



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)

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

TRANSCRIPT OF PROCEEDINGS

MONDAY, 15 JULY 2019

Hervey Bay

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The committee met at 3.32 pm.

CHAIR: Good afternoon and thank you for your attendance here today for what is a very important inquiry that the health committee of the Queensland parliament is undertaking into aged care, palliative care and end-of-life care, and for the first time in Queensland we are asking Queenslanders to share their views on voluntary assisted dying. I start by acknowledging the traditional owners of the land on which we are meeting today and pay our respects to elders past, present and emerging.

I am Aaron Harper, chair of the committee and member for Thuringowa. Other committee members are Mark McArdle, deputy chair and member for Caloundra; Marty Hunt, member for Nicklin; Joan Pease, member for Lytton; and Barry O'Rourke, member for Rockhampton. Thank you so much for attending today. We have quite a program to get through. If we have time, some people have already expressed an interest in sharing their views and we will open up the hearing at the end to get people on the record. Michael Berkman, the member for Maiwar, is unable to join us today and sends his apologies.

The committee is a statutory committee of the Queensland parliament and as such represents the parliament. It is an all-party committee which takes a nonpartisan approach to its inquiries. The inquiry into aged care, end-of-life care, palliative care and voluntary assisted dying was referred to our committee on 14 November 2018 and we are required to report our findings by 30 November 2019. Today we are in Hervey Bay—your beautiful part of the world—to hear your views on these topics. We are very keen to understand what care people can access now and what care people need but cannot possibly get and what this means for people's comfort and dignity. We are also very keen to hear your views, as I said earlier, on the issue of voluntary assisted dying.

These issues affect everyone in this room and this is arguably one of the most important inquiries the Queensland parliament has ever undertaken. This hearing is your opportunity to share with us, the committee, any thoughts or experiences you have on any of these issues. This is your chance to tell the parliament what you think. Some of you may share experiences and insights today that are very personal and some may be painful to talk about. I ask that everyone respect the rights of others to hold and express their particular views. I also ask anyone who will be speaking about voluntary assisted dying to please take care when referring to acts of suicide or euthanasia.

This hearing will start with Dr Richard Osborne from the Wide Bay Hospital and Health Service. We want to get a snapshot of what is available here before we open up to the next session. We will then hear from people who provided written submissions to our inquiry and others who have asked for the opportunity to speak. We want this hearing to be as informal and as relaxed as possible, but it is still a formal proceeding of the parliament and, as such, is subject to the Legislative Assembly's standing rules and orders. I must remind you that intentionally misleading the committee is a serious offence.

This public hearing is being recorded and transcribed by Hansard. All those appearing this afternoon have been provided with a copy of instructions to witnesses and we will take those as read. These proceedings are covered by parliamentary privilege, which means that speakers are protected from legal action in respect of the evidence they give the committee. If they 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. For any media present, I ask you to 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 note that it is a public meeting and, as such, you may be filmed or photographed.

OSBORNE, Dr Richard, Consultant in Medical Oncology, Clinical Director, Cancer Care Service, Wide Bay Hospital and Health Service

CHAIR: I welcome Dr Richard Osborne and thank you for being here. I ask you to perhaps give an overview of what is available in terms of end-of-life care or palliative care.

Dr Osborne: Thank you for inviting me to participate. I just need to say a few things in preparation. Because of time constraints, I have not been able to prepare a detailed summary of all the relevant facilities available in the Wide Bay Hospital and Health Service. To start off with, as you are probably aware, the hospital and health service in this region does not deliver any aged-care services in the form of nursing homes and so on, so I will steer away from that.

I think there are three areas in which I can contribute. The first is that as a senior doctor in Hervey Bay Hospital I have oversight of what services are provided there from a medical point of view and also from a palliative care point of view. The second area of expertise that I have is as a practising cancer doctor, which I have been for 30 years. The patients that I deal with, almost without exception, are those who have incurable malignancy. What that means is that the majority of those patients die of their disease. Over the course of my 30-year career I have personally cared for more than 6,000 patients in that phase of their life. I would hope that my experience and insights into that would be of value. The final thing is that here in Hervey Bay we have been fortunate recently to be granted funds to establish a charitably founded hospice for end-of-life care. I can perhaps say a bit about that.

Turning to the hospital and what the Wide Bay HHS provides here in Hervey Bay, Hervey Bay Hospital is a busy public hospital. There is a relatively limited amount of private inpatient care in Hervey Bay, so the vast majority of people access their inpatient care through the public system. There is a wide range of surgical and medical services that are present and available there, and of course many patients have life-limiting illnesses in the sphere that I am involved in, which is cancer. We have hundreds and hundreds of patients referred each year for treatment. The sad thing is that a number of those patients, whether they have cancer or other life-limiting diseases like cardiac disease and respiratory disease, will die from their disease.

I will focus a bit more precisely on the oncology side of things, which is what I know about. On the one hand, we are very fortunate in the Cancer Care Service here in Hervey Bay and in our sister unit up in Bundaberg to have palliative care expertise integrated within the Cancer Care Service. That is something that is not seen in every cancer care service. What that comprises is specialist nurses who assist in the management of cancer patients at the time in their life when they have problems with advancing symptoms from an advanced disease, and they do a sterling job. The shortcoming, however, is that there is no consultant oversight of those nurses, so there is not one consultant in palliative medicine in Wide Bay. By definition, that means that the service is hampered by a lack of the expertise that those nurses would benefit from. The other area of deficiency is with regard to palliative care beds—that is to say, inpatient care people with advanced disease who cannot be managed in their own homes. Although there are some beds in Maryborough Hospital that are designated for that purpose, once again they are not supervised by consultants in palliative care. By definition, these must be the patients who have the most profound problems, but we do lack consultant-led service there.

CHAIR: Sorry to interrupt, but how do the palliative care nurses then consult? Do they speak to you?

Dr Osborne: That is a good question. We are of course very dependent on primary care such as the patient's general practitioner, and our nurses are very expert at liaising with a patient's GP, giving them an assessment, which is usually structured, accurate and experienced, and making recommendations about the use of drugs—often opiate drugs—and making requests for prescriptions and things. In other circumstances, if the patients are known to us—known to me personally or to my colleagues in oncology—they will come to us. It does depend on senior nurses practising at quite a high level with perhaps limited medical support.

CHAIR: Do you know the types of facilities and the bed numbers at Maryborough Hospital, which you mentioned, plus Bundaberg and Hervey Bay?

Dr Osborne: There are, as far as I am aware, seven or eight designated palliative care beds in Maryborough. In Bundaberg they have a palliative care facility with about the same number of beds. I believe you will be speaking to Debbie Carroll tomorrow. She will be able to give you more details on that.

CHAIR: Hervey Bay Hospital?

Dr Osborne: Hervey Bay Hospital has no designated inpatient beds for palliative care.

CHAIR: If people get sick in Hervey Bay, where do they go?

Dr Osborne: Once again, we need to draw a distinction between the group of patients I am intimately involved with, which is the oncology ones, and those with severe obstructive airway disease and so on. Basically, if you get ill and you have end-stage disease of any kind, you get admitted to the acute public facility at Hervey Bay Hospital and then put onto a medical or surgical ward, often near a shared facility—in a bay.

CHAIR: Are there no other hospices or anything like that?

Dr Osborne: Zero.

CHAIR: I come from Townsville. You would be familiar with Dr Will Cairns and his 40 years of service. The further we get away from South-East Queensland, there less access there seems to be. If you had the wand, what would you want to put in here?

Dr Osborne: I have the advantage of having worked in other health services and in the UK. Most towns would have a hospice that could be a facility with as many as 20 beds. In moderate sized towns of 60,000 or 100,000 people, even that is often not sufficient to meet their needs. What one would want to have here in Hervey Bay is a hospice along classical lines, which would be a 24/7 facility with expert nurses and inpatient care. Happily, we have been granted the funds to establish one here in Hervey Bay. That will serve only Hervey Bay and Maryborough; it will not be serving any wider area. The prospect is for that to be established and up and running within the next year. I think that kind of facility is essential.

CHAIR: We stopped at Katie Rose on the Sunshine Coast in the Noosa area to look at that facility. It is a charitable organisation. Where did the funding come from?

Dr Osborne: That came from state funding, which involves money for building the hospice and running it for three years. We are currently in negotiation with the local council to look for support in the provision of a plot of land to build that.

CHAIR: How many beds do you anticipate?

Dr Osborne: It is going to be six to eight to start off with and then probably opening another four to six after that.

CHAIR: An amount of \$17 million was announced in the state budget for regional and remote areas. This is a year-long inquiry and I know that the health minister is watching this. I think that is a good step going forward. How much was funded for this area?

Dr Osborne: Seven million dollars: \$3 million for building and \$1.5 million for the next three years, roughly.

Mr HUNT: I will start by acknowledging my colleague Ted Sorensen MP. It is good to hear that you have that funding for the hospice in this area. That is great. Well done. Are there no palliative care specialists in Hervey Bay?

Dr Osborne: No.

Mr O'ROURKE: Thank you for the information that you have provided so far. Are there any in-home palliative care services available here?

Dr Osborne: There will be organisations like Blue Care that provide generic and highly valuable nursing care for people who are increasingly frail—at the end of their life. Of course, general practitioners, to a greater or lesser degree, remain responsible for these patients and contribute to a greater or lesser degree. Our hospital based palliative care specialist nurses visit patients in the home and assess them. Where they are well known to a hospital based doctor like me, they will liaise with us to try to steer the management of those patients and then these specialist nurses will also liaise with the GPs. Essentially, it is nurses with palliative care backgrounds and experience assessing patients and trying to assist them.

Ms PEASE: Thank you very much for coming in today. We have heard in other locations that there is a relationship with other HHSs so that you can contact a palliative care specialist at different times. Do you have access to a similar service?

Dr Osborne: Not on a formal basis with any kind of contract and so on. Of the one in 100 of our patients who has contact with the palliative care service, the nurses have been able to discuss cases with a consultant or specialist in palliative care—say on the Sunshine Coast—but I think that is sticking plaster.

Ms PEASE: Do the nurses who provide palliative care have any specialist training that you are aware of?

Dr Osborne: I believe they have the necessary diplomas of higher training, but then there are two, three or four of those nurses in Wide Bay—two or three here and two or three up in Bundaberg.

Ms PEASE: Who assists them, particularly with the delivery of medications, particularly the stronger medications up to end of life?

Dr Osborne: Patients will often be on some form of strong opiate analgesic for pain prescribed either on discharge from hospital or by the GP. These nurses are very skilled at assessing patients' needs and advising about the escalation of doses. Ultimately, the responsibility for prescribing those drugs rests with either the GP or a hospital doctor such as me, but it is second-hand, if you see what I mean.

Mr McARDLE: Doctor, thank you for coming in today. I also acknowledge Ted, the local state member. I am keen to understand more about the number of palliative care nurses in Maryborough. You said that there are two or three. Can you be more precise than that?

Dr Osborne: Yes. The palliative care nurses are based in the cancer care service at Hervey Bay Hospital. That is where they are physically based. That is where their office is. The Maryborough Hospital ward is essentially a medical ward staffed by what might be called generic nurses. It is not as if there are nurses there—

Mr McARDLE: An RN?

Dr Osborne: That is correct, yes. That is my understanding.

Mr McARDLE: For a patient in Maryborough who goes to the hospital for oncology treatment, where do they go for end-of-life treatment in those circumstances?

Dr Osborne: All patients in cancer care receive their treatment at Hervey Bay Hospital. The only reason they would be admitted to Maryborough Hospital would be for problems that cannot be handled in the home. If they are in the catchment area of Maryborough, if it is convenient for them, they would be admitted there. If they are in the catchment area of Hervey Bay, they would be admitted here. These beds in Maryborough are designated as palliative care beds. They really are not that much different from an ordinary hospital bed—an ordinary medical bed. For those patients who are in a slightly more acute setting in Hervey Bay Hospital, if it is clear that they do not require acute inpatient care—dealing with monitors and that sort of thing—and they are in that terminal phase of their life but they cannot be discharged home, they are transferred to Maryborough as a sort of step-down facility. It is basically just accommodating them in a nursing facility.

Mr McARDLE: From what you have said, if a patient from Maryborough is in end-of-life care they come to Hervey Bay?

Dr Osborne: If they live in the Maryborough catchment area, if they get ill they can often be admitted to Maryborough Hospital and they may remain in Maryborough Hospital for end-of-life care under the supervision of a medical consultant on a medical ward.

Mr McARDLE: If I live in Hervey Bay and need end-of-life care, I am admitted to Hervey Bay?

Dr Osborne: Hervey Bay.

Mr McARDLE: How many nurses in Hervey Bay undertake palliative care?

Dr Osborne: Three.

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

Dr Osborne: It is about 60,000, I think.

Mr McARDLE: What is the demographic aged over 60?

