. It is a privilege.

Ms Hope: It is absolutely a privilege.

Ms PEASE: It is a privilege, is it not, to be able to do that?

Ms Adams: It is not all doom and gloom. I am thinking of a lot of the happy times. I think the thing is to remember that there can be a lot of joy given. If you ask many people what matters to them most—and that was our theme for National Palliative Care Week—what matters most to them is not their diagnosis, it is the dog, or their connection with family, or being able to jump out of a plane and so on. I am not trying to simplify the fact that we have some issues, but—

Ms PEASE: Your comments around the capacity of communities are interesting. We have just done a trip out to Longreach and met the wonderful Marlene, who is a palliative care specialist out there. She does an amazing job.

Ms Hope: She is just fabulous.

Ms PEASE: The whole community does. That is a wonderful statement and there is evidence to support your statement.

Ms Adams: Thank you.

Ms Hope: That is where I think the third or fourth priority that we talked about comes from. We always think about the health services. We really have got into a system-led model. We are trying to flip it on its head to being a needs and individual holistic-led model. The community is a big part of that. It is different out there. People in Longreach look out for each other, because they have to. I may not know my neighbour next door at The Gap, but out in those rural areas—

Ms PEASE: They do.

Ms Hope: It is different. Yes, absolutely.

Ms Adams: I think people in communities have lost their confidence to ask each other how they are doing. Probably three-quarters of my nursing life has been in the primary care setting. Carol is probably the same. When you are looking at general practitioners and primary care providers—your residential aged-care teams—the biggest thing is they need to phone a friend. They can do a lot. They are quite amazing and resilient but they need to have somebody they can brainstorm with. There are a number of programs that are available that have worked really well within emergency departments. With your low acuity response units—LARU is the terminology—in Cairns, they are able to do some troubleshooting and not have to take these elders out into an acute bed in the middle of the night to deal with their issues. They can support, enable and build capacity and confidence. There is a lot of work to be done to start to have some collegial respect among the sectors. The residential aged-care community is doing some amazing work.

CHAIR: Member for Lytton, I can only echo your sentiments.

Mr McARDLE: Page 4 and up to and including page 8 of your submission contains the recommendations covering funding, care services, community, advance care planning and workforce development. It is a very strategic document. You have very clear guidelines and, shall we say, KPIs. You also make the comment that we need to have our own palliative care strategy document that sits alongside end of life, or complements it.

Ms Hope: Yes.

Mr McARDLE: Do you feel that that document should be a stand-alone document to take into account these recommendations that can sit side by side with the national strategy and the end-of-life strategy as well?

Ms Hope: Yes is the simple answer to that. I would say as well, though, that that particular recommendation comes from a place of a little bit of frustration as well. Palliative care affects us. I keep saying that it affects every Queenslander at some point during their lives, yet we do not have anybody within our Department of Health that singularly holds a portfolio of palliative care. It sits across what we understand to be three departments. It has been incredibly difficult to navigate that, because funding comes from one place, strategy comes from another and then we have the end-of-life project in another. These sit within different divisions of Queensland Health. I think one of the things moving forward for Queensland has to be that this comes into one place and that it is recognised as being an important part of what we do in health care and beyond.

Mr McARDLE: It should sit under a deputy director.

Ms Hope: Yes. It needs a home. It is very difficult to navigate through that system. I understand the different functions of those departments, but that is where that one strategy comes into place where there is one source of truth.

Mr McARDLE: I understand there are 16 HHSs in Queensland. Each operates independently of the others in relation to how they roll out, if they roll out, palliative care. Your model would look at an overarching body that would cover all HHSs. Am I right in saying that?

Ms Hope: Our model would see that there would be a single place within the system manager, which is the department, that would then provide that policy framework for HHSs to work within.

Mr McARDLE: Yes, so there would be a uniform policy across—

Ms Hope: Yes.

Mr McARDLE: There would need to be individual differences, wouldn't there?

Ms Hope: Absolutely.

Mr McARDLE: It is obvious that we are a far-flung state.

Ms Hope: Absolutely.

