



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

Member in attendance:

Mr DJ Batt MP

Staff present:

Mr R Hansen (Committee Secretary)

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

TRANSCRIPT OF PROCEEDINGS

TUESDAY, 16 JULY 2019

Bundaberg

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The committee met at 12.08 pm.

CHAIR: Good afternoon everyone and welcome to this public hearing of the Queensland parliament's health committee. We are inquiring into aged care, palliative care and end-of-life care, and for the very first time in Queensland we are asking Queenslanders their views on the issue of voluntary assisted dying. It is fantastic to be here in Bundaberg and we thank you for having us here. I would say that this is probably the best and biggest audience we have had to date. Well done. Give yourselves a round of applause. You have narrowly beaten the Hervey Bay audience. We were at Hervey Bay last night and there was a similar sized audience.

I will start with a couple of procedural issues. I ask that mobile phones are switched off or turned to silent mode. I now declare this public hearing of the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee open. I would like to start by acknowledging the traditional owners of the land on which we meet today and pay my respects to elders past, present and emerging. I am Aaron Harper, the chair of the committee and member for Thuringowa. The other members of the committee with me today are Mr Mark McArdle, the deputy chair and member for Caloundra; Marty Hunt, the member for Nicklin; Joan Pease, the member for Lytton; and Barry O'Rourke, the member for Rockhampton.

I want to make a couple of announcements. We have a councillor here from local government, Councillor Greg Barnes. Welcome. We also have the member for Burnett, Stephen Bennett. Welcome, Stephen. It is great to have here the local member for Bundaberg, David Batt. I ask David to make a few opening comments.

Mr BATT: Thank you, Mr Chair. I thank the committee for selecting Bundaberg as one of the areas and for coming along. I know that you are going right across Queensland. We have so many people from Hervey Bay and Bundaberg here because a very large population of people in their senior years have come here to retire. On a good day, people like to walk by the river. It is fantastic weather all year round. That is why we have such a great number of people here who have a lot of interest in this inquiry. I thank everybody for coming along and showing that interest and being able to have their say today. This is not about Steve or me as we are your representatives. Enjoy what you have to say. Give everyone a turn. Thank you very much, Mr Chair.

CHAIR: Thank you, David. I also make apologies for Michael Berkman, the member for Maiwar, who is unable to be with us today. This committee is a statutory committee of the Queensland parliament and as such represents the parliament. It is an all-party committee that takes a nonpartisan approach to its inquiries. The inquiry into aged care, end-of-life and palliative care and voluntary assisted dying was referred to the committee on 14 November 2018. The committee is required to report its findings to the parliament on 30 November 2019.

Today we are in your beautiful part of the world, Bundaberg, to hear your views on the issues that are before us. We are very keen to understand what care people can access now, what care people need but possibly cannot get, and what this means for people's comfort and dignity at end of life. As I said, we are also keen to hear your views on voluntary assisted dying, or whether it should be legalised in Queensland.

These issues affect everyone in the room. This is arguably one of the most important inquiries that the Queensland parliament has ever undertaken. This hearing is your opportunity to share with us any thoughts or experiences that you may have on these issues. This is your chance to tell the parliament, because what you say is recorded in *Hansard* and shall remain forever in the history of the Queensland parliament. I think it is important that we get the views of Queenslanders.

Today you may very well share experiences or insights that are very personal and may be painful to talk about. I ask that everyone respect the right of others to hold and express their particular views. I also ask anyone who is speaking about voluntary assisted dying to please take care when referring to acts such as suicide or euthanasia.

This hearing will start with Debbie Carroll from the hospital and health service. Debbie will assist us to paint a picture of what is available in the area and what could possibly be improved, and then we will move to the people who have submitted. For anyone who wants to register to speak, I ask you to go to Rob Hansen, who can register you. We will try to get as many people up to the table as possible.

We want this hearing to be as informal and as relaxed as possible, but it is still a formal proceeding of the parliament and 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 also being recorded and transcribed by our Hansard staff. If you speak, make sure that you give us your details so that we can send you a copy of the transcript to check. For the benefit of Hansard, could you speak into the microphone and say your name when you speak.

These proceedings are covered by parliamentary privilege, which means that speakers are protected from legal action in respect of the evidence they may give to the committee. If you give evidence today that reflects adversely on an individual or organisation, it should not be taken as proof of those allegations being made. The committee may choose to receive but not publish that evidence. For any media present, I ask that you adhere to my directions as chair at all times. That means that people may be photographed here today.

CARROLL, Ms Debbie, Executive Director, Acute Hospital and Community Services

CHAIR: Good afternoon, Debbie, and thank you for being here. I ask you to make an opening statement to give us an idea of what is available to the residents of the Bundaberg and Wide Bay areas. Then will open up for questions.

Ms Carroll: Once again, thank you for the opportunity to speak. I apologise for Adrian Pennington, the CEO of the HHS, who could not be with us today. I joined Wide Bay HHS in 2006. My original role was the executive director of nursing. I transitioned into more of a general management role in 2014, undertaking the chief operating officer role. That then was renamed to something that is a little less easy to say: the executive director of acute services and community services for the HHS.

Wide Bay HHS provides services to around 214,000 people over about 37,000 kilometres. We have 11 facilities within the HHS, the three major facilities being Bundaberg, Hervey Bay and Maryborough. We also have rural facilities. A number of those rural facilities are MPHS multipurpose services. They provide residential aged care as well as acute services. They are in Childers, Biggenden, Eidsvold and Mundubbera and are very much an important part of the care that we provide. We do not have any state managed aged-care facilities within the HHS.

As mentioned, we have quite a challenging population base. We are older than the Queensland average, with 25 per cent of our population being over 65 compared to 14 per cent—

CHAIR: You might have to speak up for the benefit of the people at the back. I apologise. It is important for the audience to get an idea of what is available here. Thank you, Debbie. I will ask you to continue.

Ms Carroll: As I said, we have a challenging population. We have challenges within our population base that is older, sicker and from a lower socio-economic base. On the services that we provide in aged care, certainly within all of our facilities we have subacute care as well as our multipurpose services within the rural facilities. We provide palliative care services in the community, which is a nurse-led model, as well as inpatient services. In Maryborough there are six palliative care beds. In Bundaberg we have the PARAS Unit, which is the Palliative, Acute Rehabilitation, Acute Stroke Unit. It is quite a mix of services. It has flexible arrangements depending on the care needs.

CHAIR: How many beds are in that unit?

Ms Carroll: There are 24 beds and it can flex up to 27 beds. We could have up to 12 palliative care patients in that unit or it may be less. We do need to be flexible in those arrangements. Palliative care is also provided within our children's ward for the care of dying children. We provide palliative care in other wards. It depends on the needs base. The community based model of palliative care is coordinating care, access to services, triaging and providing home support, as well as education based services.

I am pleased to say that yesterday we commenced two palliative care dedicated nurse navigators, which is a new service for us for palliative care. In the nurse navigator space, we also focus on the aged, chronic disease, mental health and complex paediatric care. We have tailored the nurse navigator service to some of the vulnerable people within the community.

In addition, we certainly provide education support for our staff. We have undertaken projects on advance care planning in 2018 and certainly we try to make sure that staff are supported, as well as the families within our community. That is probably a brief overview of the services that we provide.

CHAIR: Thank you very much for that. It does paint a picture. I am very pleased to hear about the nurse navigators. We heard about that in Hervey Bay yesterday. I think they are also starting a \$7 million palliative care unit.

Ms Carroll: Yes, in Maryborough.

CHAIR: You mentioned some of the challenges in delivering palliative care in the community. I want to get a better idea of what that looks like in terms of the nurse-led model. What does the team look like? Can you also add commentary to this: it has been well articulated wherever we have gone—Mount Isa, Mossman, Townsville, Cairns, Longreach—that people are waiting for home based care packages. Yesterday at Hervey Bay, someone told us that they have been waiting four years to access a home care package that will deliver some care. The average wait is 18 months to two years. In fact, we have heard of some people dying before they receive their home care packages. Can you articulate what the nurses who work in the community are seeing? If people face delays in accessing that Commonwealth funding, the burden must then go onto the public hospitals. Do you have any views on that? Firstly, what does the team look like?

Ms Carroll: The team is quite limited in structure. It is similar for both ends, on the Fraser Coast and in Bundaberg. You have a CNC coordinator for palliative care. You have 1.5 clinical nurse positions, which is quite limited. In Bundaberg we have about a 0.4 assistant in nursing and one administration officer. As I say, we do not have any medical component within those work groups. We have been trying to recruit a VMO position for some time, unsuccessfully. We are just trying to look at that and remodel it to see if we can recruit. Certainly that is something that we are still looking at.

CHAIR: For the benefit of the audience, VMO is a visiting medical officer.

Ms Carroll: Yes. We did attempt to diversify the model and recruit two nurse practitioner roles, but once again we could not recruit those roles. It is a continual workforce issue of trying to be creative in the model of care, to try to deliver the services for the community.

CHAIR: That is something that we also heard about in Hervey Bay yesterday. They reported that they did not have a specialist palliative care doctor. To get around that, obviously, they have telehealth and a few other things are used. Our job is to make recommendations at the end of this inquiry on how to improve services. An observation is that already the state budget has allocated \$17 million to improve palliative care, because they are following what we are doing, in the public space. It is no secret that Palliative Care Queensland has also recommended that we get more palliative care nurses and doctors. If you had the ability to make a wish list, what would it be for the Bundaberg area?