Dr Osborne: Much older. There are many more people aged over 60 in Hervey Bay than in the rest of the country.

Mr McARDLE: Could we say that well over one-half of the population is aged over 60—not unlike the Sunshine Coast, to an extent?

Dr Osborne: I would not be able to give you precise figures.

Mr McARDLE: Does it worry you that, as I understand it, we have no palliative care beds in Hervey Bay at all?

Dr Osborne: I think it is a very poor state of affairs.

Mr McARDLE: Do you believe that the number of palliative care nurses is woefully inadequate for the population base, given the cohort that is now moving into that age group?

Dr Osborne: I would suggest that the current provision of palliative care expertise is deficient both in terms of its numbers and in terms of its depth—that is to say professional consultant leadership.

Mr McARDLE: One of the concerns that we have right across Queensland is that palliative care is not, in my opinion, clearly understood by the population as a whole—except for those here today, of course. The other concerning point is attracting people to the regions. I think you mentioned Hervey Bay

six to eight beds to begin with and then four to six more in time. If you are looking at opening the new hospice in, say, 12 months to two years—and it could take that long—how are you going to recruit not just the palliative care nursing, but I would have thought that by that time you would need a palliative care physician as well? The cohort is becoming so large. With respect to you, Doctor, and your colleagues, to try to run it would become very onerous and the expertise is required.

Dr Osborne: There have been attempts over the years to attract consultant-level expertise to Wide Bay in palliative care, and those have failed because of the reasons that we are all well aware of—attracting people to regional areas—as well as the really remarkable shortage of palliative care specialists in any case. We are always going to have difficulty in that area.

Mr McARDLE: I would imagine they are going to come to you. You are an oncologist. You have been a de facto consultant, shall we say, for palliative care. What is needed to attract a physician and more palliative care nurses? We could have all the figures in the world. I do not care which colour is in government. Unless you get the numbers up here, you can kiss it goodbye; it cannot work.

Dr Osborne: I think the advantage Hervey Bay has is that over the past three to five years the cancer care service has grown and become very well recognised as an emerging centre of excellence. I think senior palliative care doctors would want to be working in that sort of environment, so we are laying the groundwork for attracting them by having a high-quality cancer care service that they would slot into. That is how we are going to attract people: by making Hervey Bay Hospital excellent in that regard.

Mr McARDLE: Do you not also need to attract the partner? For example, you get a palliative care nurse. They have a partner or a spouse and they have children. Unless you accommodate the family unit, you get a short-stay individual. Despite there being great schools up here, once the children turn a certain age they go back down to Brisbane because the parents perceive that the education is better down there. The package has to be simply more than the qualification of the individual. I am pushing the point. It may be outside your scope. I will take the advice of my colleagues to my right. I will leave that hanging. That is a very important question, as far as I am concerned.

The issue of palliative care is an ongoing scenario. What advice would you give this committee in relation to how HHSs deal with palliative care? My understanding is that, leaving aside the \$7 million, the HHS is not bound to provide any funding it does not desire to palliative care. Therefore, the HHS here, in Cairns and Toowoomba is quite different. Do you see that we need to set aside money definitively for palliative care in HHSs and make that accountable for each year of a budget?

Dr Osborne: I think the service should reflect the need. I think this process is going to highlight what is needed and the deficiencies that exist—the ones that I have talked about and we have outlined here—and I think strong recommendations should go to the fund holders in the HHS if it is perceived that there are big gaps in their provision.

Mr McARDLE: What is the matrix that the HHS uses to determine the need for palliative care in this HHS?

Dr Osborne: I am not involved in that process.

Mr McARDLE: Fair enough. I might give some thought to your comments.

CHAIR: We will come back for supplementaries. Before I go any further, can I ask the good member for Hervey Bay, Mr Ted Sorensen, to address the audience and thank people for coming along.

Mr SORENSEN: Thank you. First of all, I would like to thank the committee for coming to Hervey Bay. I think it is very important to have the committee here. From what I have been told, this is one of the biggest crowds the committee has had so I congratulate each and every one of you for coming along here today.

Hervey Bay has an ageing population and we do need extra beds. I have been going on about that for a while and people think I am whingeing. Cancer is a terrible disease. It is something that I wish nobody would have to suffer with in the future. We have some people here today from the Clem Jones group, which does a lot of research into different diseases. It is very important that we keep the research going. I believe this committee will focus on that as well.

It is great to have you all here. Thank you for coming. Once again, to Aaron Harper and the committee, thank you for coming to Hervey Bay. This is a very important issue in this town because of our ageing population. I would like to thank Dr Osborne for coming along and giving evidence here today as well. I think you should put your hands together for the doctor. It is good to hear what he has to say. Thank you.

CHAIR: Thank you, Ted. We invite you to stay at the table to hear the views of your local constituents. Thank you for attending today.

Doctor, for us it is about giving recommendations to reflect what is required or desired in a practical sense to deliver good palliative care or aged care in all parts of Queensland. We are steering towards asking each HHS just what that looks like. You are the experts working in that area. That is something we will take forward. This does not have to be a personal comment, but you have 30 years of experience in dealing with people at end of life—some 6,000, I think you said. I asked Dr Will Cairns the same thing in Townsville. In your experience of looking after those people, did you have patients at end of life asking just to end it all: 'I am sick of it. End it all.'?

Dr Osborne: The short answer is yes. In practice it seems a surprisingly small number of people, but I think that is because people are aware that it is not available and they just do not go there. I think more important than anything I could say is that in the evidence I have read on the website in the submissions that have been made to this committee as part of this inquiry, which are incredibly eloquent, the majority of them have clearly stated that there is unmet need there. I can go into a little bit more detail.

Most doctors do not cure anybody, whether it is diabetes or heart disease. Similarly with cancer, it is commonly the case that people have incurable disease. As a doctor, your one job is to do your best for that person—that is, doing your best as an individual, doing your best with the technology that is available, whether you are a surgeon or in my case using chemotherapy drugs, doing your best informing them, advising them of things. What you want to do in these difficult, incurable circumstances is get the best out of the situation. My feeling, having thought about it in recent days since being invited to participate in this, is that for some patients you will get the best out of the situation if they do have access to assisted dying. I know that it is a deep and complicated area, but I do think if you imagine that what you are trying to do is for each individual person to get the best out of the situation with a limited life span, for some people that is going to be an appropriate way forward.

CHAIR: That is very similar to the views of Dr Will Cairns.

Mr HUNT: I want to drill down a bit further into the details of what happens if one of your patients, for example, has a terminal diagnosis and, living in Hervey Bay, gets to end of life. Do you have access to specialist palliative care via telemedicine or things like that? Does that consultation go on?

Dr Osborne: There are different kinds of telemedicine, as you know. There would be consultations with external experts, but we do not really need it. Palliative medicine—providing palliative care, symptomatic care at end of life—is pretty straightforward. It can be complex because there are psychological needs as well as physical needs as well as needs for specialist drugs and so on, but it is not rocket science. What you need is just time, interest and the necessary level of expertise and knowledge of the kind that somebody like me has. I am perfectly capable of managing the terminal phase of a person's life personally if one of my patients is an inpatient.

Mr HUNT: From some of the information we have heard from palliative care specialists, that might not be the case so much with GPs.

Dr Osborne: I think GPs are in a difficult position. They do not see a huge number of these situations. They are very busy. It does require, if you are talking about inpatients now, 24/7 support and they do not work 24/7. Then, of course, it does come down to personal interest or willingness. I am an oncologist because I am interested in that. If you are a GP you might be very interested in dermatology. I think people can feel out of their depth if it is not their area of expertise. Each individual GP is different.

Ms PEASE: If a GP's patient does end up going into Hervey Bay Hospital, is the GP allowed to visit them and treat them while they are in the Hervey Bay Hospital?

Dr Osborne: I certainly hope they visit and I would imagine that they could easily liaise professionally with the consultant who is responsible for that patient and a joint approach would be taken. Essentially, these are acute patients on an acute ward being looked after by specialist medical teams.

Ms PEASE: One of the things we have heard whilst we have been travelling is that often the medication the palliative team needs is not readily available locally. Is that the case here or, because it is all done through the Hervey Bay Hospital, are you fine with getting access to that medication?

Dr Osborne: The main medication we are talking about are opiates which are used entirely appropriately in this setting. There are very tight rules on the amount of these drugs that can be prescribed. That is a difficulty for patients, and more particularly their relatives, because they are

burning through these limited number of drugs in their prescription over a short period of time, so there is a logistic problem there. There are a few specialist requirements in terms of other drugs that have to be brought from outside. It is really just about getting access to the necessary strong opioids in sufficient quantities so that people are not spending every waking hour thinking, 'I have to go to the pharmacy tomorrow to get more.'

Ms PEASE: I know that you do not specialise in aged care, but do you have aged-care facilities in the area?

Dr Osborne: I think there are lots of aged-care facilities, yes. Looking at this hospice that we are building, the question comes of where you locate that. We have gone around the question of whether it should be co-located with one of the aged-care nursing homes but felt that it is probably best to have it freestanding. I think nursing homes need to speak for themselves about how they deal with dying patients.

Ms PEASE: Do you know if many of the aged-care facilities or residential homes will send their patients to the Hervey Bay Hospital at end of life or for other ailments?

Dr Osborne: I think it is all about planning. Things are pretty advanced here in terms of advance care directives. People are aware of this as an issue, so I think people approach it very sensibly. If a person clearly is on that trajectory and is actively dying then they will stay in place in their nursing home. We do not see too many people coming into the hospital in the last 12 or 24 hours of their life.

Ms PEASE: You did mention the advance health directive. I take it you make use of that at the Hervey Bay Hospital?

Dr Osborne: That is well developed, and we are fortunate once again in cancer care that our allied health team, social workers and others are very proactive in promulgating that.

Mr O'ROURKE: In regard to pain relief medication, what happens when a staff member believes that a person's current medical condition needs adjustments within pain relief? How long does that take to get sorted out?

Dr Osborne: The way it works that I am experienced with is: my senior nursing colleagues who are caring for these patients assess their needs, make recommendations and then will discuss it with me to get their recommendations sanctioned or rubber stamped—whatever you want to call it. Because I know these people and trust them, I am prepared to do that without sight of the patient. Then it is a simple matter of getting the prescription written. That can be done by a doctor in the cancer care service, faxed to the pharmacy and the pharmacists are usually very quick at getting things turned around so people are not waiting days and days.

CHAIR: We have had GPs talk to us about accessing residential aged-care facilities, of which you have a number. Generally, 80 per cent of people would rather die at home surrounded by loved ones but the reality is that around 14 per cent do. That is the data that was provided to us. Some of the GPs have commented that when accessing drugs, particularly opioids to provide pain medication for end-of-life care, the TGA comes down on them. This seems to be a common thread. In our recommendations, do you think we should be addressing that at the Commonwealth level?

Dr Osborne: I cannot see a situation whereby if a GP feels that the patient needs that drug they cannot write the prescription and make appropriate documentation and then that prescription will be dispensed and administered and then that continues on for as long as that patient needs it. I would not be worried about somebody coming and checking up on me if I was writing these prescriptions.

CHAIR: We have had some comments at a previous hearing.

Mr McARDLE: Doctor, you mentioned that there are two or three palliative care nurses in Maryborough and the same number in Bundaberg.

Dr Osborne: Yes.

Mr McARDLE: However, they are not the same nurses, are they? They are quite distinct cohorts?

Dr Osborne: That is correct.

Mr McARDLE: There are up to six across the HHS at this point in time?

Dr Osborne: That is correct.

Mr McARDLE: Do you have any idea, outside their wages, what amount was spent on palliative care in the 2018-19 financial year or the 2017-18 financial year?

Dr Osborne: I think that is a question that would be better answered by the person you are speaking to tomorrow, the CEO.

Mr McARDLE: That is fine. I want to go back to the new hospice. You said there were six to eight beds being planned.

Dr Osborne: Yes.

Mr McARDLE: However, there was no matrix as to need across the HHS. I am trying to determine how that figure was derived. What was the oversight and what were the calculations?

Dr Osborne: That is a very good question. We have partnered very closely with Toowoomba Hospice and we have also spoken to hospices in Ipswich. We are really modelling ourselves on their way of doing business and getting established, based on similar sized populations.

Mr McARDLE: The \$7 million—and I understand what you are saying to me—runs out three years post construction of the building and opening.

Dr Osborne: Yes.

Mr McARDLE: How will the funding occur after that? Will that not then be absorbed into the HHS's budget and will not be a standalone pool of funds?

Dr Osborne: Fundraising is going to be an important thing. That seems to be the model that has been successful in places such as Toowoomba. The hospice plan and proposal is entirely separate to the Wide Bay HHS. Discussions have been held with Adrian Pennington, the chief executive. There has been a proposal or a suggestion that running costs for staffing after that period would be picked up by the Wide Bay HHS, but I assume that the Wide Bay HHS would want some income to be able to meet that.