Mr McARDLE: It would be overarching but realising the distinction between Metro North and, shall we say, Central West?

Ms Hope: Absolutely. That is the beauty of our system and the fact that we have this huge state is that we do have that opportunity by having the HHSs to be able to meet local needs. At the moment the situation is that there is no overarching expectation, policy or KPIs that everybody has to meet. What that then translates to is that it really does depend on where you live, what your diagnosis is and how old you are as to what services you can access and, more to the point, how you can get funding to access those services.

Mr McARDLE: Fundamentally, it also dictates the HHSs' attitudes towards palliative care as to what they put into the field.

Ms Hope: I am not sure that I would be brave enough to say that.

Mr McARDLE: I will make the comment. You may say, 'I don't know,' but my concern is that individual HHSs, if they have that individual silo, have the capacity to differ from the next HHS with similar demographics potentially, theoretically.

Ms Hope: Yes, absolutely.

Mr McARDLE: I understand that you do not link palliative care to voluntary assisted dying. They are quite distinct topics and you say that they should not be mixed in relation to one leading to the other. I get that. Palliative care, end of life and voluntary assisted dying are three elements of the one question—how a person passes away. Would you say that discussing those three topics together to get a fulsome picture of what is available in regard to each of those headings is important to inform the community as to what is taking place?

Ms Hope: I think we can understand and acknowledge why those three subjects have been put together for this inquiry. It makes sense on one level, but there are risks in that obviously people think that they are very much synonymous with each other when they are absolutely not. I understand from a legislator's perspective and from parliamentarians that, yes, you need a full picture. My concern and our concern at PCQ is the message that gives to the community, but it is our job to make sure that we have our own key messages around that.

Ms Adams: Bringing it down from a strategic level to the coalface and the people that we deal with day to day in practice, I think that over time we have become not just medicalised but we prescribe to people what they need in terms of care and services. We should flip that and ask them, 'What do you need at the moment?' and explore those options and then have policies and procedures to refer people to. It is like if a child asks a question about the birds and the bees and you go a little bit too far into that description about what it is and they come back and say, 'I just wanted to know: do they live in a flower?' We think we know what people are wanting but we do not listen very well, and I can say that after 35 years. We really do need to listen more to what it is people are wanting.

Ms Hope: One of the questions that I am asked all the time, because obviously my friends and family know my background, is: if we get voluntary assisted dying laws in Queensland, how many people will be really interested? The reality is that we do not know. We have absolutely no idea because we do not own death and dying. We see a very small proportion. We can only talk from experience. We have no idea. We try not to engage in that conversation with the community because we do not want to mix the messages around palliative care and voluntary assisted dying, but we make it really clear at the same time that our position is very neutral and it is up to you as a committee to decide that.

CHAIR: Thank you very much to both of you. I think you articulated the point that they are two very separate things—voluntary assisted dying and palliative care. All I can take from the significant interactions we have had with PCQ to date is that your contributions have been welcomed by the committee. I hope that the money you saw coming out of the state budget is a step forward. They are obviously watching what we are doing very closely. My question is: if you had a wand and you had the ability to put a dollar figure on it, what would you like to see in terms of improving patient care?

Ms Hope: I am going to go absolutely ridiculous here and tell you that we need $100 million—a hundred hundred million dollars, not $100 million.

CHAIR: $17 million is a good start.

Ms Hope: Yes, $17 million is a good start. Let me set the scene and tell you the reason why I would love to be able to give you a figure but I cannot. Again, I am sure you have heard a lot of conflicting statistics, numbers, dollars and amounts. Palliative care is really difficult to price. There are far smarter people than us who have been working on this for many years. You cannot put a dollar figure on it for many reasons. One is the fact that funding comes from so many different funding buckets. You have hospital and health services. That is the one we can look at because we can see in terms of activity and what is happening in that subacute specialty how much is being spent, and there are the service agreements with the hospital and health services.