Ms Carroll: What we want are sustainable services that meet the community's needs. Home based palliative care is a very important aspect of that. Having palliative care medical specialists is certainly something that would support the model of care and more trained nurses. We are fortunate that we have very skilled nurses who work for us. I have to commend them. However, they have only so many hours within a day to provide those services. It is also important that the allied health services, the psychological supports and the social work supports are all part of it, to make sure that you have a multidisciplinary approach to care.

CHAIR: I will make a comment before I move to the member for Nicklin. You talked about home based services. We are hearing that when people are diagnosed with a terminal illness they would prefer to be surrounded by loved ones at home. Eighty per cent of people would like to pass away at home, surrounded by loved ones. From the reports that we have, the reality is that around 14 per cent end up staying at home and the rest go to a hospital or palliative ward. There is definitely a need for improvement there. I will open up to questions.

Mr HUNT: Thanks for coming today. Can Bundaberg residents get access to community palliative care on a weekend?

Ms Carroll: There are issues. We script out for the care component, which might go to an external provider. At times there are problems with accessing that care. We try to set up the packages for the delivery of care over seven days, but I certainly know of some issues where people have struggled with accessing those services, particularly if you have to commence a syringe pump on the weekend. We only do Monday to Friday services.

Mr HUNT: If somebody needed that on a weekend, what would they have to do? Would they call an ambulance and go to hospital?

Ms Carroll: Potentially they would, if they could not access their GP. They may end up in the hospital setting if they could not provide adequate pain relief.

Mr HUNT: Does that happen often?

Ms Carroll: I could not give you the statistics off the top of my head. I would have to take that on notice. Certainly I would not say 'often', but I imagine it does happen.

Mr HUNT: For someone receiving palliative care in a hospital setting in Bundaberg, what does that look like? By whom are they cared for? Who oversees it? How does that happen in practice?

Ms Carroll: Certainly it is overseen by a medical specialist, who provides the care for them while they are in hospital. Obviously, multidisciplinary allied health services are there to manage their symptoms, support families and provide access to care.

Mr HUNT: Would they have access, for example, to a counsellor and that sort of thing?

Ms Carroll: Yes. It is a multidisciplinary approach.

Mr HUNT: You mentioned the medical specialist. Would they oversee the care on site?

Ms Carroll: They would be on call. We certainly have 24/7 on call for all consultant type specialists—physicians, surgeons, PHOs et cetera. It is 24/7 care but not physically on site.

Mr HUNT: Do they have access to a palliative care specialist via telephone, telelink or anything like that?

Ms Carroll: We provide telehealth services and you could contact Metro North, but it is not something where you have 24/7 palliative care physicians on call, no.

Mr O'ROURKE: Debbie, are there palliative care and end-of-life services for children available here?

Ms Carroll: We are very fortunate that we have a very stable and skilled paediatric consultant team and nursing team, as well as a new position recently for a social worker for the paediatric side. I believe they do palliative care extremely well. I know of circumstances of dying children and supporting the families, so I would say, definitely, yes.

Ms PEASE: Thanks very much for coming in and speaking today. I want to inquire about how the general public access your palliative care services. Do they come via a GP or do they have to be admitted to the hospital and are referred on exit from the hospital?

Ms Carroll: You can come via GPs or you can come via the hospital as well. There is a variety of referral pathways.

Ms PEASE: With regard to people who want to access palliative care services, particularly those who are living in community, are you aware of any delays that patients may have in accessing the packages through the My Aged Care system?

Ms Carroll: My Aged Care is not my area of expertise, but I am certainly aware of delays through the My Aged Care process. I know through our social work team that they have certainly raised concerns about that.

Ms PEASE: I know you are not necessarily in a position, but what impact does that have on your ability to provide the best possible palliative care to the residents of the area?

Ms Carroll: Certainly it might increase the length of stay in a hospital. Arranging for discharge plans to make sure that people are safe to go home may increase the hospital stays. People want to go home to their own environment, so it will impact on that.

Ms PEASE: Throughout all of our inquiries we have heard that there are some lengthy delays and it can take up to 18 months. People have actually passed away while waiting for a package, which is heartbreaking as people have expressed their wish to be at home. Sadly, we heard yesterday of a woman whose husband waited for four years for his care package. Have you come across anything like that?

Ms Carroll: I have not come across anything with those lengths of waiting for packages. Maybe some of the teams have. Stories like that are certainly heartbreaking and that is not what we want for our patients.

Ms PEASE: Thank you very much for the great work that you do. It is very much appreciated.

Mr McARDLE: Thank you for being here today. We do appreciate not just you being here but also the work that you do. It is a difficult job juggling a hospital in this day and age—public or private for that matter as well. You referred to \$7 million as state money for the palliative care unit. Is that right?

Ms Carroll: Yes, capital money.

Mr McARDLE: It is state money, not capital money?

Ms Carroll: Yes.

Mr McARDLE: We were told yesterday that there are some six to eight beds to go into that complex when it opens, increasing by four or six more. Is that correct?

Ms Carroll: Can I clarify what capital build you are referring to?

Mr McARDLE: You mentioned \$7 million.

CHAIR: That was for Hervey Bay—

Ms Carroll: Maryborough. That has happened. They are in place.

Mr McARDLE: Is there a hospice being built also in this area?

Ms Carroll: Not from the public health side of things. We are not funding a hospice, but I know there is work being done in the community looking at that, particularly in Hervey Bay.

Mr McARDLE: Are you aware of the details of that hospice?

Ms Carroll: No, because we are not involved in that. It is community led.

Mr McARDLE: Did they come to you for advice as to bed numbers required and other services and staffing levels, given the HHS's dominance in the area?

Ms Carroll: Not that I am aware of, but I do know that one of the medical consultants in Hervey Bay is on that group but from a private point of view.

Mr McARDLE: You mentioned that there are six palliative care beds in Maryborough. What is the palliative care nursing number in Maryborough?

Ms Carroll: They are cared for within the ward of Maryborough. They are not just palliative care patients within the wards. We go through a process of determining the staffing and requirements using the business planning framework for nursing. You look at what level of nursing is required.

Mr McARDLE: They are in the surgical and medical wards, are they?

Ms Carroll: That are not in a surgical or medical ward. They are in Maryborough, which is a subacute facility. There are other patients in that ward as well.

Mr McARDLE: We were advised there were two to three nurses in Maryborough involved in palliative care. Are you saying that that number really is two or three across a range of issues or range of patient type?

Ms Carroll: Within the palliative care community based model there is a CNC and clinical nurses, 1.5, and admin within the palliative care team. They provide liaison services and support across the Fraser Coast and then you have the inpatient ward within Maryborough.

Mr McARDLE: There are six beds at Maryborough?

Ms Carroll: Yes.

Mr McARDLE: There is the inpatient ward, correct?

Ms Carroll: Yes.

Mr McARDLE: That has a CNC, 1.5; is that right?

Ms Carroll: No, the CNC and 1.5 is community palliative care.

Mr McARDLE: How many in the inpatient?

Ms Carroll: Nurses?

Mr McARDLE: Palliative care nurses.

Ms Carroll: I could not give you a number off the top of my head. I would have to take that on notice.

Mr McARDLE: Would those beds be part of a mix of patients as well?

Ms Carroll: Yes.

Mr McARDLE: How many nurses are in that facility—acute?

Ms Carroll: Once again I would have to get the staffing ratios. I could not just give you the number.

Mr McARDLE: Are those nurses also trained in palliative care, or are they senior nurses who have had years of experience and therefore qualify for palliative care services?

Ms Carroll: Once again I would need to check the profiles of those nurses. They are certainly trained, as in upskilled, in palliative care. When we were establishing those beds we developed the model of care, what was required under the palliative care standards, and education was provided to those nurses. I was certainly part of that development. As to postgraduate certificates, I could not give you that number. I know we have changed that.

Mr McARDLE: Could you take on notice how many beds are purely palliative care, how many are mixed beds in the acute section and what is the mix in relation to nursing and qualifications in that unit? Is that possible?

Ms Carroll: Yes.

Mr McARDLE: You also mentioned Bundaberg. You have 24 beds and up to 27 beds, but again I suspect it is across a spectrum. It is chronic, palliative care, stroke and other acute conditions as well. Are you able to break those bed numbers down? At least for planning purposes, are there X number of palliative care beds, X number of chronic and X number of stroke? Can you give some idea of the nurse-patient ratio and also qualifications of the nurses in relation to caring for palliative care patients?

Ms Carroll: Basically, focusing on the 24 beds, the flexibility of palliative care is around six to eight beds. For stroke beds it is six to eight as well and then rehab beds. There is a flexible model that slides depending on need. Once again, in relation to the ratios of staffing I would need to take that on notice as well.

Mr McARDLE: Absolutely.

Ms Carroll: We work on hours per patient day in the PARAS ward as opposed to ratios. That is tailored to that mix of patients within that unit.

Mr McARDLE: Could we get also the qualifications of the nurses? That ward would not be subject to the ratio that applies to surgical and medical wards?

Ms Carroll: That is correct.

Mr McARDLE: One is to four or four is to one, as the case may be. Do you have a standard ratio in that ward?