Mr McARDLE: They would want a budget increase to determine that they could actually outlay those funds?

Dr Osborne: Yes.

Mr McARDLE: We can assume now that the hospice will be a private facility initially although with state government funding, but there is no concrete guarantee that post the three years, outside of fundraising, we can say we can secure the future years?

Dr Osborne: At present, it is not secure.

Mr McARDLE: Doctor, how do you define 'palliative care'?

Dr Osborne: 'Palliative' means to make better. That means you have people who have symptoms and you provide treatment to relieve those symptoms. Palliative care could be managing the severe distressing breathlessness of advanced lung disease or the severe pain from bone metastases from prostate cancer. It is traditionally used as a term to describe end-of-life care in patients with cancer, but really it needs to be looked at more broadly because people with end-stage heart disease and end-stage respiratory disease—all of which are very common here—deserve palliative care.

Mr McARDLE: How would you define 'palliative sedation'?

Dr Osborne: I do not think that is a term I have ever heard. What I would say is that one's job is to relieve people's suffering. Some suffering is distress. People can be distressed by pain or breathlessness. The drugs that are given to relieve pain can sometimes make people less distressed by making them more sedated. The sedation that comes with the use of some of these drugs actually serves a purpose, because it relieves distress as well as the symptom of, say, breathlessness or pain.

Mr McARDLE: But that term is fairly new to you?

Dr Osborne: I do not think I have heard that term before.

Mr McARDLE: You were asked a question about Blue Care. Blue Care is an organisation that has a lot of involvement in the community. Does Blue Care, either deliberately or via a de facto method, become a provider of palliative care?

Dr Osborne: I do not have a lot of knowledge of how they work, so I really cannot answer that accurately.

Mr McARDLE: Outside of the bed and nurse numbers that you have here, would you say there is limited palliative care in this region, not by the HHS but generally in the region governed by the HHS?

Dr Osborne: I will just turn to the Blue Care question. I think that essentially they provide nursing care predominantly. There will be some people in the final phases of their life who do not suffer distressing symptoms but just need nursing. I think that is really where Blue Care sits. Coming to your question about the adequacy of provision, I think without designated inpatient beds with specialist oversight, such as hospice beds, there is a deficiency of provision in this area.

Mr McARDLE: Tomorrow we are meeting officials from the HHS in Bundaberg, if I am not mistaken. Is there somebody we will talk to tomorrow who can give us more data about the hospice planning and number of beds? Is it Adrian Pennington or somebody else?

Dr Osborne: Tomorrow I think you are speaking to the chief operating officer, Debbie Carroll. As I said, the HHS is not involved in any way in planning the hospice. That is an entirely separate project.

Mr McARDLE: Would they be involved in the discussions with the state government for funding?

Dr Osborne: No.

Mr McARDLE: Who is involved in that hospice?

Dr Osborne: It was entirely done by the Fraser Coast Hospice Association. We notified the HHS and kept them informed of the plans, but it really was done independently.

CHAIR: The deputy chair mentioned the term 'palliative sedation'. Are you familiar with the term 'terminal sedation'?

Dr Osborne: Both of those terms have a slightly pejorative edge to them, suggesting that there is a deliberate aim to sedate patients rather than to relieve their symptoms. The medicines that are used to do that have with them a tendency to sedate people. There is an important distinction to be drawn between sedating people just to keep them quiet and what we do as specialists in this area, which is to identify the symptom and give appropriate medicine for that, and those medicines will sometimes cause the patients to be more sleepy and, indeed, go to sleep and never wake up.

CHAIR: I was going to say, because the end result is that the person will die.

Dr Osborne: Yes.

CHAIR: Using the respiratory distress of a person with lung cancer as an example, the side effect of giving opioids is respiratory depression?

Dr Osborne: Correct.

CHAIR: Do you have any views on aged care in terms of people awaiting levels 1 to 4 aged-care packages to receive nursing support or some kind of support at home? Have you had any experience of that? We are hearing that sometimes people have to wait for up to two years and/or die before they receive it. There is one person in the audience who has been waiting for four years.

Dr Osborne: I am afraid that I tend to stick to what I know, and I know that there are coordinators inside the hospital who liaise with the external agencies and do their best. I think they are best placed to answer that.

Mr McARDLE: Doctor, I asked about palliative sedation and you said that it was a term that you had not heard before. My colleague asked you further about it and you then said it was a matter of helping people get sedated and that at some point in time they may pass away, which is what it really is. Is it not also the case that palliative sedation has a primary function to alleviate distress and pain? The secondary may be that the person passes away. There is a clear distinction between that and providing a drug to a person with the express intent of the person passing away. Would you agree with that?

Dr Osborne: I think it is very important to be very precise in this area. I think I have expressed it as saying that if a person has severe distressing symptoms our job is to treat those. When it is pain, we know that the painkillers will also cause respiratory depression and can sometimes sedate people and they never wake up. For people who are severely breathless, often you use the same sort of drugs with the same consequence. However, sedation implies trying to put somebody to sleep deliberately. That is not the direct aim. We are not talking about people who are distressed by being wakeful; they are distressed by being breathless or with pain. I think it has a slightly pejorative tinge to it when you talk about sedation and it is not a term that is commonly used in medicine.

CHAIR: Thank you very much, Doctor. It is a fine line on that last point. We have heard from palliative care specialists who reflect your views. I thank you for your time. For almost an hour you have provided a very good overview of the current services available and what can be done better.

ALLEN, Mrs Judy, Private capacity

O'BRIEN, Mr Anthony, Private capacity

TURNER, Mr James, Private capacity

CHAIR: Welcome. I will ask each of you to make an opening statement of a few minutes and then we will move to questions.

Mrs Allen: Hello and thank you for having me. My name is Judy Allen. I am a retired registered nurse, chemotherapy nurse and palliative care nurse. I worked at the Maryborough Base Hospital and sometimes had shifts at the Hervey Bay Hospital in those capacities. I have been retired for eight years, so I am thinking that I retired a lot earlier than I should have, given all of this. After I retired I was involved with starting up the palliative care unit at the Maryborough Hospital. It has just gone nowhere. I am very disappointed.

Mr Turner: I am James Turner. I am a retired civil servant who has lived in Hervey Bay for more than 10 years. I do not have any medical qualifications like the lady on my left, but I do have certain issues and matters from personal experience that I will be presenting to the committee today.

My understanding of the recent Victorian assisted dying legislation is that it provides for patients in the last 12 months of life with diseases that ravage the body but leave the mind and cognitive ability unaffected, such as motor neurone disease and terminal cancer. There is another class of patient that I wish to talk about today. These are patients who are diagnosed with a disease that destroys the mind first before affecting the body. I refer primarily to Alzheimer's and I will use my father, Joe, as an example.

He was diagnosed with this in January 1988, aged 69, until his death in September 1995, aged 77—although, with the benefit of hindsight, there was evidence of a problem at least 18 months before diagnosis. On average, life expectancy after diagnosis is about eight years, which corresponds with my father's experience. Alzheimer's itself does not kill but the disease's complications do—complications arising apart from the massive degeneration of the brain; for example, aspirational pneumonia, bed sores, sepsis infections from undiagnosed urinary tract infections, infections in general, injuries from falls, malnutrition and dehydration. In Joe's case, his complications leading to death that I am aware of were pneumonia and malnutrition. A solidly built man became a skeleton covered in skin. For a once highly intelligent scientist with a witty sense of humour, there really was not much, if any, dignity in his death. His level of pain or discomfort was unknown.

I have heard it said that Alzheimer's skips generations, so hopefully I will miss out. But if not, with much greater awareness and far more advanced tools for early diagnosis than in the 1980s, I would, to put it plainly, like the option to sign a consent form for voluntary assisted dying years in advance whilst still of sound mind with cognitive ability—unlike Joe, who most likely was diagnosed too late anyway to make such a decision.

Having seen his demise, there is no way I would ever want such a thing for myself. I am sure that such a proposal would open a Pandora's box of issues, so let us look at four of them. One, who assesses a person's ability to consent upon diagnosis using previously agreed criteria? I would suggest at least two mental health professionals. Two, at what stage of the disease would the consent become active? Maybe when the patient is bed-ridden, unable to move and communicate, wearing a diaper and physically wasting away with no hope of that situation ever changing—that is, with only a few months left to live. Three, who would decide about acting on this consent if and when it became active? I was thinking two or three trusted family members and/or friends selected by the patient could hold a joint medical power of attorney, and only then on the advice of the treating doctor or doctors. Lastly, who would be tasked with carrying out the patient's final wish and how could it be done? That is a hard question, and all I can say is 'a willing and compassionate healthcare professional using an approved method'. Given the time constraints today, this concludes my submission. Thank you for your attention.

CHAIR: Thank you. I should explain to anyone coming forward that we will allow two to three minutes for opening statements before we move to questions.

Mr O'Brien: I am Tony O'Brien. I am retired. I was a research scientist and an international consultant for many years. To the question as to whether voluntary assisted dying should be legalised in Queensland my answer most definitely is yes. I would prefer to use the term 'dying with dignity' as a better representation of my views.

I saw both my parents die horrible deaths because of the lack of available VAD and suitable palliative care. At my age of 84, I am most concerned by the quality of my remaining years and determining the circumstances of when and how I die. Quality of life and dying with dignity are very important to me. I want to be able to include VAD and prequalifying circumstances in my AHD. The VAD legislation should not be hedged in so many restrictions as to become meaningless. It should not be confined to terminal illness cases. It should include quality of life.

At a minimum, when intellectual impairment is involved and reduced quality of life through loss of mental capacity is apparent, a person should have the right to deny medical intervention to keep them alive through an AHD. Preferably, a person should have the right in these circumstances to include VAD in their AHD. The medical fraternity must be made legally culpable to search out the directives in an AHD before applying medical assistance. This legal culpability must especially apply to emergency first responders and emergency department staff in hospitals. There should be a legally responsible place for storage of AHDs so that they are easily accessible by all medical fraternity, including first responders.

I am sick of seeing the medical fraternity make money out of the business of dying. Keeping people alive by any and every means is morally reprehensible. Even something as simple as a flu vaccine can be morally unjustifiable for a dementia patient with no quality of life. I have never given my right to make decisions about my future to priests or the medical fraternity. I resent such persons trying to make decisions for me. Intellectually and morally, they do not have an exclusive hold on the truth.

CHAIR: Thank you very much, Mr O'Brien. I respect your views. Both gentlemen talked about advance healthcare directives. I ask the people in the room: who has an advance healthcare plan? Well done to you. Perhaps the question should be: who does not have one? One thing we consistently hear is the views expressed. It is an incredibly difficult area in the legal framework of protecting vulnerable people. As we have heard from the legal fraternity, people's wishes can be expressed within an advance healthcare directive. The issue of voluntary assisted dying is a separate one. I do not know what questions I have for you. I understand that your wishes are almost the same and can be put in there.

Mr O'Brien: Access to an AHD is very much a part of what you are looking at in voluntary assisted dying, aged care and palliative care.

Mr Turner: I have not researched the various systems for voluntary assisted dying in Victoria, other jurisdictions or overseas, but if there is no legislation in other jurisdictions dealing with being able to sign a consent form six or seven years before you are going to be in your end stage, would Queensland have the guts to set the precedent and actually do it? That is the thing. I do not want to see that sort of thing happening to any of us in the end stages of Alzheimer's if we had the option when we were diagnosed to say, 'Look, don't let us linger.'

CHAIR: Mrs Allen, how many years were you in nursing before you retired?

Mrs Allen: It would be 45 to 50.

CHAIR: Well done. I will ask a similar question to the one I asked the good doctor who dealt with patients at the end of life. What was your experience? Did people want it all to end?

Mrs Allen: Of course. A lot of people wanted to die at home too, but that is not always possible. As Dr Osborne said, we can eliminate symptoms with medications if they are given properly and at the right time, but that is not always the way either. I do not know. Palliative care has its place. From my experiences, I think assisted dying has its place. I think we should look at each of them equally. Everyone has to die. Life presents us with choices, and that has to be one of the choices: how do you wish to die?

CHAIR: You mentioned that pain medication can eliminate symptoms. In your experience, is there a gap sometimes where they cannot?

Mrs Allen: Yes, there is. That is where palliative care comes in. The palliative care nurse or the person delivering care can sit and listen. Not a lot of people have a lot of time in their working life to just sit and listen. I remember when I first started doing community palliative care work. My friends at the hospital would often say to me, 'What do you say to these people who are dying?' I had to sit and think. I do not know. Often I say nothing; I just sit and listen. A lot of the time, all that people who are dying need is for someone to listen to their problems. If you can alleviate some of their problems and they are peaceful, that is the definition of palliative care.

CHAIR: Do you think people should be given a choice at the end of life?

Mrs Allen: Of course I do, because not everyone is the same. Not everyone has had a similar life and not everyone can handle what they are being given at the time regarding pain and regarding other pressures and stress—family matters and all sorts of things.