What we do not know is when we look at things like aged care how much of it is being spent in palliative care. We have no idea. We know that not everybody in aged care who requires palliative care is even labelled as requiring palliative care because they can get more money by using other mechanisms. Then we have aged-care packages. Who knows how much of those are going towards palliative care. With a two-year wait for aged-care packages in some parts of the state, we are trying to meet that demand through what is called Commonwealth home support program funding, but again we do not know how much of that is specifically going to palliative care. We know that our community services are having to look at different pots of money to try to meet the needs of individuals within their service group. If you then add in the under-65s in the community and the NDIS, we have no idea.

What we do know is that we estimate around $100 million is currently spent through the hospital and health services. If we use that very conservative figure of a third of all deaths, we would then work that out to be maybe $300 million but that is just in the hospitals. That is to provide the service to the level that we are providing now, and we know we have lots of gaps in service—for example, spiritual care, bereavement care and those kinds of things. We need an expansion of nurse practitioners and all of the things that we need. I am going to go with a hundred hundred million dollars. How much is that? Is that $1 billion? I was never good at maths.

Mr HUNT: $1,000 million to $1 billion.

Mr McARDLE: I wish you all the best with that.

Ms Adams: Can I say on behalf of the workforce particularly in residential aged care and the general practitioners in our state that we value the work and contribution through education and the availability of our unregulated workers who actually make up over 60 per cent of the workforce in residential aged care. They are very thirsty for training and support. Having a mobile workforce that is able to reach people face to face is a really good thing, as well as supporting GPs.

Ms Hope: Can I add one thing? I would not expect for one minute that that figure comes from the state government. That is ludicrous. We know that the vast majority of palliative care happens in the community. What I do think we need to do is start looking at needs and needs based care rather than putting people into funding boxes because that is what we do at the moment—looking at where we can get little bits of money that then makes them a palliative care patient. We need to work together—state and federal governments—to look at a system. I think I was there for the previous health reform when the ABF funding was all brought in. We can do that again for the community and work together to find a more suitable system, a model, around funding appropriately, understanding that people have different needs at different parts of their journey.

CHAIR: On behalf of the committee, I thank Palliative Care Queensland for the work that you do. We look forward to engaging with you throughout this process.

Ms Hope: Thank you for the opportunity.

COLEN, Dr Sue, Private capacity

CUMMINGS, Ms Georgia, Private capacity

TENNYSON, Mr Ben, Private capacity

CHAIR: Welcome, Georgia Cummings, Dr Sue Colen and Ben Tennyson. Thank you for being here as long as you have. I hope you have taken some good things from today, particularly from that last session with Palliative Care Queensland. It has been an interesting day for all of us. At the table we have Ms Georgia Cummings, who is a retired palliative care nurse.

Ms Cummings: Yes, that is right.

CHAIR: How many years experience do you have?

Ms Cummings: Twenty-eight years.

CHAIR: Just a few! Thank you. We have Dr Sue Colen, who is still practising.

Dr Colen: Yes.

CHAIR: Thank you very much for being here. We have Mr Ben Tennyson. Ben, we appreciate the difficulty that you have had in dealing with a loved one. I can only say that because your submission is not published at this point. I just remind you that we are not a complaints commission, but we will take anything that you can offer in terms of how we can better improve palliative care, aged care and end-of-life care. We have the Office of the Health Ombudsman and other avenues for any complaints going forward. I just wanted to set the tone.

Mr Tennyson: I am certainly not here to complain, but I am here as someone from the community to share my lived experience.

CHAIR: Thank you for being here and for staying as long as you each have. I might start with Georgia. Would you like to make an opening statement? We will move from left to right and then we will ask some questions.

Ms Cummings: I am here as a community member as well. Although I am no longer working clinically as a nurse, I tutor at the University of the Third Age and I teach meditation and self-compassion practice for my peer group. I am 71, and people in my class range from 55 to 85. We often have healthy discussions about voluntary assisted dying, about dying at home and about end-of-life care. It is on the radar once you get to our age, so you have no trouble thinking about it. It is not something to be scared of.