Ms Carroll: It is not a ratio; it is hours per patient day on the mix of patients. Palliative care patients would have a higher hours per patient day, as well as acute stroke, whereas rehab patients might have slightly less, so it is a—

Mr McARDLE: You have an acuity model?

Ms Carroll: Yes, very much so.

Mr McARDLE: When you look at the 2018-19 budget for the HHS and the 2017-18 budget for the HHS, outside of the wages, which are somewhat difficult to define in terms of palliative care and other care, what was spent on palliative care by the HHS? You can take that on notice.

Ms Carroll: I would need to take that on notice to give an accurate figure.

Mr McARDLE: That was 2017-18 and 2018-19, leaving aside the wages. What other funds were spent on providing palliative care? That would be great. You mentioned the workforce issue—a specialist palliative care physician. You have had an ad for someone of that type running for some time, have you not?

Ms Carroll: Yes, we have.

Mr McARDLE: How long has the ad been running for?

Ms Carroll: It has probably been at least eight months. We have run it a couple of times unsuccessfully.

Mr McARDLE: At any point in time has there been a position of that note in the HHS?

Ms Carroll: Yes, previously that position was filled.

Mr McARDLE: Was that public or private?

Ms Carroll: It was a visiting medical officer, a GP.

Mr McARDLE: I take it that one of the major issues the HHS has with those very senior qualified people, with respect, is that they do not believe coming here is going to advance their career. As I see it, they do not see that coming to a rural setting is the best opportunity to improve their skills. I take it also that when you are focusing on the practitioner you have to consider the partner or the spouse. What happens is that when the children reach grade 7 they go back to Brisbane on the false belief that there are better schools down there. That is an ongoing issue in this region. Have you found that, with palliative care nurses coming on board as well, that is a very similar concern you have had?

Ms Carroll: It is probably not as much so in the nursing side, which is fairly stable. However, that scenario you have just described has happened—maybe not grade 7 but certainly high school, university or opportunities for the children or the partners and you end up losing the consultant.

Mr McARDLE: They are here for two or three years and then they are gone and the gap is enormous and almost impossible to fill because the corporate knowledge of the person goes with them, which is so critical to delivering services.

Ms Carroll: Yes.

Mr McARDLE: The other point is that Blue Care operates in the HHS arena. How much work do they do in regard to palliative care—that is, home care and other services that you may also provide in a hospital or community setting?

Ms Carroll: We certainly outsource to Blue Care. They do provide care for our patients. As to the quantity of that, I cannot give you a figure on that.

Mr McARDLE: Can you give me that figure on notice as to what is the arrangement with Blue Care—how many exactly?

Ms Carroll: From our front desk? Yes.

Mr McARDLE: Do you have a matrix or some form of document that you could overlay the HHS to define the need for palliative care, end-of-life care? Is there a model that you look at to consider what you spend in a financial year?

Ms Carroll: We could certainly identify what we spend in a financial year through activity based funding, looking at what palliative care activity we have and the resources we used for the palliative care in the home model. We could—

Mr McARDLE: What if I asked you now to explain the matrix that you would use to define the palliative care needs in the HHS? Could you do that by looking at a document that explains how that is done or do you have to analyse every year?

Ms Carroll: We would need to look at activity. The HHS has just undertaken the health service planning activity. Palliative care has certainly got a mention within that document that has just been completed, looking at the model of care consistency across the HHS and what we need to do to make improvements in that space. In terms of having a matrix to overlay and say, 'This is the formula,' we do not have such a document but we certainly know the flows, the demands and the feedback that we are getting from the community, which is all part of health service planning.

Mr McARDLE: What proportion, generally speaking, of the HHS budget is set aside for palliative care each financial year?

Ms Carroll: As in percentage, that is once again something I would need to take on notice to get the figures to look at what actual funding is provided.

Mr McARDLE: That would be good. If you have a percentage, that must be based upon a calculation?

Ms Carroll: Yes.

Mr McARDLE: Could you provide not the details but how that calculation is formulated as well?

Ms Carroll: I will certainly check with our finance and performance team as to what is available.

CHAIR: It goes out to a cost per day per bed, I imagine?

Ms Carroll: Yes.

Mr HUNT: Are there sometimes waiting lists for people to get into palliative care in the Bundaberg Hospital?

Ms Carroll: There are certainly times when patients may be housed in other units. In terms of a waiting list to come in there is not, per se, but there is certainly demand for the community model. If we cannot get access into the unit then we need to look at other units that we can place patients in—

Mr HUNT: In another part of the hospital?

Ms Carroll: Yes, that is correct. I must say that the rural facilities all provide palliative care in the rural communities. They have dedicated rooms that are set up for palliative care patients where the family can stay as well. We try to keep people in their local communities.

CHAIR: For each of the hospitals, be it Bundaberg, Maryborough or Hervey Bay, or any other ones that you might have mentioned, are you able to take on notice how many beds are currently used by people waiting to get into a residential aged-care facility?

Ms Carroll: Yes, we do have those numbers. We do monitor those numbers. Our issue is unreasonable access to aged-care beds. One of the issues we have is that people in the community might not quite meet the need to go into an aged-care package—some of the lower care or respite care. That certainly creates some issues. We do not have the large volumes of people in the acute setting waiting for beds, but at times it does peak, particularly in winter.

CHAIR: We just came from Gracemere and they said they have a waiting list for people waiting to go in. Our concern is the burden placed upon the public hospital system of people using a bed, creating potential bed block. We know that we have an ageing population and there are some challenges in front. There being no more questions, we thank you very much.

ADLER, Ms Julie, Private capacity

BARNES, Mr Greg, Private capacity

BULL, Mr Tony, Private capacity

ROBINSON, Ms Corina, Private capacity

TOMLINS, Dr Richard, Private capacity

TONTI, Father Peter, Private capacity

CHAIR: Welcome. Given the number of people who want to speak today, we will limit opening statements to three minutes before we move to questions. We will start with the ladies on my left. Julie Adler, would you like to make an opening statement?

Ms Adler: I am Julie Adler. My mother had been in a Bundaberg aged-care facility since 2008 and was transferred to a high-care facility in 2014 until 26 April when she passed away under horrific circumstances. I would like to talk about the issues around that. She had dementia, had been bedridden for a number of years and was totally reliant on full nursing care, including for feeding and drinking. She was non-verbal but communicated through eye contact, facial expressions and distinct vocalisations when in pain or discomfort.

There was an incident on 13 April whereby our 91-year-old mum reportedly fell from her shower chair and hit her head. It was reported that she had lurched to the left and tipped the chair over. She was hospitalised and was diagnosed with bleeding on the brain. She had eight staples put into the left side of her head to stop profuse bleeding. She was then admitted to hospital, where doctors discovered a chronic and severe hip fracture. Subsequent CT scans revealed that it was inoperable, and Mum passed away some days afterwards. We were told that the hip fracture was not a result of the incident on the 13th and had happened sometime prior, more than weeks beforehand. This injury was never reported to us by the home, never treated medically and only discovered on admission to hospital.

The doctor reported the death to the coroner as a violent unnatural death and a healthcare related death. We are currently awaiting the outcome of this investigation. We are emotionally distraught, contemplating the pain and distress that Mum must have suffered over a sustained period of time with no pain management and being unable to communicate whenever she was repositioned in bed, changed positions for feeding or changing, or moved into a sling or chair for showering. The injury occurred despite having a family member visiting on a regular basis. We are in the process of completing our formal submission to the royal commission for the aged, and we have detailed a long list of incidents that arose over the five-year period she was in the home.

Some of the recommendations I would like to address today are the basic ones. Currently, personal care workers who have approximately six weeks of formal training work mostly with the residents on a day-to-day basis. These people cannot make clinical judgements around their care. For example, it was not recognised that Mum was constantly crossing her left leg under her right. Associated with her moaning and resistance when moving, this may have constituted a symptom of a hip fracture. This situation worsened when the carers were given the task of administering medication. We would like to see a minimum standard set for nurse-resident ratios, particularly for high-needs residents, and more face-to-face contact with registered nurses who can make clinical decisions with regard to the health of their patients on a daily basis.

CHAIR: Thank you, Julie. We might come back to you. I apologise for the time constraint, given the enormous crowd that we have. This was a terrible situation for you, your family and your mother to go through. We do thank you. We are working with the royal commission as well. We report a year earlier. Did you submit that submission to us?

Ms Adler: No.

CHAIR: Please see Rob after and we can consider that for tabling.

Ms Robinson: I would like to share my thoughts and views on assisted dying and why I think it should be legal. Basically, I am an end-of-life doula. For those who do not know what an end-of-life doula is, I am the one who sees you to the end of life and your last breath. I have been an unofficial doula since 2003, since which time I have seen many deaths. The first one I saw was a friend of mine who was diagnosed with cancer. He was 47 years old at the time. He was given three months to live

and I became his carer. During that time, only chemo was available. There were very limited services in terms of home palliative care. It was his wish that he die at home. We had discussed that. The doctors were okay with that because chemo was limited; it was pointless. From then on, it was a ritual of managing his pain, doing whatever we could. This is basically just my experience.

Imagine how it felt for me to watch this every hour of those weeks before he died—his agony, his screams, his pain. I resorted to getting cannabis for him, because the pain was so bad. Had I been caught with cannabis in the house, I would have been convicted and treated like a criminal—and for what? Trying to give someone dignity in death, something the government and politicians had no intention of granting him. It was his personal right to choose his death, and the only choice he felt was to die at home but it was not peaceful. We give animals the right to die in comfort and honour but we are forced to deny our loved ones that. Why? This is the question to which no-one can give me a valid answer.