Mr HUNT: Tonight we have heard that people in Hervey Bay do not have access to the best quality palliative care. Do you think they have access to good quality palliative care?

Mrs Allen: They have access to some but, as Dr Osborne said, there are not enough people to deliver it. It can be beautiful. It can be essentially given without any problem, but it needs to be given on a standard. To me, palliative care needs to be given under the guidance of the hospital system because they have standards, protocols et cetera that need to be upheld. Palliative care needs to be same. It needs to be delivered under certain situations—a lot of listening, caring, understanding and time with their patients. You do not need hundreds and hundreds of beds just sitting there waiting for palliative care patients to take over. It is not always delivered to elderly people, either. Anyone can die at any age. It needs to be understood that palliative care should be given under certain standards by people who understand what it is all about.

Mr HUNT: Who should be involved in that? This morning at Katie Rose Cottage we saw that they have access to nurses, specialist palliative care, counselling services, accommodation for families and a lovely setting. All of those things are part of good quality palliative care.

Mrs Allen: All of those things are a good part of any medical care too. People have to understand. As I said, life is full of choices. You cannot make a choice in anything unless you understand it. You should not be made to make choices that you do not want to make either. I know there is a good quality of palliative care in the community that is delivered through the health system here and it expands out through Wide Bay. I have had recent dealings with those nurses and they are just wonderful and they do assist people to die in the home. However, when you are in a hospital situation, it needs to be separate to the normal hospital wards et cetera, like the ward up in Maryborough. It has not ended up to be exactly driven this way. It is in amongst everything else, and there is just not enough time, not enough gentleness and not enough listening because of the time constraint.

The protocols that I was talking about within nursing and medical situations within hospitals have to still be kept up if it is in a hospice section. The hospice section needs to be funded by the hospital section too. It cannot be a private thing, because once you get the private situation happening with funding there are people who reap benefits financially and there are people who miss out et cetera. This is just what I have observed over the years and what I have heard people say to me.

Ms PEASE: Thank you very much for coming and talking today. Judy, thank you for your years of service in the palliative care sector. It is amazing.

Mrs Allen: It is a pleasure.

Ms PEASE: It is. It is a privilege.

Mrs Allen: It is.

Ms PEASE: What is your position with regard to appropriate training for people who want to work in that sector? Do you think we provide enough or proper training for people in that sector?

Mrs Allen: No.

Ms PEASE: Do we pay them well enough to encourage a better quality of people to be in that sector?

Mrs Allen: No.

Ms PEASE: What sort of training do you believe should take place for people to work in the palliative care sector?

Mrs Allen: Not in a university for a start. I do not believe any nurses should be trained in universities. They should be trained on the premises with the patients, with senior people who trained before them guiding them along. They should be being exposed to experiences all the way through and then being spoken to and everything explained to them so they can then take it on board and not take it to heart.

Mr McARDLE: Judy, I think we might bring you back into nursing.

Mrs Allen: I wish I could.

Mr McARDLE: You are anointed. Mr Turner and Mr O'Brien, you are both of the same mind—that is, the dementia diagnosis should trigger a train of events that could lead at the end of the day to dying with dignity being put in place.

Mr Turner: There is just one differentiation between a dementia diagnosis and an Alzheimer's diagnosis. My father died from Alzheimer's. My mother at the age of 97 had age related dementia but she was nowhere near in the same condition as Joe, so we have to differentiate when we talk about dementia and keep them separate. Another problem we found with Joe in the nursing home was that he would find himself in a position where he was disrupting dementia patients who did not have Alzheimer's. One of the things I did not mention in my address is possibly keeping Alzheimer's patients in nursing homes separate so they do not impact on those who do not have Alzheimer's.

Mr McARDLE: So aged-care patients?

Mr Turner: Yes, aged-care patients.

Mr McARDLE: Could we just for the conversation use the word 'dementia' to encompass all of those who may fall under voluntary assisted dying?

Mr Turner: I would rather not. I would rather keep Alzheimer's separate from age related dementia.

Mr McARDLE: Okay. Let us talk about Alzheimer's then in that scenario. I can sign an advance health directive today that says I am not to be given medication or nourishment at certain points in time in my life, but I cannot sign a document that says if I have a diagnosis of Alzheimer's I am not to be treated. What you are saying is that if I can give that earlier direction then why can I not give the secondary direction that is Alzheimer's. Is that right?

Mr Turner: What I am saying is that you can request not to be treated, as you have said, but it is different if you have Alzheimer's in those end stages, in the last six months, and you signed a voluntary consent when you were lucid at first diagnosis to tick actively assisted in dying. Someone who has a sound mind with, say, motor neurone disease and only has a few months to live could do that and they would be assisted, but someone with Alzheimer's at the end stage does not have that mental capacity.

Mr McARDLE: What you want to do is have that enforced?

Mr Turner: Yes, that is right.

Mr McARDLE: I think we are talking the same thing.

Mr Turner: It is sort of different. There is a difference between withholding treatment and actively assisting the death. They are two separate things, I think.

Mr McARDLE: Okay.

Mr O'Brien: On that point, at the moment doctors are not legally bound to take notice of AHDs and the patient's wishes.

Mr McARDLE: What you are saying is that if a patient makes that statement in an AHD—and I will stay with Alzheimer's—and says, 'If I develop Alzheimer's, don't treat me' or 'positively end my life', then you want that as part of any legislation going forward. Is that right?

Mr O'Brien: Yes. Just on the case of palliative care, I think palliative care at home is what most people would require as a first option but, as Judy says, there are complications. I think if AHDs are to function properly we have to go through practical steps to get palliative care functioning properly not only in hospitals but also in hospices and at home.

Mr McARDLE: Mr O'Brien, which is more important, do you think? If you stay in both, do you say equally?

Mr O'Brien: I would not like to hazard a guess as to that.

Mr McARDLE: That is fine. I appreciate that.

Mr O'Brien: I am not closely associated with the industry at all, but I had parents who died horribly through lack of VAD and through lack of palliative care. In both cases the surgery was successful but the patient died anyway. There was not a quality of life before the patient died because of the treatments and multiple surgeries they had to undergo.

Mr McARDLE: I thank all three of you very much.

CHAIR: Do you have any closing statements of 30 seconds?

Mrs Allen: As a person who has worked with dying people and people in various stages of their journey through their illnesses, to me palliative care starts at diagnosis. Along the time line of that disease, the palliative care adjusts to the person's treatment regime and to the way they are coping with that regime, and everyone is completely different to the one before.

Mr Turner: I know that to act on what I have requested or recommended will require a very strong resolve. Only time will tell if the current parliament has that resolve.

Mr O'Brien: I would just emphasise the practicalities of administering any of these three areas—the aged care, the palliative care and the voluntary assisted dying or dying with dignity. There are a lot of consequences and practicalities that are part of that issue. AHDs are very much a part of that and so is in-home care at affordable prices. If you are only on the pension, you cannot afford in-home care under the current systems. That is a part of a practicality, and people want to stay at home.

CHAIR: I thank each of you very much.

BROOKS, Ms Sue, Private capacity

EINAM, Mr Scott, Private capacity

SMITH, Mr Paul, Private capacity

WRIGHT, Ms Doreen, Private capacity

CHAIR: Sue, would you like to start with an opening statement? We will move from left to right and then we will move to questions.

Ms Brooks: Thank you very much for coming to Hervey Bay and taking the time to listen to our community. My name is Susan Brooks. I like to be called Sue, but formally I am Susan and my dad calls me Susan. I am 64 years old and I care for my father. I wish to speak about the experience of my mother dying and now my father in care at home with me.

Mum was 76 years old when she died. A heavy smoker throughout her life, she suffered a couple of bouts of pneumonia but the last time she was hospitalised she was barely able to walk. Doctors called a family meeting—10 weeks, they said. They were unerringly accurate but those 10 weeks were a living hell—hell for my mum and hell for us. It was mostly spent in hospital as we tried and failed to manage at home. Mum was tied to an oxygen line and drugged.

During the last 10 days, Mum was mostly semiconscious. She lost the ability to eat, to walk, to toilet and to reason, but Mum continued to breathe and her heart continued to beat. She also became incoherent and delusional and we just sat and prayed for her to die—for 10 long, tortured days. Ten days with no ability to eat or drink and she was simply drugged—drugged until she died.

Now I care for Dad. My dad just turned 93 years old. He has dementia. We do not know what type. He has dementia. He has zero short-term memory. He is incontinent, legally blind and as deaf as a post. He also has a very enlarged prostate and has been on daily antibiotics for the past 17 months to try to keep recurrent UTIs away. Dad suffers from terrible anxiety, which is the very worst thing. We provide drugs which sedate and calm him. Dad is at home with me. My wish is that he dies at home. I will not assist him to die as I do not want to go to jail, but the prospect of jail is the one and only reason that keeps me from planning to actively help my dad to die peacefully. The dad I knew from times past would be horrified if he could see himself now.

Aged-care assistance is ineffective and so complex and frustrating that most of us just give up. I do not have the time to detail the actual hopelessness of dealing with Centrelink, My Aged Care and the money-hungry so-called providers. I am university educated and qualified, and calling My Aged Care reduces me to tears. The ineptitude of their system is incomprehensible. I will give one example. After three times informing them that my father was now living in my house here in Hervey Bay, Queensland, they were ready to send their ACAT assessment team to reassess Dad. The assessor was being sent to Dad's home in Victoria.

Unless you have sat by that bed day in, day out and watched your mother, father or child or very much loved one suffer while awaiting the inevitable, please do not even think about telling me what you believe is right for my loved ones. Nobody has the right to dictate to me how I choose to die—nobody—so please let me choose.

CHAIR: Thank you for sharing what is a deeply personal story about your mum and dad. No-one said this was going to be easy, but we are listening. Thank you. Scott, welcome.

Mr Einam: Thank you for having me. Thank you for giving me a chance to speak. My name is Scott Einam. I lost my wife to motor neuron disease at the age of 47. For the last 12 months I had to listen to her every night asking me if she could die. I wish I could have helped her. As this lady just said, unless you have had to put up with someone like that, day in day out and all their needs and wishes, do not tell me how someone should die. She died with no dignity, lots of shame, lots of embarrassment. That is not a way to die; not when you are 47 and your mind is 100 per cent. It is pretty emotional, as you say.

So, yes, I am definitely a fan of voluntary assisted dying. In fact, I was in the Northern Territory when they approved it and thought it was a fantastic thing until the federal government squashed it. How to send the nation backwards again! We do it for our pets—in fact, you can be charged for cruelty for not doing it—and yet we let our humans suffer and die in pain and with no dignity. It is really wrong, as far as I am concerned. That is about all I am going to say on that.

If you are interested in some dealings I had with the palliative care ward at Maryborough Hospital please feel free to ask. Also, after having my wife removed from that ward and being placed into a nursing home, if you are interested in staffing levels et cetera at nursing homes and their ability to look after someone in that condition please ask as well.

CHAIR: Thank you very much, Mr Einam.

Ms Wright: My name is Doreen Wright. I am a 74-year-old citizen of Queensland and a long-term member of Dying With Dignity Queensland, although I am not representing them. My comments are based on my own long-held beliefs and experiences. It first began after experiencing my father's death in a hospice in the UK where he was able to die in a relatively humane and dignified way due to palliative care and so I fully am supportive of Dr Osborne moving for a hospice in this area. The staff were there for my father and for the family and they really did a great job.

I am a very active member of the community, involved in much voluntary work focused on living and helping others in our community. This provides me with fulfilment, purpose and joy in living. However, as you age you do have more thoughts on one important issue—that of your own death. How we will die is of fundamental concern and dying with dignity is a fundamental human right. We say to other citizens you have choices in how you live and in your goals for life. As seniors we have made choices and worked hard to achieve our goals for ourselves and families. Why do we have so few end-of-life choices if we are facing a prolonged, painful death?

I am stating that I strongly support the legalisation of voluntary assisted dying in Queensland. Under our existing laws it is legal, if you are dying and suffering beyond medical relief, to end your life by slowly starving, if you are able, or being slowly drugged into a coma or, if you are able, by committing suicide alone and often unsuccessfully. How can it be said that prolonging and ignoring the situation is morally right or, indeed, anybody's right other than the individual's with a doctor's assistance.

As I said in my opening, palliative care can be an effective and humane option. However, as AMA Queensland states in its media release on 23 May 2019, Queensland has only half the number of specialist palliative care services it needs to meet community need forcing many people to die without the dignity they deserve. It has called, and I am sure many people do join them, upon Queensland Health to create statewide multidisciplinary palliative care units to coordinate services. It needs to cope with a variety of ages, cultural practices and living conditions. Funding needs to be increased so the estimated 90 per cent of patients who can benefit from palliative care are able to do so.