I am very interested in the fact we are having this debate soon about voluntary assisted dying. It would be almost unanimous in the people who come along to my classes at U3A. They are all interested in having a choice because none of us wants to end up in residential aged care. The more stories we hear, the stronger our desire to have a choice becomes. I think it is wonderful that we have the End of Life Law in Australia website from QUT, which is so informative and helps people to understand the difference between euthanasia and voluntary assisted dying.

I was interested in the previous discussion about nurse-led models because I strongly believe that palliative care needs to be a nurse-led model because end-of-life care is nursing. Although we need medical care, essentially it is nursing care. That is something that I think would definitely be a good solution.

I am also interested in the dying trajectory. I heard some discussion about how much palliative care costs. A lot of good research has been done in working out the cost of the stages of illness, whether it is heart failure, cancer, motor neurone—whatever it might be. There are different stages in each illness and you can work out what the costing might be for each stage: the early stage at diagnosis, the stage where the person is deteriorating and then those last days—perhaps the last seven days. It is possible to find research on that which would probably help to ascertain how those various stages might be funded.

Lastly, when someone receives a diagnosis of a terminal illness or they are an older person, they might be told, ‘You’ve got heart failure. You probably have two years.’ When a family is expecting a baby, usually there is a visit to the GP, then you are referred to an obstetrician and then you are registered with a hospital. However, it does not really happen like that in palliative care. It is very ad hoc; it is not structured. Although there is a wealth of information about palliative care and all sorts of tools and training for aged-care nurses and certificate III workers, people do not realise how much is already available that they can access. For example, for me in South Brisbane, I can go onto the website for Queensland Health and I can find out what services are available close to where I live. Helping people to understand how to find the information would be good. I did bring a piece of paper about death literacy because I recently held a death cafe with a colleague.

CHAIR: We are about to have one in Townsville from the people who came to the Townsville hearing.

Ms Cummings: A death cafe is a really good idea to have an informal conversation about death and dying and to find out people's views and opinions.

CHAIR: We just have to procedurally table this. Leave is granted.

Ms Cummings: It is from some research that has already been done. I just took some points from it.

CHAIR: We think advance care planning, being informed and health literacy is absolutely something we have taken on board to date. Have you had 28 years of nursing in palliative care?

Ms Cummings: No. After my graduation from hospital based training, I was working in acute care in mental health and drug and alcohol nursing. Then I kind of gravitated towards oncology nursing and then palliative care.

CHAIR: How many years experience in oncology nursing and palliative care do you have?

Ms Cummings: I suppose from 1989 until I retired in 2009.

CHAIR: Thank you very much. I will save some questions for later.

Mr Tennyson: Thank you for the opportunity to participate in this public hearing. Tonight I am delivering a prepared statement as a community representative. I have been reading the inquiry submissions with interest and noted their emphasis on whether an individual does or does not have the right to end their own life. However, the reality of both hospital and community palliative care is largely absent from this narrative.

In 2018 my mother spent over 100 days in the Prince Charles Hospital palliative care unit before being sent home, without her consent, to die. As someone who visited palliative care every day during this time, I believe I am in a unique position to share our family's observations and experiences. I appreciate the panel has had the opportunity to read my submission, but I will provide a brief account of my mother's palliative care experience for the benefit of the audience. I also invite both the panel and audience to consider whether some aspects of this account constitute abuse.

My mum was diagnosed with colon and liver cancer in early February 2018. She was a patient with private health insurance in the public health system at Brisbane's Prince Charles Hospital. After four rounds of chemotherapy, mum was unable to leave her bed at all and was almost exclusively dependent on others. She was, however, able to communicate effectively. In early May a senior oncologist advised that mum had approximately two weeks to live and transferred her to the palliative care unit. It should be noted that 30 minutes prior to this decision, the medical team incorrectly informed me they would be transferring mum to Brighton for mobility rehabilitation.

At the palliative care unit mum completed the hospital statement of choices document and in response to one of the questions clearly identified that she wanted to die in hospital rather than at home. Despite the senior oncologist's prediction, mum went on to spend over 100 days in palliative care where both she and our family witnessed decisions and incidents ranging from deeply disturbing to simply unjust.