Tom had such a bad night before he died. He was pleading with me to end it and saying that he could not take it anymore. Do you know what it is like to look into the eyes of someone you love and know that you are helpless while his family scream at you to do something? Tom died in the early hours of the morning. His last words to me were that he was sorry. What did he have to be sorry for? He was sorry because he had asked me to help end his pain. In the final moments of him being conscious he heard his family screaming at me in tears while I was holding his hands saying that I was sorry, that I wished I could have helped him. That was Tom's death—needlessly painful. That was my first experience being a death doula and not my last.

A friend died recently after suffering a massive brain stroke that left her once-vital body to die over a period of weeks. How was it fair that her children had to watch this woman who loved life fade away? She was denied the dignity and grace with which she lived her life. My own mother died in February. She wanted to die before Christmas on her terms because her body was shutting down. I remember seeing her on oxygen and her skin turning black.

I am about to become a death doula in an official capacity, and I can only ask that consideration is given to the rights of people themselves. These decisions should be made with no bias or religious pressure, because our personal life is ours and ours alone—not our families, not the doctors and not the do-gooders who think we should be kept alive at all costs.

CHAIR: Thank you very much, Ms Robinson. Yesterday in Hervey Bay I do not know how many times I wrote down the word 'choice'. Thank you for sharing that with us.

Father Tonti: I seek leave to table a letter that Dr Nicholas Tonti-Filippini wrote to the Hon. Mike Rann, former premier of South Australia, on voluntary euthanased dying, as we call it.

CHAIR: Is leave granted? Whilst we are granting leave, I will just go back to Julie Adler. Do you want table your submission with those recommendations?

Ms Adler: Yes.

CHAIR: Is leave granted for Ms Adler? Leave is granted. We will get a copy of that as well. Father Tonti, do you want to talk to this letter?

Father Tonti: Although it is a little dated, I suggest that the premises and the comments contained in the letter are just as relevant as they were nine years ago. Dr Nicholas Tonti-Filippini passed away in November 2014 from complications regarding his terminal illness, a combination of renal failure, advanced heart disease, rheumatoid autoimmune disease. He was dependent on dialysis and palliative care. He died at the Austin Hospital. Previously, Nicholas had recovered from the complications but that night the clinical expertise and nursing competencies were not available.

Nicholas was a nationally and internationally renowned ethicist. I suggest that anyone researching the area of palliative care reads his work, including one of his many books about bioethics, caring for people who are sick and dying. Nicholas lived in pain—15 angioplasty procedures, eight stents, a failed coronary bypass, dialysis 20 hours a week and numerous other complications. He reached the limits of what palliative care could offer. Nicholas died. Nicholas was my younger brother. He wrote—

I cannot speak for all people who suffer from illness and disability, but I think I can speak more credibly about suffering, illness and disability than those people who advocate for euthanasia presenting an ideological view of suffering and disability. Facing illness and disability takes courage and we do not need those euthanasia advocates to tell us that we are so lacking dignity and have such a poor quality of life that our lives are not worth living.

Nicholas could not be better credentialed. There is a long list here—Australia's first hospital ethicist, a lecturer in bioethics at university and the chair of a National Health and Medical Research Council working committee. He implores everyone to read those submissions. Each year he would dread the letter from his health insurer reminding him how much he cost and what a burden he was

on community and on family. Can you imagine his sense of burden and fear? How do people needing palliative care think about their own self-worth? Imagine the conversations in aged-care facilities that I have experienced when they already speak about being put in high care as being on death row.

Nicholas lists the present inadequacies of palliative care in Australia including the current entry requirement limitations, pharmaceutical subsidies restrictions, availability of palliative care in regional areas—as we heard today—lack of doctor training, underfunding of services and the long waiting lists, unconscionable for those suffering chronic pain. He speaks about those suffering yearning for connectedness, care, respect, wanting to be wanted and empathy—and that is a big one. Decisions about these areas are made under such duress that the sufferer often succumbs and seeks to opt out. They have lost their hope and purpose. He speaks about the failures in requirements in places where the right to be euthanased is exercised, including the Northern Territory, Belgium and the Netherlands. It can give you more daunting figures that he showed us.

Dr Mary Walsh, his wife, said to me yesterday that where she practises, at the Doncaster Medical Centre, the doctors this week are about to discuss the challenge to their and other medical agencies' ideological stance for life because of the legal difficulties facing them. I could go on and on. Crucial to good palliative care is the support of patients—socially, emotionally and spiritually. It is not a simple matter of relieving pain. The person needs to be loved, supported, wanted and given empathy. From my experience, I thank very deeply all those who work in palliative care—underpaid, under-resourced, long hours and under-recognised—for their intimate support, love and patience for those who need them the most. They are a gift of life. Thank you.

CHAIR: Thank you very much, Father. Thank you for sharing your brother's experience.

Mr Bull: Thank you for taking the time to hear my story. I am the husband of Jillian Bull, who recently passed away from terminal pancreaticobiliary adenocarcinoma, which is bile duct cancer. My family and I would like to see the delivery of palliative care and end-of-life care improved by extending the operating hours to include after hours, public holidays and weekends.

I wish to present my personal experience, having dealt with the shortfalls of the palliative care service in Bundaberg and, more specifically, the services—or lack thereof—over a weekend. My reason for wishing to illuminate the problem is so that I may be able to help the constituents of the Wide Bay electorate avoid the experience that my family and I endured during the last weekend of my wife's life.

Prior to outlining my concerns, it is important to express that I am extremely appreciative of some of the aspects of care that was provided to my late wife. I am writing this now as it appears to me that my wife's suffering during that weekend could have been avoided had a palliative care unit been operating and available, or a medical practitioner for advice and/or medical ministrations on a weekend. I am sure it is obvious to all that medical needs, including palliative, do not subside just because it is not a weekday.

To give you a background to my wife's condition related to this very aggressive cancer, Jill was only 67 years of age and became very frail as her body wasted away over a relatively short period of time. Towards the end of her life, she was reduced to literally skin and bones due to the severity of her condition. Her skin became not unlike tissue paper and any movement or handling resulted in her skin peeling off. I do not tell you this for the shock effect, but it will become necessary to be aware of that fact soon. We were constantly patching her up with all sorts of dressings that had little adhesives. These, too, tore skin from her body.

Jill's request was to be at home and not linger in hospital, so my son and I looked after her with the help of palliative care and Blue Care. We wanted for nothing. That was until the final weekend, when we discovered that these services ceased, phone numbers went unanswered and no backup plans appeared in place. From Friday night, 24 May this year, until Sunday evening, me, my son and my daughter, who was up from Brisbane, battled with Jill's extreme pain, with medication administered every three hours, with her hallucinations and her inability to properly form words making it impossible to communicate, therefore, to determine where her pain was emanating from. At our wits' end, on Saturday we called the palliative care phone number provided to us on a fridge magnet, which is the local number, only to be greeted with a message to say that it has been shut off or unattended. Messages were also left on the Blue Care service, and the Bundaberg Hospital switchboard operator was contacted for help, which could not be provided.

It was not until Sunday lunchtime that we were advised that Jill may have a urinary tract infection, as she was not passing urine. In desperation, we contacted the local mobile home doctor service and waited for three hours to get professional help. The doctor who arrived advised us that Jill's bladder was on the verge of collapse, being extremely swollen, and that this was likely the source

of the unrelenting agony. It was later found that Jill had approximately one litre of fluid built up. The doctor did not offer any further help or advice or make any attempt to drain the fluid by catheter but appeared extremely eager to leave so as to pursue other Medicare funded call-outs.

CHAIR: Sorry, Mr Bull. We can accept the rest of your statement, if you would like to table it. Then we can move to some questions in regard to it. Thank you. I think you have articulated the terrible situation of lack of services that you experienced. Is leave granted to table the rest of that statement? Leave is granted. Dr Richard Tomlins, welcome.

Dr Tomlins: I am a general practitioner with more than 45 years experience, primarily in Australia but quite a long time overseas as well. My submission is much more focused and I think represents the general concerns of many general practitioners about impending euthanasia and the whole end-of-life inquiry. The concentration is on general terms and issues that arise from voluntary euthanasia which we expect to somehow occur in following legislation.

Voluntary euthanasia is the basic problem. Voluntary euthanasia is the most significant and most personal of all personal decisions. Hopefully, the role of this inquiry is to find a legal, non-judgemental way to facilitate that decision, whether it is for or against euthanasia. As you know, at the moment euthanasia is an illegal procedure so protection along those lines would be essential.

I want to make a couple of points quickly. Despite the call for the legal end-of-life service such as euthanasia, there are fewer than about 10 requests per year in Victoria following their legislation for voluntary euthanasia. One of the reasons is that greatly improved palliative care services have reduced the need for euthanasia. Somebody pointed out that there was no correct answer to the underlying question of euthanasia. I might give you two brief general practice experiences or examples. Firstly, 'Doc, can't you just bump the old girl off? She's not going to get any better. We're a bit short of dollars at the moment and need the inheritance.' Secondly, an elderly terminally ill patient, there was no hope of recovery—'Doctor, you don't know this but I had four sons. They were all killed in the war. If there were a God, he would have kept me just one son, so I want to go now in the hope there is an afterlife and I can see my sons again. Can you please help me do that?'