My main concern is for the estimated five per cent of patients whose suffering palliative care cannot relieve. Losing control over your body is painful and distressing. Having no control in ending your suffering or that of your family and friends is far worse. We need laws to protect people from unnecessary and unbearable suffering at the end of their life, laws to give doctors a legal right to assist their patients in these conditions who voluntarily request assistance to have a humane and dignified death.

Only you, as our elected representatives, can make these changes. They are needed now. Thank you for the opportunity to present my views and for providing so many people in Queensland the opportunity to do this. Thank you.

CHAIR: Thank you very much.

Mr Smith: My name is Paul Smith. I lost my son Corey at 28 to cancer in March this year in the Hervey Bay Hospital. Corey was suffering from cancer for about 18 months. It was a rare, aggressive form. He went to Brisbane for treatment. I do have some thoughts on treatment and palliative care. We got Corey back here about three weeks before he unfortunately passed away. I suppose the hardest thing, and why I am here today, is to talk about voluntary assisted dying and why I believe it is so necessary.

He was without a doubt the toughest bloke I have met in my life. As a kid he broke bones, he broke teeth, and he just got up and laughed. He had such a high pain threshold. Those last few hours will be with me for the rest of my life and are the most horrible I have ever seen. I feel for the medical staff who were there. There were four people trying to find a way to arrest his pain. I have read that the Queensland palliative care doctors say that nobody is suffering in palliative care. That is absolute nonsense and I will not take it. Even post-mortem his muscles were still activating in pain. When a nurse turns around and tells you we have given him enough medication to put down a horse and yet you are holding your son who is skin and bones and he is in tremendous amounts of pain that is unacceptable. It is undignified and that is not the way we treat any living being in this world.

We need to give serious thought to this. I understand there are grey areas and I understand there are exceptional circumstances, but in my case it was black and white. This was my son. This was my mate. He was far tougher than I will ever be and if I have to stare down the gun of a terminal diagnosis and treatment and I know what is coming I know I will probably, and a lot of people will, make a different decision and that is just an impost on society. That is an impost on our medical staff. It is unfair, it is undignified and it is not right. I would ask you to seriously consider how you would feel in these situations and give it due consideration.

CHAIR: Thank you very much. I might open up for questions. I think you all articulated your stories very well. Sharing your own experiences is pretty tough. Scott, I might start with that last part. Talk to me about the aged-care experience.

Mr Einam: I am not bagging the nursing home. In fact, they were fantastic—really. They are just not set up to care for someone like my wife. She was essentially a paraplegic by this stage. She could not do anything for herself. The nursing home she was in had a staff of three at night dealing with 35 rooms. My wife needed 24-hour care so my mother, myself and my stepson provided that.

CHAIR: Thank you. Paul, with your son's diagnosis and going through what you have been through, I think it is a hell of a personal experience you have shared. I might open up to questions.

Mr HUNT: I want to thank you for sharing those personal stories. I am not about to grill you with questions. I am sure that you have said what you wanted to say here today. I just want to say thank you very much for that. I know it is difficult.

Ms PEASE: Thank you very much everyone for coming in and sharing your stories. It is invaluable and very much appreciated. Paul, I am particularly sorry for your heartbreaking loss. Prior to your son's death, had you or your family ever thought about voluntary assisted dying?

Mr Smith: It is a funny story. I travel a lot with work and I listen to a lot of podcasts. My parents are elderly, both in good fitness, and it has always worried me that my dad might come down with some sort of dementia because that would be just horrible for him. I have listened to a lot of podcasts. I have listened to a lot of Andrew Denton's theories on it and the investigation he has done overseas. I respect those people who do not want it, but all we really ask is that those people respect the people who do want it. It is a choice thing. It is not mandatory. I believe a lot of the fears are pretty well unfounded, but I respect that people have an opinion. In my case being young there was no complication there, it was pretty straightforward.

Ms PEASE: Scott, thank you for the love and care that you gave to your wife. I know that it would have been very difficult. Also, Sue, with your parents, it is a privilege to be able to be there with your loved ones to give that support. Thank you.

Mr O'ROURKE: I am not going to ask any questions. I am just going to say thank you. I really do appreciate you sharing your stories.

Mr McARDLE: Thank you for coming today. Scott, your wife was diagnosed with motor neuron disease at 47 years of age.

Mr Einam: Actually, she passed away at 47.

Mr McARDLE: My apologies and my condolences as well. She was in palliative care in Nambour Hospital, I think you said.

Mr Einam: No, Maryborough.

Mr McARDLE: Why was she placed in a nursing home given her condition at that point in time?

Mr Einam: We were asked to remove her from the palliative care ward at the Maryborough Hospital.

Mr McARDLE: Were you given a reason for that?

Mr Einam: She wasn't sick enough, and 13 days later she was dead.

Mr McARDLE: This committee is charged with investigating a range of matters. That places an onus on us to ask some questions, but they are not meant to be or to be taken as an attack on yourself or your loved ones. We have to investigate and try to bring forth some of the things we need to know. What you said to us is very important. Let us assume that we do have voluntary assisted dying in Queensland. You have all been through or are going through one very, very sad situation. Who should qualify for voluntary assisted dying? Can you define a patient and where they are at in their diagnosis? For example, we heard Mr O'Brien talk about dementia as being a trigger. Do you have an idea of where we should be looking in legislation along those lines? That might be very difficult, but it is important that we understand what the public of Queensland want to achieve.

Mr Einam: Firstly, I agree with the gentleman who was up here previously who said that it should be part of your advance health directive. I really do think that is the best way to go about it. That way, when people are of sound mind they can make the decision to choose to have voluntary assisted dying. As to when that happens, as you just said, it is a very difficult situation because, quite frankly, every disease is different. With motor neurone disease it is very difficult to quantify when someone is going to pass away. It might be six months, 12 months or 18 months. It is very difficult, so do you put a time frame on it? I think in Victoria—and correct me if I am wrong—it is six months from diagnosis of terminal death. That is very difficult in a lot of circumstances to determine. My suggestion is that it needs to be made and kept on your advance health directive or something to say that this is what you wish for, and then I guess at some stage it has to be up to the health professionals to say, ‘Look, it’s time for this to happen.’

Mr McARDLE: Are there any other comments by other people?

Ms Wright: Yes. It is, as we know, a very complicated area. I go back to the hospice with my father. They had time. They could talk. He was concerned about my mother in particular. People could listen and so they were making informed medical decisions which I do not think was possible for us as the family to do, so it varies. If it is unbearable suffering psychologically and physically, the medical people, with the person asking, are the people who really could say, but you have to have time to listen and understand what is going on.

Mr McARDLE: Thank you. Paul?

Mr Smith: In Corey’s case it was pretty straightforward. He had a degenerative disease. His organs were shutting down. He was jaundiced three weeks before and down to about 40 kilos. On that side of things, from what I have read with the consultation period as far as trying to get psychologists involved to talk to people, I think that sorts a lot of the problems out and defines it. I think that is the protocol that has to be in place to measure that person’s incentive to die and why they want to die, because obviously there are cases where maybe they are not quite so sure where they just do not want to be a party because they do not feel like they are a part of the world anymore or they are mistreated or neglected and just think they are better off without, so I think there are protocols to put in place for that. In the black-and-white cases, as I say, I do not think it is a case whether we should or should not have. We should definitely have voluntary assisted dying, but the amount of feedback you can get on what framework works is obviously where the decision has to be made.

Mr McARDLE: Thank you. Sue, do you have a comment to make?

Ms Brooks: When both my parents were younger we used to sit around the table and speak about such things. My parents grew up in Malta during World War II, so as teenagers they were in the middle of a war. Malta nearly got bombed out of existence but survived and they did too, so we had those conversations as a family. Both of them were adamant that if they could not wipe their bums and feed themselves they did not want to be alive anymore and both of them got to that stage. Dad is incontinent. He can still walk and feed himself and that is about it, and being deaf and blind makes life for him even harder—he is legally blind but not totally blind—but it is terrible for those who are left to care. I totally agree that with my advance health directive, if I am at that stage of life I want to make the choice now that I do not die like Mum did after nearly two weeks of useless life. With Dad, I am watching him every single day, and it is not time for him to die now but it will soon be that time. I have been told months, not years now, with Dad.

I will highlight some information about Dad’s experiences with Hervey Bay Hospital and my experiences with Dad. I have taken him there four times to the emergency department. When I first started caring for Dad, which is just nearly two years ago, he started suffering really bad anxiety attacks, mostly in the evenings. I had no idea. His anxiety attacks are shortness of breath—he cannot breathe—he gets terrified and cries upset, ‘Take me to hospital.’ I took him to hospital. The emergency department—and this was the old emergency department before the upgrade; we have been there once since the upgrade—has not changed much. Triage does not accommodate for a man with no short-term memory and advanced dementia of a very frail age who needs to go to the toilet every five minutes because he is usually there with a UTI.

If you are sitting in a waiting room with a person with no short-term memory for over two hours—two hours is minimum, and that was the most recent stay—every 30 seconds you are telling that person where they are, why they are there and saying, ‘We will go home soon, Dad, but you’ve got to see the doctor, Dad.’ Everybody in the waiting room hears that conversation repeated hundreds of times because they do not remember what happened one minute ago. That is the reality. When Dad was taken into the emergency part, the staff were fabulous. They did tests, ECGs—everything—and tested his lungs. They could see my distress. Because I was not coping at home, they offered to admit Hervey Bay

him. I said, 'Fine.' It was a Friday night. Dad did not leave the emergency department. Monday afternoon when I went in there to see him, he was still in the short-term stay unit. He did not get to a ward. He did not get a geriatric specialist to assess him, as they advised me would happen. They did not shower him because Dad at 92, which he was then, refuses to have a shower if you ask him. They are like children. You do not ask them; you just say to them, 'Come on now. It's time to have your shower.' They will say, 'No, I don't want one.' You say, 'Come on. Let's go and have your shower,' and you shower them. For three days my dad did not have a shower and did not move from a room with a curtain.

They had an AIN who spent a lot of time with him who was fabulous, but he did not get care. He did not get his eye drops for his glaucoma put in. I took him home. He was better off at home. The doctor stood there and advised me to leave him. The social welfare person at the Hervey Bay Hospital told me he would be better off at home. I found a nurse practitioner in palliative care—slightly different to what the doctor initially said—via Facebook. People told me her name. I emailed her. I do not know how she came into my life, but she is my godsend because she can prescribe and I do not have to try and take Dad out of the house. Dad does not want to go anywhere. If I put him even outside the door, he will have an anxiety attack, so I have to drug him to take him anywhere. He will not go in a wheelchair. He is still intelligent and he is still able, but his short-term memory and his anxiety stuff it all up.

The practitioner nurse comes to the house. She has told me in no uncertain terms, 'If you have a crisis with dad, don't take him back to the hospital. You don't want him to die in a hospital. Keep him at home, Sue. You will manage. I will help you to manage.' I am terrified of what nursing Dad as he dies will be like. I have no experience of that other than my mother's death in a hospital. If Dad was admitted into hospital, at the moment he sleeps between 14 and 16 hours a day quietly in his bed in his room with the curtains drawn. He can get up and go to the toilet. He sometimes forgets where the toilet is, but he manages because he is comfortable in what he considers now to be his home. How would he cope because, as the doctor said before, we do not have a palliative wing? If I take him into the hospital he will be in a ward, so how will he sleep peacefully for his 14 to 16 hours a day without being interrupted with lights, with activity, with other patients being cared for?

There is a lot that is not good with hospitals for someone at the end stage of dying. I do not know how the nurse practitioner lady gets paid—the nurse. She comes. She helps me. She prescribes drugs so I do not need to try and get the doctor to do a prescription without seeing Dad, and she is the only reason I am coping. Thank you.

CHAIR: Thank you very much, Sue. We keep hearing good things about nurse practitioners and the role they play. We thank all of you for your time and for sharing your stories with us today on the record.

Proceedings suspended from 5.23 pm to 5.33 pm.

BROWNE, Mr Phil, Private capacity

FOLLING, Mr Neil, Private capacity

PATTERSON, Ms Sally, Private capacity

SELFE, Mr Wayne, Private capacity

YOUNG, Ms Anne, Private capacity

CHAIR: Would you like to make an opening statement?

Ms Young: Thank you for giving me the opportunity to speak. My name is Anne Young. I am the coordinator of the hospital chaplaincy team at the Hervey Bay Hospital. I have some 40 years professional experience in community work, in counselling and in working with people with disabilities and working with people who have been addicted to various substances. I would have been present in the dying or the death of dozens of people but not the thousands that the good doctor had.

The dead people include my son, my husband, my twin and my parents. My husband and son both had illnesses such that I needed to care for them over their lives and they came to their death within 40 days of one another. My mother had many illnesses including cancer over the years. She certainly asked to die. She said, 'Why won't they let me die?' With psychological assistance and aged care, she came to a quiet acceptance of her situation and died a quiet and peaceful death, thank God. My father and my brother both died in hospices in England and I feel the treatment there certainly made a great difference. My brother had a particularly painful and vicious form of cancer that mimicked motor neurone disease and it actually ended up killing him with lung cancer. The situations with all of them are very different.