While on the oncology ward, mum was given a pressure pad pendant cord, a more sensitive hospital buzzer, because she no longer had the strength to press a regular buzzer. This buzzer was taken from her in palliative care and given to another patient. I was told this decision was based on need and that there were only a couple of pressure pad pendant cords in the hospital.

The Prince Charles Hospital apparently conducts 30-day reviews to determine the most appropriate setting for patients and whether they should be transferred elsewhere. We were not informed of this process or remotely aware that mum may be sent home from palliative care until well after the second review. Without her consent, the hospital informed mum she would be discharged from the palliative care unit as her condition was stable and she was declining slowly.

When a family member asked the palliative care doctor, 'So basically, you're saying she's not dying quickly enough?', she replied, 'That's right. That's right.' As a family, we repeatedly challenged that mum's condition was stable and requested to see the hospital's policy regarding the discharge of patients from palliative care. The hospital was unable to produce this information and were dismissive of mum's wish to die in hospital as indicated in the statement of choices.

It should not be assumed that a palliative care health worker is compassionate by default. Mum was subjected to highly inappropriate and unprofessional remarks by nursing staff on numerous occasions. 'The sooner you accept your fate and believe in God or whatever it is you want to believe in, the better off you will be.' 'They're just like lollies, aren't they?', after requesting breakthrough pain medication, and a nurse to a student nurse, 'When they've been in here for over 100 days you get to know their number.' The nurses who made these comments are rotated as team leaders. It is deeply concerning that staff with such a deplorable level of professionalism are considered fit to supervise their colleagues or trainee nurses.

After being discharged from palliative care, mum revealed that on one occasion two nurses were having obvious conflict and tried unsuccessfully to engage her in their disagreement. After they left the room one of the nurses came back and tried to engage mum again. Mum raised her hand slightly to indicate she did not want to get involved. The nurse allegedly said, 'Don't you point your finger at me. I'll put a pillow over your head.' Mum did not tell us at the time because she knew we would make a complaint and was concerned about the possible repercussions if she had to return to the unit. When the incident was reported to the hospital, Human Resource Services failed to contact or interview family members about this allegation and then dismissed it in an email stating, 'There is not enough evidence to substantiate the allegation you have made.'

Mum passed away approximately four weeks after being discharged from the hospital. Ironically a letter arrived shortly after her death asking whether mum, a pensioner, wished to continue to donate to the Prince Charles Hospital. Some palliative care patients may consider dying in their own home preferable to dying in a palliative care unit, but I remain unconvinced that Queensland Health has the resources or workforce capacity to support this option.

What did being discharged from palliative care to die at home look like for my mum? It has being told your condition is stable enough to travel in an ambulance, even though you have not left your bed for 100 days. It is vomiting continuously on that journey from the hospital to home because your body has not experienced motion for so long. It is house plans, photos and door measurements being provided on request to a hospital occupational therapist to plan re-entry into the home only to learn on the morning of discharge that this information has not been shared with ambulance officers. It is being moved out of an ambulance, back in and then out again in showery rain while a transfer solution is found—namely, being placed on a canvas sling spread on the front lawn in front of your neighbours.

It is a qualified therapist at the Prince Charles Hospital saying it will only take 15 minutes to train family members in manual handling. It is arriving home to negligible services because your My Aged Care application has not been processed even though staff at the palliative care unit have advised that this would not be the case. It is learning that you are entitled to five hours per week of Blue Care in the final weeks of your life and that if you soil yourself outside of these hours, your family will need to perform manual handling tasks to undertake your personal care. It is staff from Blue Care and community palliative care visiting the house at the same time and openly arguing with one another in front of you about what tasks they will and will not perform because their roles have changed. It is community palliative care informing you that they will only become involved in your mother's support at the absolute point of death, at being unable to articulate how anyone could possibly know when that will be. For the record, they were not present at the point of death.

It is two siblings without any medical training standing either side of a bed in the middle of the night trying to make a decision about whether to administer Midazolam subcutaneously to their mother, who can no longer speak or communicate her needs. Perhaps most frighteningly, it is that small number of Queensland Health staff, the good ones, recognising and initiating conversations about your concerns and quietly encouraging you to make noise because they believe the public health system is inherently flawed.