That leads on to general discussions about euthanasia. Generally, GPs do not admit patients to hospitals and are less involved in end-of-life decisions. I have one important point. To overcome that problem, in New South Wales there are about 150-plus doctors currently undertaking a government course to become a legally registered end-of-life provider. That sounds horrendous to me, as it is particularly ignoring the general medical dictum of first do the patient no harm. That leads to these presumably legally introduced euthanasia services only being provided in specialised care. What about remote areas where there are no relevantly qualified doctors? It is a horrendous thought.

Also, the other problem is will the age range for euthanasia be legislated to include children, as occurs in Holland? Will it include the severely disabled? Who makes that decision? What about severe intractable mental health problems? Who makes that decision? There are many others, but I will leave it there.

CHAIR: Thank you very much, Doctor. I see at the end of your submission you state that any policy allowing voluntary euthanasia will never have 100 per cent support. It is a difficult line. I think, as you have said, protecting the vulnerable is something that needs to be considered going forward.

Dr Tomlins: That is right. I think those providing this horrendous service need legal protection. For example, for a GP providing that medical service at end of life, is it legal?

CHAIR: Yes. I figure that your submission is down the middle of the road. I could not find whether you are for or against it.

Dr Tomlins: A flexible, legal, formalised, professional end-of-life service should be available. That gives protection to the doctors providing that but it also gives help to those who choose a formalised legal service for euthanasia. It also helps those who choose not to have euthanasia. To me, total public and religious support for any decision is unlikely.

CHAIR: Thank you very much for clarifying that and for your submission. Councillor Greg Barnes, welcome.

Councillor Barnes: Good morning. Thank you very much. Can I start first of all by thanking the Queensland government and the committee before us and also our two state members for the opportunity for this community to have input into this somewhat sensitive issue. Can I also clarify that the comments that I make today are not related to the council and are mine alone and do not reflect the opinions of the council or any individual councillor.

I hope that my input today will give a different perspective to the subject of assisted dying. I had a loved one who was assisted in dying contrary to the legislation of the country in which she was. It was not in Australia. That person was my mother. The country she died in had similar legislation to the Australian states at the time. We are going back quite some years now. It was at a time when the thinking of legislators was less progressive than this debate.

Mum had had bowel cancer for some time and was in and out of hospital for various treatments. I remember on the Tuesday she rang me up and told me that the next day she was going in for some more tests. We had a brief conversation and that was about it. The next afternoon we received a call from my father saying that Mum had passed away.

Mum was very proud, and believe you me she was somewhat pragmatic. I later found out that Mum had gone into hospital. She had been given a massive dose of morphine. She went into a coma. She opened her eyes in the afternoon and my father and my sister were there. She closed her eyes and passed away peacefully.

Dad went back, as you would, to the house. Mum's paperwork was all done. Her desk and her office were neat. All her files were complete. All her directives were available. All her clothes had been removed from the wardrobe. Her shoes and those clothes were given to the op shop, as was her custom jewellery, and all her valuable jewellery was secured in the safe. Mum had planned this for quite some time.

I often get people say, 'You must feel like you were cheated.' Indeed, Mum discussed with my father before she passed that she was worried that I might be angry about what she had planned. Quite the opposite. Mum has the greatest respect that I can give for any person. She knew that she was going to die. Her condition was getting worse. Was she in a state where she could not look after herself? No. As I said, she was very proud and very pragmatic and she did not want what all the doctors told her was coming. Whatever deal was made with the medical staff at the time, Mum was given an injection and passed away. The phone call that Mum made to me must have been extremely difficult because, in essence, she was saying goodbye, but it relieved me and it relieved other members of her family from having to go through the pain with Mum and watch her meet her final end, which was inevitable. Thank you.

CHAIR: Thank you very much. There has been a common theme of improving palliative care with this particular group at the table, providing choice at end of life. Julie, I want to ask if you had any views on voluntary assisted dying. I know your mum has gone through a really horrible situation in the aged-care sector. Do you have any views on anything else before I open to questions?

Ms Adler: We actually found that the palliative care was very good for Mum and it was taken out of our hands essentially, the decision, so the family was happy with that. I think it is a very personal thing and I would like to see a referendum held to make a decision in that regard.

CHAIR: That is at a national level. We are tasked with a state matter.

Mr HUNT: Father Peter, you were finishing something on your document there. Is there some more information there that might be helpful to us? Through the chair, you might want to table that.

CHAIR: We have it.

Mr HUNT: Were you reading from the same thing you tabled?

Fr Tonti: Close to, but not all.

Mr HUNT: Are there some statistics that might be helpful to us?

Fr Tonti: There are just a couple of little comments. I remember when I was in Emerald at the aged-care facility there, which is doing its very level best, but the people, when they were moved from care to high care, were making comments, particularly when I came in on any regular basis, such as, 'Who is now on death row? How long is it going to be?'—all those sorts of things. The other comment was that I think we need to ask the question why our Indigenous brothers and sisters so deeply fear white man's hospital. I think there is something there that we need to explore a little bit. I could go through all sorts of statistics in Belgium and the Netherlands, but I think you probably have those statistics already, around some of the horrendous things that are happening there now, where it has got to despite all the requirements.

Mr HUNT: I want to go to you, Corina. When you were describing caring for Tom at the end of life, do you think Tom had access to good quality palliative care? Firstly, was it in Bundaberg?

Ms Robinson: No, at the time I was living in Brisbane. He had been at the PA Hospital for quite some time in and out but when it was discussed that chemo was not going to prolong his life, in fact the chemo would have just given him more pain, the decision between all of us was to bring him

home to die. He wanted the option of dying at home. I understand not many people can do this. I think one of the things that we need to explore too is the fact that we talk about palliative care in hospital and hospices, but I would like to see what I believe is something more like, I would like to call it like Butterfly House, where you don't go to go and die in sterile surroundings, you actually go to die somewhere that is nice, if there could be a nice thing. He died at home and it was very painful. I was taught to inject him with morphine and, as I said, I had to resort to getting him cannabis because that was the only thing that would relieve pain.

Mr HUNT: What made you make that decision? Did you have some sort of qualification to prescribe or anything like that?

Ms Robinson: No. The amount of dosage that I could give of morphine, the prescribed dosage at the time, was not helping as time was going on. In the last week before he died the pain was excruciating. I can sit here and tell you that if I had my time all over again I would be sitting here either convicted of murder or manslaughter, at the least as the law stands today, because he begged me so many times to pick up that morphine needle and inject the whole bottle into him. The night he died I had his relatives screaming at me to do something because the pain was so bad.

Mr HUNT: Was that care being advised along the way? When you say you were only allowed to give him a certain amount of morphine, was it reported back that it was not working and that sort of thing?

Ms Robinson: Yes. The nurses would come out and we would consult with the doctor and it would be upped. The problem is that they can prescribe a certain amount and you cannot say that my death is going to be the same as your death so I might be okay with, say, 10 milligrams but someone else might need 20 milligrams. That 10 milligrams might be the required dosage or the prescribed dosage. I just think you need to look at it in terms of as the pain gets worse there is more pain relief and I am talking about not just general pain relief, it is a whole thing that we need to look at, it is not just one simple thing.

Mr HUNT: We have heard throughout the inquiry palliative care specialists overseeing a dying person with all the bells and whistles so to speak being able to increase doses over time to a point where they are sedated until they die.

Ms Robinson: That sounds good and well, but, you know, my question is why do we insist and why do we force people to die an absolute undignified, painful, horrible, slow death because someone says it is legal? How is that legal? If I took an animal to you and said, 'This animal is dying. It is in pain. It is awful,' and I sat here and did nothing you would have me charged with animal cruelty so why are we being cruel to our own people? I certainly have said to my son if ever the time comes when I am no longer going to be in this world and my death is going to be painful you are not going to go through those haunting memories that I went through.

Mr HUNT: We certainly would not give an animal palliative care.

Ms Robinson: No, we don't.

Mr HUNT: I was just trying to explore the level of care available to somebody who is dying.

Ms Robinson: There are good levels of care available. That is not the issue.

Mr HUNT: We hear those stories of people being in absolute agony and screaming how they do not have access to the pain medication they need.

Ms Robinson: The problem is even though they may have access to the pain medication, even though it might be increased, at the end of the day they are going to die so why are we allowing them—and this is my question—and why are we forcing them not to have a humane and dignified and honourable death? My only question for everyone, and it is a yes or no question, there is no debate about it, my yes or no question is should we be, as people and as keepers of our own rights, allowed to choose a humane and dignified death wherever possible? There is only one answer and that to me is yes.

CHAIR: We have no further questions for this panel. We thank you for your contributions today.

CORBETT, Mr Alan, Private capacity

HERRON, Mr Mark, Private capacity

JACKSON, Ms Moya, Private capacity

LADEWIG, Mr Douglas, Private capacity

WAGNER, Ms Phyllis, Private capacity

WORKMAN, Ms Cynthia, Private capacity

Ms Workman: Hello, my name is Cynthia Workman. I am a member of Dying With Dignity Queensland and I am here speaking as an individual. I, along with many others, wish this legislation passed in parliament for the benefit of all Queenslanders. Suffering through an unnecessary, painful death is cruel and inhumane when we have the medical capabilities to relieve suffering at the end of an insidious disease that has ravaged our body. My father-in-law went through the most hideous last four weeks of his life. His pain was uncontrollable, even with the drugs administered by the palliative care he was receiving. His body was slowly shutting down, which was so distressing for him, with needing to use nappies and the indignity of having to be bathed and changed by another person. His breathing was laboured. His mouth was dry. Eating was getting harder and in the end all he could eat was soft foods. This once proud man had had enough. Unfortunately, he had to put up with all of this suffering until his last laboured breath.