I want to make a very quick submission in favour of the improvement in palliative care because I have seen what really good, accessible palliative care can do for the state of mind of people who are dying and for the comfort of those who care for them. I would also like to see the advance care directives be given legal status so that a doctor and a family are bound by the wishes of the patient. When the patient states that at a certain time of their life they do not want their life to be needlessly extended by constantly resuscitating them—in my father's case, for example, he had Alzheimer's. He was dying—he was in end stage—but he actually died of pneumonia. The doctor withheld treatment for pneumonia because he said before he lost his mind that he did not want his life needlessly extended. He quoted that part of the doctor's oath that said something to the effect that, 'I shall not strive officiously to keep alive.' I think perhaps that is something that gets forgotten, that when people are dying we do not have to keep on and on and on keeping them alive beyond their youth, beyond their use, beyond their capacity to reason or to care. We are not doing them any favours; we are not doing the loved ones any favours. At the moment it stands—and I have had a couple of doctors and nurses say this to me—'If we don't do this we could be sued by the family because the advance care directive does not have legal standing.'

There are occasions—and I am not saying it is widespread—when a patient is perhaps kept alive beyond the point at which either any kindness or compassion is being shown. I think that pretty much covers what I want to say.

CHAIR: Thank you very much. We will come back to questions.

Mr Selfe: Good afternoon, members. I am a retired engineer. Unfortunately, we have only moved to Hervey Bay recently but I am very happy that we have moved here. I am actually in favour of voluntary assisted dying. My reason for that is a result of seeing my father suffer and die horribly through prostate cancer, albeit 21 years ago. He was in hospital briefly and was transferred to a hospice. In the last month he chose to be at home. At the time my stepmum could not cope with the stress. I was the eldest in the family, so I was designated to look after my dad and see him go from an able-bodied person walking around to being bed ridden, to lose all his faculties and to being in so much pain. His doctor would come to him daily and administer morphine, but he just said, 'Look, I can't do any more for his pain.' When you are sitting beside somebody and you are close—as you can see, it is all those years ago, but it is still vivid—you sort of want to put a pillow over his head to stop him from suffering. You ask, 'Why is it legal?' when you see somebody going through that. That is why from my personal experience I do not want to see anybody else go through it.

CHAIR: Thank you very much.

Mr Browne: My experience as a health professional has led me to strongly believe that VAD should be legalised. As a palliative care RN, I have seen many good deaths, but I have constantly seen the failure of palliative care to relieve distressing and grievous symptoms, especially extreme Hervey Bay

pain, excessive respiratory secretions and faecal vomiting from bowel obstructions. I support expanding palliative care services, but no amount of money will guarantee all Queenslanders good deaths.

Terminal sedation is a commonly used palliative care practice, which I call 'VAD lite' or 'Clayton's VAD'. Death can take hours to days and this is against many patients' wishes. The WA parliamentary end-of-life choices inquiry raised serious legal and ethical issues regarding terminal sedation, and these issues can largely be resolved with a VAD law with appropriate safeguards.

I have had frank discussions with patients about their suicide plans. Some with advanced disease and desperately suffering, including people of faith, have asked me to help them die. I believe that two of my patients committed suicide while on half-day leave. They saw what other palliative care patients endured and they decided this was not for them.

I was also a Queensland ambulance paramedic for a number of years. This involved attending suicides, mostly by hanging. I attended two suicides where it was known that the people killed themselves due to worsening suffering, one from a terminal condition and one from an advanced, progressive, incurable, debilitating condition. Both involved firearms.

CHAIR: Take a minute if you want.

Mr Browne: I will never forget having to step over the metal and timber rifle to access one of those patients and being terrified it would go off again. The injuries were devastating and horrific. The top of his head, his brain and half his face were gone, leaving an open cavity. Thousands of splatters of human tissue were blasted over every surface of the home. Reading his suicide note was awful and his family was inconsolable. Imagine the desperation, fear and isolation this man felt before pulling the trigger. Plus he did not have the comfort and support of the people he loved in his final minutes. How could the family even continue to live in the same house after this?

Every week Queenslanders are enduring grievous, irremediable, end-of-life suffering and some take their lives by violent and horrific means. We must allow these people the compassionate option of VAD. The need is urgent and to reduce suffering this reform must occur in this parliamentary term. Allowing registered nurses to administer VAD medications will increase access to VAD in remote areas without an appropriately trained doctor. Though most eligible people will not use VAD, just knowing it is an option will give great comfort to many. Legalising VAD will not mean more people die; it will mean fewer people suffer. Mr Chair, I have two documents that I would like to table, please. Is this the appropriate time to do that?

CHAIR: Leave is granted.

Mr Browne: I notice in previous hearings there has been a fair bit of discussion over whether or not palliative care medications hasten death. I have here a copy of the MIMS pharmaceutical literature, which guides all Australian doctors and nurses regarding the prescribing and administration of medications. This clearly states, and it is consistent with my clinical experience, that adverse effects of morphine administration include respiratory depression, apnoea—which is the cessation of breathing—respiratory arrest and cardiac arrest. I put it to you that palliative care medications certainly can. In my submission I completely omitted any mention of my experience as a paramedic. I believe the committee must understand the impact these largely preventable, in some cases, suicides have on emergency service workers. There is a brief statement there about the impact that has.

CHAIR: Is leave granted? Leave is granted. We will take those documents. I am a fellow emergency service person with 25 years in the Ambulance Service and we have a former police officer sitting at the end of the table, so you are not alone in your travels. Thank you very much. Mr Folling, welcome.

Mr Folling: My name is Neil Folling. I am one of the parsons of Hervey Bay Baptist Church. It sounds like I am in the minority, but I think the other side needs to be heard. I argue the case against legalising voluntary euthanasia on the basis that it puts at risk the lives of society's most vulnerable—the elderly, the lonely, the sick and the depressed. Euthanasia sends a message that some lives are no longer worth living based on the subjective standard of quality of life. It encourages patients to seek death as a way out, rather than caring for them as valuable members of society.

The compassionate answer to suffering is to recognise a person's inherent dignity, regardless of their physical capacity or their mental abilities or health, and to strive to provide the best possible care for those with disabilities or who are at the end of their lives. I argue that crafting a euthanasia bill that provides adequate safeguards for the vulnerable or marginalised in society is impossible, because it is too complex. For this reason, for nearly two decades now euthanasia has been consistently voted down in Australian parliaments.

There are three major concerns with legalising euthanasia: elder abuse, creating a culture of death and the hampering of the doctor-patient relationship. Elder abuse can come in the form of pressure, real or imagined, to die when an elderly person feels they have become a burden on loved ones. Even if most people withstand any perceived pressure, a culture accepting of a medical profession that will at times assist the death of its patients will inevitably create pressure.

Euthanasia creates a culture of death by undermining the inherent dignity of human beings. Legalising euthanasia may not result in a sudden increase in suicide, but it would affirm that suicide is a legitimate way of dealing with pain.

The doctor-patient relationship is hampered because the ethical obligation of doctors is to preserve the life of their patients. You go to your own doctor to get better, not to be killed. Medicine's longstanding Hippocratic ethic governs the care provided to all patients and residents—that is, to put into practice the ancient commitment of the medical profession to cure where possible, to care always and never intentionally to inflict death.

In most cases, pain can be treated. The concept of intolerable pain is experienced, but it is rare. In practice, if good palliative care is applied as Dr Osborne stated, palliative care can be done in a dignified way very well. I ask that we improve the palliative care system in Queensland.

CHAIR: Thank you, Mr Folling. We have heard the views of palliative care specialists who have asked for more. Certainly Palliative Care Queensland and Queensland Health have each put forward their views in that space. You have someone sitting beside you who has just talked about people who obviously did not have a choice or made a choice to end their life in another horrible fashion. We must respect the views of everyone, but we do thank you for your submission and for your verbal submission today. This is another tough panel and it will be a tough afternoon. No-one said it was going to be easy, but we have to reflect the views of everyone.

Mr HUNT: Anne, I did not quite catch exactly what you said around your experience in England and how it was so much better. Can you please expand on that?

Ms Young: The one I think you are referring to is my father's death specifically, although my brother also died in a hospice of multiple cancers. It had to do with the standard of care and the space of care. It was to do with having a beautifully furnished room that was adequately staffed and nurses who were in and out all the time. They did not have so many patients to look after so that somebody got to the point where their pain medication gave out and they were therefore in pain. The nurses were constantly monitoring their patients. Families could come in and out, stay overnight, do whatever they wanted to do. On the odd days that the patient was feeling reasonably well, they could be wheeled outside and into a garden. The standard of care and the dignity with which we were treated were quite different.

With my father, it was a situation where, as I said, he had Alzheimer's. Before he had Alzheimer's he had made it very clear that he did not want anybody to keep him alive beyond. That was in the early stages, when he was really able to reason these things. He quoted a quote which he said was part of the Hippocratic Oath and I keep meaning to check it. It says, 'I shall not strive officiously to keep alive.' In other words, it simply means that you do not keep somebody alive under all circumstances. When they get to a point, they should be allowed to go. He developed pneumonia. The doctor simply withheld treatment and he was allowed to die. He was permitted to die. That is what I am saying. In terms of that, that is not voluntary assisted dying; that is simply permitting somebody to die at a point when life is obviously going to be intolerable and keeping them going is not compassionate.

Mr HUNT: In circumstances where they have what sounds like good care.

Ms Young: Exactly. Again, it was a hospice situation.

Mr HUNT: Mr Selfe, you mentioned your father was in a hospice but decided that he wanted to go home.

Mr Selfe: That is correct. He decided he wanted to be around family and, I suppose, in an environment that he knew and felt better in. Basically, it was me looking after him. He was not able to get the full care and treatment that we wanted, plus he was only a pensioner so he was struggling financially. He would get Blue Care in every now and again, as he could afford it. It was very hard watching him firsthand like that.

Mr HUNT: At that stage, did he feel it was a better option for him?

Mr Selfe: He did. It was not for those looking after him, unfortunately.

Ms Young: I make the point that the hospice care was not financially onerous for the family in any way, shape or form. It was like aged care: you looked at people's means and they paid on that basis. It was not like private care, where you have to pay in full to get that care. He was getting Hilton style service on motel money.

Mr HUNT: Certainly the one we visited this morning similarly offers free care to patients. Mr Browne, if I read your submission correctly, you made a statement that under any voluntary assisted dying legislation if a religious organisation is running a service and is receiving taxpayers' money they should be required to participate. We had Catholic services submit to the inquiry a week ago, I think. I am losing count. They indicated that they would be happy to transfer a patient, but if they were required to participate in voluntary assisted dying they would remove themselves from the industry altogether. Knowing that and knowing of the large amount of services that they provide, would you concede that it might be worth mediation there or some sort of give and take in that situation?

Mr Browne: Some of the issues to do with this are that we know the majority of the population supports voluntary assisted dying. From credible polls of over 2,000 people we know that 77 per cent of Catholics and 88 per cent of Anglicans support voluntary assisted dying. I worked in a 100-bed Catholic hospice in New South Wales. The closest hospice to that was also a Catholic facility and it would have had very close to 100 beds. That is 200 people at any one time receiving palliative care. If those institutions are able to put a blanket rule on all of their staff saying, 'No, you can't do that in this facility,' where on earth are those people going to be transferred to? Not everyone is going to want that. For those who do, they have to be shipped out. We are talking about people at end of life, with very poor quality of life. That is a massive inconvenience to them. Going back to the institution I was in and in all other health settings I have been in, the majority of my health colleagues, both doctors and nurses, would be quite willing, I believe, to participate.

Mr HUNT: You have outlined the reasons they should participate. Knowing that they will not and that they will withdraw the many services that you have talked about, do you think there should be some room for compromise? If we did legislate that they must, according to them in their representations to us we would definitely lose those services and need to fill those gaps.

Mr Browne: I do not have a clear answer, but there should be discussion, I agree, yes. The big problem is that if those institutions ban VAD in their facilities, they are going against the clear wishes of, I believe, the majority of their staff as well as the majority of their patients who would want a choice of VAD.

CHAIR: People of faith have reflected some views—not all of them—and that was a particular one that I recall as well. What would your message be in response to community faith leaders who are saying that they will potentially pull out?

Mr Browne: I would say: listen to your patients, listen to your staff, listen to your parishioners, because I believe that a very strong majority of all of those categories—staff, patients and parishioners of the churches—would overwhelmingly support giving people the option of accessing VAD.

CHAIR: Thank you, Phil. We heard from palliative care specialists before the faith groups came in. I talked about my experience as a paramedic of giving morphine knowing that the side effects cause respiratory depression, hypotension, bradycardia.