During the time my mother spent in palliative care I was compelled to write several letters to Steven Miles, Minister for Health and Minister for Ambulance Services. The reply correspondence written on his behalf was consistently incorrect or poorly informed, evasive and dismissive. Minister Miles also declined to meet with me personally. With this in mind, I would like to present a range of recommendations for the panel's consideration that may inform palliative care service provision in Queensland.

These include: the writing and implementation of a clear policy about the discharge of patients from Queensland Health palliative care facilities; the development of an easy English version of this policy that is physically accessible to palliative care patients in hospitals; the provision of general written information about palliative care to patients and their families on admission or made available in patient rooms; a review of the legal rigour of asking a patient to identify in a statement of choices document where they wish to die and then transferring them home when they have requested in writing to die in hospital; a systemic analysis of the number of community palliative care patients and the available community palliative care workforce and whether this model can be effectively and sustainably resourced and operationalised; clear definition of the roles and responsibilities of community palliative care as opposed to external organisations; that no palliative care patient is transferred home prior to their My Aged Care or similar care plan being processed and timetabled services put in place; that Queensland Health staff adhere to professional standards and are genuinely held to account if their conduct is inappropriate; that patients and family members are actually interviewed by Human Resource Services at the Prince Charles Hospital or equivalent branch at other hospitals when an allegation of harm by a Queensland Health worker against a patient is made; that pressure pad pendant cord buzzers are standard issue for all palliative care patients; and that consideration is given to the design and infrastructure of future palliative care facilities so that patients do not have to witness the door to their room being closed, sometimes several times a day, while the bodies of recently deceased patients are removed from the unit.

In closing, I hope this account may provide a voice for the diverse community members I saw at the Prince Charles Hospital palliative care unit who may not have had the skills to advocate on behalf of their dying loved ones. This includes people with disability and people for whom English is not their first language. It would be easy to dismiss the issues I have raised as grief related or the discontent of someone with unrealistic expectations about the public health system, but we will all die and may one day find ourselves as palliative care patients seeking appropriate choice, care and dignity.

CHAIR: Thank you very much, Mr Tennyson, for sharing that deeply personal story of you and your mum and family. It is difficult to go on from here. You have made some recommendations which we will take on board with regard to forming our recommendations on how we better deliver palliative care, whether it be in a hospital or community based. Some of the issues you raised with regard to My Aged Care are nothing we have not heard throughout Queensland where plans are not put in place and funding is not there. It is certainly concerning when we hear of limited hours of nursing contact in those last days or weeks. We do appreciate you sharing your very personal story with us.

Mr Tennyson: Thank you for the opportunity to share the truth.

CHAIR: I will move on to Dr Sue Colen.

Dr Colen: Thank you for the opportunity to appear this evening. Ben, I offer you my sincere thoughts on what has been such a difficult time for you and your mum.

I have spent 25 years as a GP and my submission is from me personally. The last 10 years I have combined that with palliative care. I have looked after people who have died at home, in hospital and also in residential aged care. I have looked after people with life-limiting illnesses. I would draw a distinction here between palliative care and end-of-life care, because palliative care is much broader than just end-of-life care. A lot of involvement with palliative care is people who have been diagnosed with a life-limiting illness who have symptoms that need specialised help. There is certainly evidence to suggest that people with life-limiting illnesses, if engaging with palliative care earlier on, can sometimes live for longer because their pain is treated and other symptoms are dealt with.

My observations from my work as a doctor are that death is profound, final and universal. Quite often in my experience patients will express they are not afraid to be dead. Most, though, will have fears about the process itself, and that fear can include fear of symptoms—they are worried about pain and shortness of breath in particular—but they also have fears that are of the unknown and leaving family and loved ones. Sometimes in the medical profession we have not been as astute as we could have been in helping to address the fear of the unknown with people. We tend to go straight to what we hope we can do for them.