I put to you at this stage of his dying why would another human deny him the relief of a peaceful death that is foreseeable by administering a drug that will relieve him of suffering further? I implore you to see that the people have thought long and hard about the VAD act and it is needed to be brought into the parliament and to be implemented at the earliest opportunity. This act is for all Queenslanders to know that if they desire to die without having to endure pain and suffering that it is available to them. Knowing the choice of having voluntary euthanasia available takes away the distress from the person who is facing the last weeks of their life.

What do I want the panel to do? I want you to make recommendations to the parliament to enable this law to be voted on with a conscience vote by the individual party members. As part of the doctor's consultation with the patient as an overall talk on treatment going forward I feel that doctors should be able to also include the voluntary euthanasia choice.

Another area that needs addressing is remote and rural areas where a doctor is not in the area on a full-time basis. Are nurse practitioners going to be trained to do the first assessment for a VAD, as when one is incapacitated they are unable to travel huge distances to see a GP? I would like a provision in the act stating that if you are in a situation where you are unable to speak up for yourself and have already stated on your advance health directive that you wish to use the voluntary euthanasia options your wishes are respected. Thank you for the time.

CHAIR: It is interesting you talked about rural and remote areas, as did the doctor earlier. We are looking at the Western Australian ministerial expert panel that reported on their bill.

Ms Workman: I read that and I thought it was very relevant to Queensland.

CHAIR: I picked up on that and I thought your point about the nurse practitioner was of interest as well. We will move now to Mr Douglas Ladewig.

Mr Ladewig: Good afternoon, panel. Doug Ladewig is my name. I am a member of DWD Queensland but I am here to speak as an individual. From a young age I was told that we were all born to die and there was nothing we can do about it. I did not expect that at 16 years of age I would lose my mum at 51. She went to hospital and they opened her up and she had cancer of the liver so they closed her up, kept her for two days and sent her home to die. My sister looked after her but she only lasted four days. Back then there was nothing they could do. At 37 I lost my dad to lung cancer. He was in palliative care in Brisbane, but not all the time was he pain free. If VAD had been available then that is what he wanted.

I, like Cynthia, hope that the government takes the word of the people and brings it in. It will be similar to WA's, but with the Victorian one you have to go through so many steps to be able to get granted a prescription for the medication, and that is how it should be. It only caters for people who have a terminal illness, even though every illness could be seen that way. I have COPD and it is terminal, but it is not within six months. Hopefully in time if it comes in we will be able to look at people Bundaberg

who have things like motor neurone disease and dementia so that if they get to a certain stage they also will have the choice rather than spend their life either in a wheelchair or in a home. All I can do is hope that as a panel you put forward that it happen, and that is all I can hope for. Thank you.

CHAIR: Thank you very much, Mr Ladewig. That is certainly something we heard yesterday—it was common, actually—in terms of planning for people with advance healthcare directives if they get chronic dementia in years to come. That is something that was really commonly discussed yesterday.

Mr Ladewig: Yes, I have it in mine because I am only going to end up on a gas bottle.

CHAIR: Yes. Thank you. I welcome Mr Mark Herron.

Mr Herron: Thank you very much. I, too, am a member of Dying With Dignity in Queensland. However, I am speaking today as an individual. I would like to tell the committee that the state of Queensland is in great need of voluntary assisted dying legislation. We need it drafted and legislated and implemented as soon as possible. I have seen the legislation that was tabled at your committee meeting Friday week ago and I think it is a wonderful piece of legislation. I would like to add to Cynthia's comments about the addition of nurse practitioners a la Western Australia being very relevant to Queensland given our geographical size. I just want to second her comments.

Similar legislation has been operating in the state of Oregon in the United States for 20-plus years—1997 I think it was brought in—and I have to hand a report of the state of Oregon on the use of that particular dying with dignity legislation. I just want to indicate the quantum of people who are accessing the scripts and actually using the scripts in Oregon. Since the law was passed in 1997, prescriptions have been written for a total of 2,217 people under the DWD Act. Some 1,459 people—that is, 65.8 per cent—have died from ingesting those medications. During the 2018 period, the estimated rate of DWDA deaths was 45.9 per thousand total deaths in the state of Oregon. In 2018, 249 people received scripts and 219 used them.

Oregon is a state of similar socio-economic layout and similar population to Queensland in that it has a very highly concentrated population in the area of Portland and is very progressive thinking there and then a very highly rural area outside the central city. The state of Oregon gives a lot of historical information and guidance as to how these laws can and should work. I have some friends over there who were social workers and to them this particular legislation is business as usual. It is not considered in the slightest unusual.

I feel that it is very important that Queensland has this legislation, not only after the deaths of two friends in Brisbane in the early 2000s from hideous bone and liver cancer but also after my experience with my brother-in-law Earl from pancreatic cancer just a year or so ago. That indicated to me that we really need some sort of legislation to allow personal choice on this particular topic. VAD legislation should be uncoerced, and the patient must be mentally competent and of age and must be duly informed about the implications of what they are about to do. In our work as members of Dying With Dignity we have spent a lot of time talking to members of the public and we find that the percentage of people who are in support of this sort of legislation ranges from 80 per cent upwards. That is casual conversation with people in terms of being approached by people in shopping centres and certainly giving talks. I have a number of opinion polls dating back to 2007—

CHAIR: Did you want to table those, Mr Herron?

Mr Herron: I am quite happy to do so if you would like to accept them.

CHAIR: Okay. Is leave granted? Leave is granted.

Mr Herron: The last one I have was on page 7 of the *Courier-Mail* of 1 September last year. It is a ReachTEL poll conducted by the Clem Jones Group which again finds more than 80 per cent of the population in favour of VAD legislation.

CHAIR: Thank you, Mr Herron. We will table those. It is interesting you used Oregon, because it has a population of 4.2 million or thereabouts, which is very close to Queensland.

Mr Herron: It certainly is analogous to Queensland demographically.

CHAIR: Thank you. I welcome Ms Moya Jackson.

Ms Jackson: My name is Moya Jackson and I am a member of Dying With Dignity Queensland. Today I am here as an individual and my thoughts are wishing this legislation as a result of witnessing my father, some 45 years ago, passing in terrible circumstances with diabetic complications and also my brother, who passed away 15 months ago with pancreatic cancer.

The committee has already indicated that it has read my submission so I am going ahead assuming that you have. You would be aware that my brother Earl was diagnosed with cancer in late 2017. He had to take the only choice that was available to him and he starved himself of food and

water from February until his death on 25 March last year. His wish to be gone was known to all. Every time he was conscious he wanted to know, in his truckie vernacular, 'What the ...'—and I cannot say it—'am I doing here? Let me go. You know I don't want to be here.' Every time he woke, that was what we got. We were devastated to see him in so much pain, and pain that could not be alleviated. His oncologist was devastated watching him and his pain. His body reacted violently, expelling foul fluids regularly, necessitating his bedding being changed frequently. He was devastated the condition his own body was in. His death was gruesome and undignified, and I will forever be haunted by the sight of his deterioration. He was a skeleton. He looked like someone who walked out of a concentration camp.

We are all going to die someday—that is a given—but it should never look like this. Palliative care has a place, but it should not be the only option available. We respect those who disagree, but please remember that voluntary assisted dying is a choice; it is not mandatory. People considering VAD have used every method possible to stay alive. Please respect those choices. People who do not believe it is the right thing to do do not need to take that option. If it is against religion to access VAD, do not take that option. Do not tell me, though, that because it is against your religion I should not have that choice. Voluntary assisted dying does not mean more people dying; it simply means less people suffering.

I put to the committee here and to all politicians: I do not want this issue to become a political football. We need to keep the debate secular. Our country has a separation of church and state and that should be reflected in debates. A politician's religious beliefs should not have a bearing on that choice, on that vote. They represent us, not their religion. Politicians who vote for this legislation should not be eviscerated by their own party if a conscience vote is allowed by that party. What I do want to happen is legislation to be enacted to provide a choice for people at their end of life. This legislation should include my right to have included in my advance care directive the right to access this choice when certain health incidents have occurred if and when I am unable to communicate those wishes. We need to learn from other states and countries and create legislation that ensures no person is disadvantaged. Queensland is a vast state, and legislation needs to allow people ease of access to choice, not barriers.

CHAIR: Thank you, Ms Jackson. Sorry, but I just saw the time.

Ms Jackson: Can I just finish this off?

CHAIR: We will come back to you with questions.

Ms Jackson: I would like to finish the last bit.

CHAIR: Go ahead.

Ms Jackson: Legislation should have bipartisan support because, as we have heard, the polls show that over 80 per cent support it. Listen to your constituents, and we need a commitment not to repeal any legislation that comes in. I want the choice as to how my life might end if I am terminally ill or suffering a chronic illness or a neurological disease. If legislation is not enacted to allow me to have a choice, how am I going to die? Am I going to have to refuse sustenance? Am I going to commit suicide, like many do, while ensuring my family have no knowledge of the impending action so they do not get charged, or will you let me die in peace with my family and friends surrounding me?