Mr Browne: To add a point there, I saw a doctor on a webcast of a previous hearing who said quite clearly that palliative care medications do not hasten death. I would like to add the point that the adverse effects that you have documented there—respiratory depression, apnoea, respiratory arrest and cardiac arrest—are dose dependent, which means that the more the person has, the larger the dose, the more likely they are to get those symptoms.

In end-stage palliative care, you are giving very frequent, very rapidly increasing, quite large doses of morphine. We are not talking about five or 10 milligrams. I might add that morphine is not the only palliative care medication but it is a commonly used one. We are not talking about the people who are walking around in the street taking five or 10 milligrams; we are talking about people having frequent, really high doses.

CHAIR: I want to get to the point of where you termed it, I think in your opening statement, voluntary assisted dying lite—a light version of it.

Mr Browne: VAD lite? Are you talking about terminal sedation?

CHAIR: Yes. I want you to unpack that a little bit for me from your experience.

Mr Browne: Sure. I noticed earlier that the doctor said he was not familiar with that term. That does not surprise me, because terminal sedation, or palliative sedation—whatever you want to call it, and there are multiple names for it—is largely unnamed in our health settings. It is not only palliative care settings; it is also general hospitals where a patient will be received. The medical team will say, 'We can no longer achieve a cure so we are going to change from active treatment to palliative care and focus on making them comfortable and maximising their quality of life for the remainder of their days.' At the end of life, when palliative care can no longer relieve their symptoms—and that does not happen for everyone but there is a small percentage to whom that clearly happens—the shift in many settings is this unnamed terminal sedation.

I became aware of the term 'terminal sedation' through an overseas YouTuber. I think they were American or maybe British—I am not sure. Perhaps it is a term that is used more overseas. Terminal sedation is definitely practised here in our palliative care settings and in our general hospitals, but it is largely unnamed.

CHAIR: The ultimate result of that?

Mr Browne: The idea of terminal sedation is that the person is rather rapidly rendered unconscious and remains unconscious until their relatively rapid death. As I said, the person can linger for some hours to some days as a rule, but the outcome is always death. To me, it is just VAD lite. We need to get serious and really address this. A lot of it comes down to intent. What was the doctor's intent? I would say there are two intentions of a terminal sedation. One is to relieve the symptoms. Relieving the suffering by bringing on death I believe is a secondary intent of terminal sedation.

Mr O'ROURKE: Phil, in your submission you have commented that there should be mandatory staff ratios in all aged-care facilities as there are in the Queensland public health system. Would you like to expand on that a little bit more?

Mr Browne: Yes. I have worked a little bit in aged care myself. It is all dependent on funding. I have not worked in aged care recently, but staffing levels used to be all dependent on funding. If you were knocked back on your funding, you had to cut your staffing levels. There needs to be a predetermined ratio—and congratulations, by the way, for the mandatory staffing in Queensland public hospitals; it also needs to go into private hospitals as well as aged care—because the patients need so many man-hours. Not only do they need man-hours; they need a skill mix—so many ENs versus assistant nurses versus RNs. I understand that there is no guarantee of that happening in reality. I believe that needs to be locked into legislation, because we need to be assured that there are going to be enough people hours to care for the people in aged care and there are going to be enough RNs on every single shift to be able to deal with anything that comes up.

Mr O'ROURKE: When we explored this issue at some of the other hearings, concerns were raised in regard to the level of care that people needed—whether it is one to four. How you can build a staffing ratio when we do not know the exact complexity of each and every client in an aged-care facility?

Mr Browne: As I said earlier, it has been some time since I have worked in aged care so I am a little bit rusty. I would say that there needs to be some formula or some way of working out what number of enrolled nurses and what number of registered nurses are required and how many must be on each shift. It would be extremely rare to find an assistant nurse in a hospital these days—meaning someone with often no training at all—but my understanding is that in nursing homes they are predominantly untrained assistant nurses, or maybe with some minor sort of training but largely unskilled.

Mr O'ROURKE: Thanks very much.

Mr Browne: Can I just clarify that that is not to put down nursing home staff. They work incredibly hard.

Mr McARDLE: Thank you for being here. Anne is leaving. Thank you so kindly for your time. I much appreciate it. I have been grappling with the issue of the ratio for some time. You mentioned the Queensland Health ratio of one to four. The Queensland Health ratio is somewhat different in that it applies to selected hospitals only—it is not across all hospitals in the state—and only for surgical and medical wards. In those circumstances they have the ratio of one to four. We have a formula based not on just the type of patient but the facilities as well.

Let me give you an example of what I am trying to get at. I have a residential place that has 60 beds: 15 for high-care dementia patients, 10 hospice style beds and the balance for aged care. Next door to that we have a 60-bed aged-care facility that is all for aged-care patients. The problem I have

is that, in those circumstances, a formula is very difficult to come down to. You have a very definitive point of view—and I accept that—but how do we get a ratio that could cover very similar bed numbers but a very distinct mix of patients—high-care dementia patients, hospice patients and also aged-care patients? How do you police that across the state? Do you work on a model that is similar to that of Queensland Health, or do you simply look at RNs as being the primary source of care during day hours?

Mr Browne: It is a complex issue and, unfortunately, I do not have all the answers. I wish I did.

Mr McARDLE: If you did, I would be very happy to hear from you.

Mr Browne: I do not believe at all that it should be all RNs.

CHAIR: I think the QNU has put in a submission.

Mr Browne: There would not be enough. I totally agree that there needs to be a consideration for the level-of-care needs of each resident in aged care. Are they high care et cetera? As to how you work out a formula, I really do not know, I am afraid.

Mr McARDLE: It might be up to us to work out, do you think?

Mr Browne: Yes.

Mr McARDLE: Right. Fair enough.

Mr Browne: But I believe that it does need to be addressed.

Mr McARDLE: I think the issue needs to be addressed properly, and we have to look into all the scenarios and come up with an answer that deals as best we can as a committee going forward. This cohort that we are going through now—and I am one of them—of baby boomers is going to exit at some point and a whole different cohort will come behind us who will be quite distinct in their make-up. In relation to voluntary assisted dying, you made the comment that doctors should listen to their patients and listen to their profession. Are you indicating that if a bill came into play a doctor could not refuse to be involved in or assist in voluntary assisted dying, or are you saying that there should be the right for conscientious objection?

Mr Browne: No, I am absolutely not saying that anyone should be forced to participate in VAD—absolutely not—and I did state that in my submission.

Mr McARDLE: I have not read that yet, so I do not know.

Mr Browne: I do not know which part of the submission you are referring to.

Mr McARDLE: That was your oral statement. I am trying to interpret what you were saying; that is all.

Mr Browne: Did I say that earlier, did I?

Mr McARDLE: You implied that we should listen to our clients and our patients. I took from that that—

Mr Browne: No, let me clarify. What I was touching on there is that, from my experience of working in many health facilities in a range of various settings, I have never, ever seen less than quite a strong majority of staff support VAD. I believe that those staff who choose to participate in VAD should be allowed to offer VAD to their patients who are requesting that. I certainly do not believe that anyone should be forced to participate. There should absolutely be a legislative option to opt out. However, in that instance I believe that a referral to another practitioner who will participate in VAD should be made within 24 hours.

Mr McARDLE: What about an organisation? The Catholic Church says, 'No way Jose. Any facility that we have'—and there are plenty around the state, the Mater et cetera—'will not be involved in that. That is a blanket policy. That is an objection we have.' Neil is quite keen to make a comment as well.

Mr Browne: That would be extremely regrettable, because it is forcing the institution's values onto every one of their patients and forcing their values onto every one of their staff.

Mr HUNT: Or the other way—forcing values onto them.

Mr Browne: No, because it would be only staff who would choose to participate. It would be fulfilling the wishes of the patient if the patient requested VAD. By saying, 'No, we're not going to allow any of our patients to participate' and going back to the example that I said—

Mr McARDLE: Not the patient. The patient can go somewhere else.

Mr Browne: Yes.

Mr McARDLE: The facility will not undertake or be party to a voluntary assisted dying method. That is quite distinct.

Mr Browne: We are talking about people who have a really poor quality of life. They are extremely fatigued. They are skin and bones. They are going to have to be shipped out to another facility. That is going to be a major inconvenience. That is really going to have a major impact on that person at their most vulnerable time in life. I think that would be incredibly sad if that happened.

Mr McARDLE: Neil, you had a comment, too, I think.

Mr Folling: The Catholic hospitals get their doctors to sign an ethical Hippocratic oath that governs that they are not allowed to do that. When they join the hospital as staff, they know what they are signing on to.

Mr McARDLE: Do you call the culture of death the slippery slope?

Mr Folling: Yes, I do.

CHAIR: Phil, with all of your experience, and Wayne, who can remember his father passing away 21-plus years ago, obviously have their views that are distinct from those of others. By the sounds of it, it is about providing choice and a compassionate choice at that point. I think that is what you are trying to say.

Mr Browne: Yes, I am here speaking on behalf of the many patients whom I have nursed over the years who have said to me, 'This is not good enough. I'm really suffering. The poop has hit the fan.' I can remember people crawling on their belly on the floor saying, 'Help me die.' I am here. I am their voice speaking on behalf of them so that the future generation of Queenslanders do not have to endure what some of the patients whom I have had have had to go through.

CHAIR: Thank you very much. Thank you for the work that you do. You are a diverse group in front of us.

DARCEY, Ms Carmel, Private capacity

GILROY, Mr Shaughn, Private capacity

RUSSELL, Ms Amy, Private capacity

SCHERRER, Ms Cecile, Private capacity

SENDALL, Ms Carol, Private capacity

WRAY, Mr Michael, Private capacity

CHAIR: We will move to our final panel. Michael, I understand you have a friend in hospital and you need to leave.

Mr Wray: He is in ICU and I have left his sister at the hospital.

CHAIR: Michael, we will ask you to go first.

Mr Wray: Thank you very much for that. I appreciate being able to talk to people about our beliefs as such. I believe that everybody is entitled to their own beliefs, but they do not have to or should not be allowed to push those beliefs on to somebody else. I have believed this since I was about 15 years old when the Catholic chemist would not sell condoms because it was his belief. He had a bus to take his kids to school. I lived in Winton, which is 100-odd miles from anywhere. I worked in a menswear store at that time—that was 50-odd years ago—and we ended up having to stock condoms because the chemist would not. Dictatorship is not for me.

As far as voluntary death is concerned, my family and I all spoke about it years and years ago. It was our belief that nobody should suffer unnecessarily. My story involves my mother, and there was not really pain or palliative care involved. She had a stroke at Winton and was flown to Townsville Hospital. My sister and I flew up to Townsville and basically we consulted with the team that was looking after my mother. My mother could not swallow. She could move her lips a little bit and she could move her eyes. It was a massive stroke; she could not do anything else. I asked, 'What is the prognosis?' and they said, 'What you see now, that's it.' She could not toilet herself. She could not do a thing. She just lay there.

They told me they could put a tube in her stomach and keep her alive that way because she could not swallow, she could not drink. There was nothing she could do. I said no to the tube in the stomach because my sister and I knew what our mother's belief was. My sister and I sat beside my mother's bed for three weeks and we watched her urine turn from white to a dark black. She died of thirst. If I did that to my animals, I would be in jail. Nobody can tell me that that was right. Everybody is entitled to their own beliefs, but they should not force them on somebody else.

If you sit beside that bed all that time and you see your mother moving her lips because she wanted a drink—she was asking for a drink, but we could not give it to her because she could drown because she could not swallow—what the hell am I supposed to do? This was about four years ago. I walked out of that hospital so angry and so frustrated, and you can probably still sense it now. It is not good for my blood pressure, believe me. That is why I am here today. I nearly did not make it here but it is so important to me that I had to. Like I said, if I did that to a pet I would be in jail or have a fine at the very least.

All I am asking for is a choice. People should be entitled to a choice not a dictatorship. Why force your views on others? I believe in live and let live. I am not forcing my views on anybody else, but I would dearly love to have that choice. It is a quality of life thing. How could you keep a vegetable alive? I beg anybody to explain to me why that was right and just.

I have to go, but the other thing I want to refer to is the palliative care which did not involve my mother. Put it this way, in Winton, they had a care unit attached to the hospital. The unfortunate part was that it was not a secure unit so consequently my mother would leave the unit at any chance she got and go home. Her only option was to be moved to Longreach, which is 200 kilometres away. She only knew a few people in Longreach. All of her friends and all of the people who cared for her were in Winton. I suggest that all of those sorts of units should be secure units so they cannot just walk out the door and go home. To finish, I hope that our grandkids are not having the same conversation in 30 years time. Thank you very much. Excuse me, but I have to go.

CHAIR: Thank you very much. Cecile, welcome.

Ms Scherrer: I live in Urraween, which is close to the hospitals here. I support and lobby for the law for voluntary assisted dying in Queensland and Australia, as this choice should be available if needed. Like the same-sex marriage law, not everybody needs it or uses it but for those in need it is there and available.