The last 50 years have seen huge medical advances. Surgery that was previously not contemplated because it was so invasive can now be done much less invasively, so people are living much longer lives. People’s lives are extended and ageing has become unpopular. The question of the usefulness of treatments is a difficult one that I do not think we are addressing particularly well. We would all, I am sure, have personal stories of the death of family members and loved ones. That death is associated for all of us with grief and sadness. From my experience there is most often a consideration of what could have been done differently. Could a symptom have been picked up earlier? Could the method of death have been different? Each death is individual and, like birth—I liked the fact that you referred to birth, Georgia—it can be slow or fast.

I have thought about birthing recently after Prince Harry said, ‘Wasn’t Meghan fantastic! What women have to go through!’ I was reminded that birthing is most frequently an undignified process for the mother, although she will be treated with dignity by those attending her. So it is with death. I would be hopeful that the person dying—I am sorry, Ben, that this has not been your experience—would be treated with dignity by health professionals, though there may seem to be some elements that are undignified at times. I think it is an interesting distinction. For instance, people can get rattly breathing at the end which sounds undignified to people looking on, but we do not think that for the person concerned it is something they are conscious of. Obviously, people's lack of control of some body functions they feel is undignified. So too people with disabilities feel they live with many indignities, but we still want to approach their lives with dignity.

Palliative care is well placed to offer comfort of symptoms, not just at the end of life but during the illness. Suffering also exists alongside physical symptoms—suffering associated with decreased mobility, the fear of death itself and anxiety for loved ones. Palliative care also seeks to give acknowledgment to this aspect of suffering. It is an area where palliative care could do with a lot more social workers, psychologists and pastoral care workers to offer help in the area of nonphysical symptoms.

A doctor's role has been to be a healer. Legalising healers in our society to be able to administer lethal injections, both as drugs or as an injection, I think sends quite a confused ethical message to our society. Certainly, I, for one, as a doctor, do not want to be involved in needing to administer doses of medications that will kill people or injections of medication that will kill people. My submission says that I am not in favour of voluntary assisted dying.

CHAIR: Thank you very much, Dr Colen. We appreciate the sharing of your personal views and experiences.

Mr HUNT: Talking about dignity is a nice way to end the day. Georgia, in terms of speaking with your peers, the concerning thing to me about what you said was the talk about wanting access to voluntary assisted dying. I expected the next sentence to be something along the lines of 'not wanting a bad death', but it was 'not to enter a residential aged-care facility'. I get that concern about the loss of dignity, loss of control or loss of mobility. People who go into residential aged care do not necessarily have a terminal diagnosis.

Ms Cummings: No, but they are vulnerable and they do not feel safe.

Mr HUNT: I validate your feelings; I get that. I understand what you are saying too, Doctor, about how we overcome that. It was a good way to end the day. Thank you both for your contribution. How you feel is important, but how we treat others and how we overcome those feelings is important as well.

Ms Cummings: It is not humane.

Mr HUNT: What in particular?

Ms Cummings: The things that we are hearing about people's experiences in aged care and even what Ben was saying. I was ashamed to hear some of those words spoken by healthcare workers. It was just—

Mr HUNT: Absolutely. We visited a lot of residential aged-care facilities and saw quite happy people taking part in activities. It can be quite enjoyable, but I understand your fear. I appreciate you bringing that information from your peer group about how they feel.

CHAIR: We have gone over time. You have significant experience between nursing and practising palliative care. In your time did you have people say to you, 'Just end it all. Take it away. I want to go. I'm done.'?

Ms Cummings: I have.

Dr Colen: I think there are three groups of people that talk to you about wanting to end it. The first group say, 'I'm finding it difficult to adjust' or 'I hate feeling that I'm dependent. I don't want to see my family have to suffer.' Often when you talk those people through what their fears are you do not hear them ask again. The second group of people are very much at the end of their life. They say, 'I've had enough.' They are probably within the last weeks of life. They will say, 'I've had enough. I'm ready to go.' That is normally the way they would ask: 'I'm ready to go.' They feel that they have lived life and they are ready to go. The third group, a very minor group, seem much more committed to the fact that they are determined to end it.