CHAIR: Thank you. It is going to be a tough afternoon because everyone has shared experiences. There is nothing more powerful. We have heard it everywhere we have travelled and we thank you for sharing your deeply personal and own experiences. Thank you, Ms Jackson. I welcome Ms Phyllis Wagner.

Ms Wagner: I thank you for the opportunity that I had to lodge my submission to the inquiry and to be seen personally. You have my story in my submission—the story that happened 19 years ago, and I have yet to get over how he died. If I am to see Jack in another life, I had better run because he is going to be mad. You see, he was under the assumption that I loved him and I would not let him suffer so.

I will now attempt to address some of the items on the issues paper. Should VAD be allowed in Queensland? Patients who use VAD are being given the respect that should be shown to them. Others' beliefs, in my opinion, should not interfere with this deserved respect. There are situations where the patients do not have any control of bodily functions. They may be unable to feed themselves. They may not be able to look forward to any conscious time without dire pain. The pain, the indignity—not for my loved ones please, and not for me. The decision lies in the Queensland state Parliament House. Is it that party leaders can so disagree that we therefore may suffer? Please let us make this a true conscience vote and may our politicians be true to their constituents. The onus is on you.

Some schemes are not providing for patients having access to VAD if they have illnesses that may not be life endangering such as motor neurone and others, but they are the cause of constant pain, loss of independence, loss of speech and hearing, loss of mobility for personal needs such as toileting, showering, feeding and so forth. I strongly believe that patients who are in those situations should have access to VAD—their choice. It is my personal opinion that Queensland should follow the Belgium request, where competent understanding is without a set age limit and will not be below the ages of nine or 10, between 12 and 16 with the consent of parents, and 16 and 17 with discussing information with the parents. For vulnerable people there will be the safeguard to always have a transparent and open doctor-patient relationship. The patient must request VAD at the doctor and demonstrate that there is no coercion.

CHAIR: Ms Wagner, we have your full submission that you are reading from and we might come back to you for some questions. We have heard about Jack and your experience in those final days as you have described it. We are mindful of time. We have everything here. We have read it. We thank you for sharing that.

Ms Wagner: You do not have the last part of this.

CHAIR: With respect, would you like to add one minute now?

Ms Wagner: One of the most controversial end-of-life interventions is terminal sedation. This is used when all other medical treatments, including palliative care, cannot control severe, intolerable symptoms. This treatment renders the patient unconscious and it may take up to 10 days for the individual to die. This is extremely upsetting for the relatives and the attending staff but what I can take from this procedure is the answer to No. 32: if the medical staff deems it necessary as a last ditch effort to render the patient unconscious until they die then I believe the patient was eligible, had a right, to access VAD. Will patients be respected enough to be given a choice in the near future? Yes, that needs to be put to a vote by our politicians. Thank you for your time.

CHAIR: On that last point, we had a palliative care nurse yesterday in Hervey Bay give evidence about terminal sedation and articulated that it may take hours, weeks or days, but that the result is the same. Mr Corbett, welcome.

Mr Corbett: Members, I am appearing as an independent witness on the issue of voluntary assisted dying, VAD. My wife died by suicide in 2017. She did not have a terminal illness but a rare, complicated and largely unpredictable one that baffled the medical establishment. She rarely saw her own doctor or pain specialist. I had to see them on her behalf. In her suicide note she wrote of the desperation she had felt and the trauma she had experienced by not being able to access the health services she required.

Members, in formulating your recommendations on VAD please do not assume that people will be able to travel from their home to an appointment at a particular time and place. They may be too old, too sick, have no-one to drive them or be living alone without family, friends and transport. I understand that a person will need to be seen and assessed. However, some alternative means of assessment other than that which involves travel outside the home must be available. Not to make allowance for these people will discriminate against them. Telemedicine comes to mind, as does some special payment for the coordinating doctor or specialist to see the person at home.

In my written submission I made reference to the nurse navigator program. This program is a nurse-led model of care. Their role is essentially to help the person with complex health needs and the carers navigate an impersonal medical system. Nurse navigators are highly knowledgeable and experienced clinicians who are able to travel to the person's home as part of their role. They get to know and understand the patient's needs. They are, as we have been told, already involved in palliative care. I was invited to speak with some navigators at Bundaberg Base Hospital after my wife's death. They found my particular experience as a carer useful.

In the implementation of any legislation, nurse navigators could help ensure that those who are restricted from travelling are able to fulfil the necessary medical hurdles which would otherwise be impossible for them to achieve. Indeed, their caring and supportive presence may well be a turning point in the patient's capacity to hold on to life and go no further. One other effect will be very real-time feedback as to the day-to-day ramifications of any legislation. A very conservative piece of legislation may not necessarily be a compassionate one. A compassionate one should help and not cause further harm.

Should legislation be passed but there is a change in government next year, I can only hope the LNP will continue this program. As they may not, perhaps the committee can recommend that qualified people be employed to fulfil their otherwise useful role under any assisted dying legislation. We have heard some reference to nurse practitioners. Thank you.

CHAIR: Thank you very much, Mr Corbett. I have no questions. I think you have all articulated your points very well. I will open up to questions

Mr McARDLE: Just a comment to Ms Wagner. I read your submission in regard to Jack. What a man! Well done.

Ms Wagner: Yes, what a man. Too fine to have gone through that—too fine.

CHAIR: Thank you. That was a very detailed submission that you wrote, I concur. Thank you for sharing that with us. We have three more groups to bring to the table. I will ask that we thank everyone on this particular panel. Thank you.

LANGE, Ms Dianne, Private capacity

MANNING, Ms Valerie, Private capacity

McCLEAN, Ms Brenda, Private capacity

McMAHON, Mr Dan, Private capacity

SCHNACK, Ms Kerry Private capacity

Ms McLean: My name is Brenda McLean. I am here as an individual although I am part of Dying With Dignity. I would like you to know why I feel so very strongly about voluntary assisted dying—having lost my father at the age of 56 with cancer, his weight being 24½ kilos when he passed, he was just a heap of bones with skin on them; my father-in-law with mesothelioma; and my partner just over two years ago with lung cancer, all of whom suffered a very undignified death at the end. My partner Bob had an advance health directive so he did not expect to be lying in bed in pain. He was hoping that the end would come a lot easier than it did. In the end he was begging for help to die.

There is no dignity for any of them, especially Bob when he lost all his bodily functions and he was still aware of that fact. The tears were running down his face. He knew what was happening. Where is the dignity in that? We tried all sort of things. We went to Nimbin and we got marijuana. That did nothing for his pain whatsoever. The cancer clinic said things were moving slowly and that he would be okay for a while, but while visiting his lung specialist he was lying on the bed in the doctor's office and he said to him, 'Gee, I hope I've still got a couple of years left.' The doctor looked at him and said, 'Mate, you're not even going to last till Christmas.' That is tact for you. I could not believe he said it, but I guess Bob had more or less asked. This was in November. He died two weeks later. I think he just gave up hope.

I have two granddaughters with cystic fibrosis, a terminal disease. Some CF patients are able to have their life prolonged with a lung transplant. This is not possible with my granddaughters. The eldest, at age 23, has said she wants to have a choice of when to die with her family with her. Neither of the girls can get a lung transplant as they have an extra strain of a bacterial gene which means if they get new lungs they would be immediately infected with the same bacterial infection as their own organs and the new lungs would be rejected. These girls have lost lots of their friends who have passed away, they have all had CF, and spent a lot of time in hospital.

Everyone has a right to say how they feel about voluntary assisted dying. It should not be a vote with religion in mind. If there is a God then he surely should not want people to lay around waiting to die with no chance of recovery. I also believe it should not be a political subject because politics has nothing to do with it. Surely we treat our pets better than this. My mother had dementia, didn't know who she was in the end, and I know she would have preferred to go home with her family and be with us while she still had all her faculties.

Please vote to get this legislation passed. Seeing as you have over 80 per cent of the population of Queensland wanting it, it should not be too hard to pass it. I can fully understand why people suicide when they know the future looks grim and they know there is no hope. They should be able to make their own decisions while they are of sound mind. It is an individual decision. This is my life, my choice. Please uphold my right to die a peaceful death at my time of choosing should I have a terminal illness. Thank you.

CHAIR: Thank you very much for sharing. You have gone through a hell of a lot, there is no doubt about it. Thank you for sharing your personal experience. Dianne, welcome.

Ms Lange: I have not written out anything like everyone else because I speak from a passionate point of view. I guess I have been with Dying With Dignity since its inception in Queensland as Voluntary Euthanasia Queensland, and it has been my passion ever since then. Being an asthmatic, it always rules your life, but I have managed to get to this age so I am doing pretty well. The thing is I know that I will die very slowly, very awfully, dying in my own fluid and it will probably take years, but that is of really no consequence because a lot of other people die a lot worse death than that. My mum, unfortunately, died and it was virtually just dying with dehydration and starvation and to me, being in a position of always wanting to be able to help her and saying that I could help her, in the end I could not help her. If I could have helped her, if the law had let me help her, I would have done so in a sec because she just wished to die. It was just so sad for my very, very strong mother to waste away. It is just such a struggle. That is all.