I have lived for 20 years in Australia with a double nationality—Australia and Switzerland. My own experience and view is that this legislation to allow assisted suicide needs to come into effect like in Victoria but possibly with less restricting points. My mother had depression and tried to commit suicide with acetic acid, which is used for toilet cleaning, when I was 11. She suffered the consequences for 22 years with a burnt gullet. No-one was able to stop her suffering. It was only when the gullet got perforated and they had to put tubes down to enlarge it when she was 60 that she was able to die of it.

My sister-in-law spent over three years in an old people's home after a stroke in Switzerland. She could not talk anymore but understood and had tears by sad stories. She was fed with a tube in her stomach and needed nappies. I myself would not like to endure this for three years or longer.

A friend's Swiss mother died with EXIT in Switzerland, and Claudia told me how peaceful everything went with her and her sister at her mother's side until she was peacefully gone. The website exit.ch has a page of frequently asked questions and it explains why I have been a member for many years. EXIT is the euthanasia organisation just for Swiss only. Dignitas and others are open to international people. With my membership of \$45 per year, I receive a magazine with people's stories. Many against euthanasia only changed their minds after they endured the suffering of a close person and their begging to be able to die. There are over 110,000 members of EXIT. It has doubled in the last 10 years, and this speaks for itself. Switzerland has eight million people and this is the membership now and there are more and more.

Terminally ill people with irreversible health issues have much comfort when there is a choice available in the last stage of their life. They know they could use it but many never use it but it is available. Despite the expansion of palliative care, euthanasia fulfils a need amongst the increasingly ageing society. Nobody should need to live against their own will. Everybody should have a choice and option regarding all aspects of their own life. I hope and wish this law will come into effect so fewer people need to commit suicide all alone—often involving innocent people and leaving family members, truck and train drivers, paramedics, police et cetera with a trauma for the rest of their life.

Thank you for helping and accepting this law to come into effect. This is my membership in Switzerland. It has a number on it. You can look it up. I decided I want to go after six months if I am like my sister and my sister-in-law. It is like the advance care directive but this is for the end of life. It is all open. You can see it. This is just information on how it works in other countries. I am happy I have a choice. Thank you very much for your time.

CHAIR: Thank you, Ms Scherrer. I welcome Carol Sendall.

Ms Sendall: Thank you. My name is Carol and, apart from everything else I do in this community, I am a mother, I am a daughter, I am an aunty, I am a wife, I am a primary caregiver in my family and often the arbitrator and negotiator of issues. That is my job. I support the right for humans to be permitted to die with dignity—for all who suffer from terminal illness to be able to choose voluntary assisted dying. 'Choose' is my important word—to be able to decide for themselves whether they want to suffer longer or just go to sleep and stop their suffering. In the past 12 months I have struggled after caring for and witnessing two people that I love eventually die. I watched them cruelly suffer for extended periods while constantly asking and begging me to help them die. I could not. The law will not allow this. They suffered, and I cried with frustration and hopelessness while I watched them struggle through each and every day until they were finally released from their own personal hell.

At 67 Bob could not breathe without an oxygen tank. He could not walk. He could not get himself to the toilet. His legs were so full of fluid that his calves were the same size as his thighs. His calf skin split and the fluid wept all over the floor on to towels placed to absorb the mess. The pain of having his legs lifted brought this big man to tears. His heart was failing. His lungs were failing. He was terminal and in agony. Trying to get staff to up his pain meds was impossible. Everyone was too busy and no-one had the authority but the doctor and the doctor was not available. Bob's mouth bled. He had lost so much weight that his dentures did not fit. He could not eat. They tried to feed him food that he could not chew. I brought him fruit. He tried for a while, but then he gave up and he decided he could not do it anymore and he stopped eating and he stopped drinking and he chose to die, but it took him six more days of agony before he found his peace.

Five weeks ago we finally said goodbye to my dad. He suffered badly. Palliative care was supposed to keep him pain free. Morphine every four hours was the script with other meds, but the RN was required to sign off on the morphine and she was overworked and could not be found. At times he would have to wait between 5½ and six hours between shots. The doctor said every four hours and he suffered for longer because of logistics. He begged me to get him an injection to end it. He told me that I had been kinder to my animals and asked why I was being so cruel to him. I eventually told him that he had to take control. He could decide which pills he took. He could decide what he ate. He was in control. He kept begging me day after day to help him and I was helpless. He wanted to come home to die. We honoured his wish. After so much bureaucratic paperwork and chasing around, we managed to get him home. I administered his morphine every four hours and he was no longer in pain, but this meant we—his children—had to put nappies on him. He could not stand. He could not breathe. He could not talk. He was still aware. He was tired, humiliated and he wanted to be gone. He could see all the things that were happening and he could not cope with it. He cried. He begged. He starved himself. He stopped drinking and eventually he, too, was released from his own personal hell.

Without mandating anything, why must some people suffer so savagely? Why can we not just decide some things for ourselves legally? I understand other people's views on this subject, but, honestly, unless you have travelled this path and struggled to watch your loved ones suffer so desperately, how can you tell me that this is not an option? Starving themselves and refusing water is not the answer, but this is the only answer they have. Where is the dignity? Where is the compassion? Where is the humanity? I vote to allow the option of voluntary assisted death for those who meet the criteria and choose the path.

CHAIR: Thank you, Carol. They say there is nothing more powerful than sharing your personal shared experience, and we do thank you for sharing that with us today. Thank you. Welcome, Carmel.

Ms Darcey: I want to acknowledge the people's stories that we have heard. I am a social worker in palliative care and I worked in a Catholic organisation down at Sacred Heart hospice in the community as a palliative care social worker and I have postgraduate studies in death, dying and palliative care from Sydney university. I am now retired. I feel it is important that when we talk about setting up palliative care places and hospices we think of the team. We need to think of the people who can support these people, not just the doctors and nurses but the allied health people such as dietitians and social workers because the families need that support—social, emotional and psychological—in coming to decisions.

I have heard so many excellent life stories here, and my paper was about who the decision-makers are. I support the final care of patients and people and also that people make their own decision about how they want to end their lives. A lot of that is being left to other people such as lawyers, ethical people, guardians, clinicians, nurses and even social workers, but we are not there to make decisions for other people. It is their decision. We need to keep in mind our ideals of palliative care practice. The Sacred Heart hospice palliative care service standards for palliative care core values help us to be culturally respectful and provide a setting within the palliative care institute that is adaptable to the diverse needs of our patients and their families and carers. The core values of palliative care are the dignity of the patient and family and compassionate care of the patient and family, with equity in access to palliative care services, respect for the patient, advocacy on behalf of the express wishes of patients and pursuit of excellence in the provision of care and support, and we have an accountability to patients and families and the wider community.

As a social worker I will advocate for changes in policy, service delivery and social conditions which enhance the opportunities for those most vulnerable in the community, and they are the people who are dying or, in some situations, slowly dying. I support VAD. I had a lot more to say, but a lot has been said about the dignity of the person. The issue is this: let us make our own decisions for our own lives and be there as a carer, if we have to be, in love and give each other permission to be our own deciders of our fate.

CHAIR: Thank you, Ms Darcey. There has been a consistent theme of providing choice that we have heard this afternoon. Thank you very much for your words. I welcome Shaughn Gilroy.

Mr Gilroy: Good afternoon. I am Shaughn and I am under 50. It is a very big topic, and you were right at the start: it involves everyone. Firstly, I have a massive amount of respect for everyone who has shared already, especially Carol. I lost a friend to cancer in a similar situation. I am going to go about this completely different, though. I will be talking specifically on euthanasia. I am not for euthanasia, but I may use some terms a little loosely such as 'worth' and 'dignity' but am not suggesting that people do not have worth and dignity if my view is different. Love between family and friends is very deep, so I do not want to take that away from people.

I like CS Lewis and he does a lot of morals, so my first bit is based on what he said about a few things and then I have elaborated on it. I will just go for it. We are quarrelling about the idea of euthanasia because we are trying to show that, in a sense, one side is right and one side is wrong. There would be absolutely no sense in trying to do this unless we had some sort of agreement as to what an actual right and an actual wrong are, just as there would be no sense in saying that, for example, a footballer has committed a foul. Unless there is some agreement about the actual rules of the game, it will not be a foul. That is a pretty lame analogy, but that is what I am trying to get at.

Human life has always been held at the pinnacle of this world—obviously above the animals and everything else—and that is why we always have that inkling and that inner ability that when we see people in need we want to help. However, I think this can get mixed up, especially when we are emotionally distraught. I myself think euthanasia is a sugar-coated lie as it suggests that we are actually helping people by ending their suffering permanently. I cannot agree on that.

If we go back to agreeing, though, as to what is truly right and what is truly wrong, I know that we can agree that life in itself is good and beautiful and obviously it comes with all the other things like pain and suffering, happiness, joy, sadness and whatnot. What I am getting at is this: why is it that as soon as someone is frail, elderly, depressed, lonely, handicapped or just does not want to live anymore suddenly their life is weighed differently in worth and dignity? Euthanasia could quite possibly be the largest form of inequality in this world, I think. Every life is worth the same and human dignity is equal from the start of a life to the end of a life, so to end it prematurely is a denial of dignity and humanity.

Especially in my case with my dear friend who passed two years ago, in his frailty and skinniness in the end I have never held him up to such high standards. I thought his dignity in the end was superb. I think we need to remind ourselves that we are not basing people's dignity on how they are in the present state. I think a lot of people feel like a burden but, even if that is a perceived image from them, that is definitely not the case. We all have the same right to dignity and humanity and I do not think euthanasia is the way about it. Thank you.

CHAIR: Thanks for sharing your views.

Ms Russell: I am here as a citizen of Australia. I am here to defend myself and to defend why I am very much against euthanasia. We are a family who dies of cancer: my father died of cancer, my mother died of cancer, my sister died of cancer, but they all died with very good dignity. I believe dignity is to give full support and love to that person. I do not believe in the dignity of killing.

Here in Australia we feel bad when we talk about God—I do not know why—whereas in America everybody is free to talk about God. I am a very strong Christian. Yes, I am a Catholic. Euthanasia, in our Catholic view, is a crime against God and also a crime against humanity, against life. I believe that it is inevitable, although I expect that all of us here will have a different view about euthanasia. I respect that we hold the right, we hold the belief, we have all the customs and traditions. I admire them and I respect them as a Catholic, as a Christian, which I am not afraid or ashamed to talk about. Each individual has a different view, but the viewpoint of the church is unequivocal. It can never be changed.

The teachings of the Catholic Church are that euthanasia is murder; it is killing. Any person who thinks that the motive that they have done to a person to help the person who is dying access suicide—even if they think they are doing it in good faith, it cannot change the nature of the murderous act, and that is forbidden at all times. It is still considered murder. Is it not enough that we have murders of babies? It is already legalised in Australia to kill babies in the stomach of the mother, the sacred place where the mother keeps the baby. They are still being killed and yet here we are.

I am here talking to the government and parliamentary officers. Are we here to kill our elderly, the vulnerable, the sick, the dying, those who need real love and care? Regardless of any illness a person is suffering, all we have to do as an individual is to help that person, to love that person, to give comfort to that person, to be with that person in their dying stages. We are not here to kill. Just because they are suffering we can introduce euthanasia? Do we think this is the only solution whereby we can help a person? Why can we not give them palliative care?

I was listening to the doctor who was here talking about palliative care. Palliative care is not about killing. Palliative care is about helping, serving and comforting the dying person. It is not about killing. Is it about giving palliative care so you can slowly give the drugs that will slowly kill the person?

CHAIR: Thank you. In the interests of time, I think you have made your point very clearly, and we thank you for that.

Ms Russell: Can I just say a little bit more? Our society in Australia should be judged by how we care for the sick and vulnerable. Everyone should be loved, supported and cared for until they die. That is what I believe. There is nothing truly dignified about being killed by assisted suicide. Suicide is always a tragedy. We know here in Australia that we are very concerned about the high level of suicidal cases. Work is being done to reduce that rate; we all know that. Here we are trying to introduce the ability of our own government to authorise killing on request by assisted suicide; we are creating a false idea of dignity. Good palliative care is not killing; it is only relieving the pain for the dying person and to help that person until the end of their life.

CHAIR: Thank you very much. I will open up to questions from the panel.

Mr HUNT: Thank you for presenting your views.

Ms PEASE: I would like to thank everyone for coming. Thank you very much for sharing your stories. I know they are very heartfelt and I am sorry for your loss. Thank you for sharing.

CHAIR: Can I thank the good people of Hervey Bay and the wider region for coming today and sharing your views with us. It will certainly help us steer towards recommendations at the end of the year. I think it is a fantastic opportunity to have your voices literally put on the Hansard which will stay in the Queensland parliament forever. We thank everyone for their contributions today. I now declare this public hearing closed.

The committee adjourned at 6.50 pm.