CHAIR: Do they ask for medication?

Dr Colen: No, but people can get medication. There was a Brisbane writer named Cory Taylor who wrote a little memoire when she knew she was dying. She sourced medication from China and she had it in her cupboard. Then one of the palliative care services became involved with her and she did some biographying of her life. She understood that her condition was leading to her death, but she came to make the most of the time she had left and she did not ever take the medication that she had. I think in our society at the moment we feel that we want control.

I did some teaching at the University of the Third Age and we would say, 'We just hope we go to sleep one night and don't wake up.' I think that is a common feeling. But of course we know that is not likely to happen, so that is why we need to think more seriously about is treatment actually useful to my longevity? I could tell you stories of people who have been offered medical treatments that really were futile. I do not like to use that word. I much prefer to use the term 'is this going to be a useful treatment'? We do have a lot of catching up to do in the medical profession as well to work out which treatments are going to be useful before they are offered to people. Unfortunately, I think sometimes doctors are trained to think that, 'There must be something I can do. I could offer this.' That is where advance care planning can be quite good for individuals to try and think through if this is going to be a useful treatment, or do I say that I am happy to go down the path without treatment?

CHAIR: Thank you very much. That is well articulated. Are there any other viewpoints?

Ms Cummings: Yes, I have a view. It is about choice. It is having a choice. I do not know if you have seen it, but there was a wonderful video recently on the ABC. It was only very short and I showed it to my class. It was the pharmacist who was explaining the procedure now for voluntary assisted dying in Victoria. It was very practical and it was absolutely to the point. He was explaining how the medications are supplied in a locked box, and the person or their carer is educated on how to use them. It is not like a doctor is coming along and injecting someone. The person has to be able to administer it themselves. The other thing which you referred to is that it is about finding out what the person needs. Not so much for the doctor to figure out what he needs to do, but what does the person need. The nurses who were here earlier from Palliative Care Queensland said the same thing. It is concordant care where you are establishing what the person needs. That might not necessarily be medically what possibly is desirable, but that is what they need and wish.

With palliative care people are given medications to control their pain, to control their nausea, to control anxiety and restlessness at end of life, but the medications are prescribed for individuals and everyone responds differently. One person being given a regime of medications might die very quickly and another person might die quite slowly. To be perfectly honest, I cannot see the difference. If someone has a terminal illness, if they have been told that they have six months to live, I do not see the difference in them having the choice of having some medications to take that will perhaps shorten their life or they might not choose to take them at all. What is the difference? They are going to die in six months time. I really cannot see how being given your medication slowly, strategically on a regular basis is really any different. That is all I really wanted to say.

Dr Colen: As a doctor, it is a very different intent to prescribe something for somebody's comfort or to prescribe it in an amount that you know is going to kill them. In other jurisdictions, for instance in the Netherlands and in Canada, the law has said that people can take the medication, but if they are not able to take it they can have it injected. Very quickly in Canada, within two years, 99 per cent of people have chosen for the doctor to administer it. Although we might think that people are taking it themselves, the doctor is prescribing it. In my mind, you are sanctioning it. The evidence coming from Canada and the Netherlands is that people do not like to take it. They do not want to do it to themselves, but they are happy if the doctor does it to them. I find that that is something I do not want to be involved in. In fact, doctors in the Netherlands now have found that quite a percentage of them have post-traumatic stress disorder. They say that they are maybe willing to do one, but it is so traumatic for them to do it.

Ms Cummings: I agree. You do not have to do that. I am not sure that I could even administer something like that to someone, but I still think that people are entitled to have the choice.

Dr Colen: I think that is the problem. You have to think about how it is going to be done as well.

CHAIR: Maybe that is a cue to finalise the day. On behalf of the committee I thank all three of you for your contributions today. For anyone who has stayed here all day to witness this, thank you for staying with us. It is a big workload. It is an important workload for the committee. We are far better informed for having listened to everyone's contribution today, so thank you. I now declare this public hearing closed.

The committee adjourned at 6.48 pm.