We do need a choice. I know there are lots of people here who never, ever think they are going to die. We do not, until something very awful happens to us and then we have to think about it. When you do think about it, all we want is a peaceful death. There are all these people the papers say have had peaceful deaths, but I do not think very many of them did. It just goes in the paper as 'natural'. The thing is that we do need a new law. We need a new law that probably has to be made by, unfortunately, politicians.

CHAIR: Someone has to make it.

Ms Lange: From my point of view, politicians do not see the struggle. They do not see the passion. They do not see the really horrific things that people have to go through to die. It is not easy to die. Let us face it: we just need a little bit of help. It is only for the people who beg for it. It is not for everyone. It will probably only be about five per cent who really, at the end, wish to die. Probably by the time they go through all the hoops and hollers like Victoria has, with about 68 different legislation hoops you have to pass through, you are probably dead anyway. We still need a choice. We do not need to see these hideous deaths.

CHAIR: Dianne, thank you. We can come back to you, but I want to point out one thing—

Ms Lange: They crossed out a piece in my submission that referred to the movie *Stop the Horror*. They crossed that out. I do not know why, because it is real. Another movie, *Fade to Black*, is real as well. That chap had a choice and he died the way he wanted to. These things are real. Why did they cross that out? Did they not want people to watch *Stop the Horror*, because it is real?

CHAIR: Can I share something that is real with you? Not all politicians are pigeonholed—

Ms Lange: I know, because you know Marjorie.

CHAIR: For the benefit of the crowd, we all have personal experiences. Every person here is no different to anyone else.

Ms Lange: I realise that.

CHAIR: We are members of the community, like you.

Ms Lange: I know Marjorie well.

CHAIR: After 28 years in the ambulance, I have seen enough people suffer in horrific circumstances.

Ms Lange: I understand from where you are coming. The only person who can make up the mind of the person wishing to die is me.

CHAIR: We have two former police officers here, too, who have responded to people in all types of circumstances.

Ms Lange: I know.

CHAIR: I wanted to point that out. We should not be pigeonholed. I welcome Kerry Schnack.

Ms Schnack: Good afternoon. My name is Kerry Schnack. I am a member of Dying With Dignity Queensland. I am the mother of three children who have cystic fibrosis. I am here today in the hope that I can get voluntary assisted dying legalised in Queensland before it is too late for us. I am losing my daughter. It is a battle that I cannot stop.

Unfortunately, I have had experience from the early age of eight of the extreme suffering of my grandpa. Our family watched my grandpa go from a strong and proud man to a feeble man—very thin, frail and suffering right up until the end. He took his last breath from lung cancer at the age of 56. My mum would often come home from the hospital saying that she just could not help grandpa die. She cried and she cried. He asked her to give him all his medication so that he could just go to sleep and not be in pain anymore. She just could not do it. She knew she had us kids and she did not want to go to jail.

I watched two of my fathers-in-law die—I have been married twice—from cancer. I sat with them for months, weeks and days, massaging their feet with hot packs or cold packs—whatever made them just that tiny bit more comfortable—and chatting to them. At times they both begged me if I knew of anyone who had drugs or poison or deadly plants—anything that could help them die quick—as they had had enough. They just could not cope anymore. I also have three kids, so I could not help them. I wished I could, but I could not do it.

I have seen my mum in so much mental trauma after her partner, Bob, my Pa Bob, died from lung cancer. She never left his side. He begged her to help stop his pain. He went from a truly burly man to a frail, ill man. He pleaded not to suffer. He begged not to be in nappies. It was disgusting. I heard him beg for more pain relief. He begged those nurses. He begged them. Still it was not enough. He was punching and jerking, crying out in pain. The morphine just does not work. It is disgusting.

My daughter Dana is now 23 and has been told she is not a candidate for a double lung transplant as she has a deadly bacteria that would only destroy her new lungs if she got them. She also has type 1 diabetes, which is CF related diabetes. She relies on several insulin injections a day. She is in constant pain in her back from coughing. She has curvature of the spine and is severely hunched. Pain relief is just not enough for her back. She constantly cries and begs. She has chronic chest pain from her hours on end of coughing and bringing up the mucous that is slowly drowning her lungs. She likens breathing to holding your nostrils tight and breathing only through a thin straw. Please, try this. You will find you have some sort of understanding. She has chronic gastrointestinal disease, with blockages that require copious amounts of medication and evacuations and, at times, operations to unblock her.

Dana is so malnourished. She requires many enzymes every time she eats and at night she puts her own nasogastric tube down so that she can have nightly feeds to try to stabilise her weight. She has endless antibiotics and inhalants for her constant chest infections and a huge physio regime to clear her airways. That is not to forget all the hospital admissions for her cystic fibrosis intravenous tune-ups, which is approximately three weeks or every four to six weeks at the most. Dana has to take so many tablets—in fact, 21 for breakfast—that she is full before she gets to eat. She sleeps about 16 hours a day and can no longer work, as she has no energy. She has a portacath as her veins gave up on her when she was approximately 14 years of age. She has had ileostomy operations, gastrostomy and bronchial lavages to try to keep her lungs clear and keep her going. At the moment, her lung function is around about 28 per cent on a good day and her weight is only 34 kilos. She is just a skeleton. She is a shadow of a young lady. People gawk at her and often comment about anorexia. Hell, no! She has cystic fibrosis.

Dana asked me whether, when her time comes to leave this world, I would support her choice to leave this earth in her own way. She said she does not want CF to take her last breath, as she has seen too many of her close friends die. Her first friend died from cystic fibrosis when she was just a few years old. Since then, Dana has lost many of her CF friends. Just recently her good friend died and she spent a lot of time with him. She does not want to go down the same struggling, drowning road. She knows that she is heading down that road.

I have spent so many years watching my daughter slowly fade away, dying before my very eyes. Believe me, until you have personally experienced this you cannot truly understand the heartbreak and the daily torture I go through as a parent watching her and not being able to help her pain and knowing that I am going to lose her sometime in the not-too-distant future.

Dana asked me to come here today to speak for her and myself in the hope that we can legalise voluntary assisted dying. She does not want to be struggling through drowning lungs taking her last breath. She has discussed with me the way she will die if voluntary euthanasia or voluntary assisted dying is not legalised and, yes, it is going to be peaceful. Yet under the law it is illegal and classed as suicide.

This is not about age. It is not about being just ill. It is about having your choice. I will support my daughter in her decision to die the way she wants, no matter what. I brought her into this world and I will help her when she goes and she will be right next to my heart. I have had my beloved poodle, my Pixie, for 13 years. She is one of my kids. If she was suffering, I would most certainly euthanase her as I would not let her suffer or I would be charged with animal cruelty. Thank you for taking the time to listen to my story.

CHAIR: Thank you, Kerry. Welcome, Dan McMahon.

Mr McMahon: Thank you, Mr Chair. I am very conscious of how difficult any discussion is in this area. I do not accept that the moral questions involved are black and white. This can be an extraordinarily emotive issue, but unfortunately often that is not helpful.

I am concerned that the narrative around reasons for voluntary assisted dying should be accepted but centre on the claim that no-one should have to endure high levels of pain in their lives. My understanding, from personal discussions and personal experience—and I put it to the committee—is that, given appropriately resourced palliative care, extraordinarily few people in this country should die in pain. It is simply avoidable.

Along with my family, I sat with my younger brother who died of cancer aged 26. For the last two weeks of his life, he was in Mount Olivet Hospital in Brisbane. Unlike his time in a general hospital, those last two weeks were a blessing. Tim was kept reasonably comfortable and cognisant. He was able to leave this world surrounded by people who loved and cared for him. We had a chance to say goodbye. His doctor at that time assured me that no-one in Australia should die in pain, and that was in 1988.

The provision of accessible and quality palliative care is essential. Pain management is a specialty and should be adequately funded and supported. I worry that for stretched government budgets voluntary assisted dying might be seen as a much cheaper alternative. Excellent provision of palliative care for all Queenslanders will be and should be very expensive, but this must be a priority for us as a community and for government.

Proponents of widely available voluntary assisted dying will also understandably point out that those suffering terminal illnesses may not wish to be a burden to their loved ones or to society. Those in our community and our families who are very unwell or in the final stages of life call the rest of us to compassion. We are called on to care for those who can no longer care for themselves and that is a very good thing. It may not be something we wish for, but how we as individuals and as a community treat those most in need is the very indicator of the quality of community we wish to create.

It is a sad reality of life today that we hear more stories of elder abuse. Sadly, it seems to be more common for older men and women to be ill-treated by members of their immediate families or others and, sadly, often for financial gain. Voluntary assisted dying legislation in this context may unleash a whole series of very unintended consequences.

For those like me who have some reservations around legalising euthanasia, the area that does cause some degree of conflict is that for the small group of people who suffer from long-term degenerative illnesses and terminal illnesses like cystic fibrosis, Huntington's disease or motor neurone disease. In this narrow group of cases, patients slowly waste away to a point of suffocation. I can more easily understand the reasons people in those categories may have for access to end-of-life strategies.

The preservation and value of human life is one of the cornerstones on which our society has been built. Doctors, through their Hippocratic oath, promise to uphold those values. The legislation under discussion has the potential to fundamentally change the society in which we live. This meeting is an indicator of how important that issue is.

I would urge extreme caution for legislators who might desire to reduce the value and the place of human life in our society. The experience of countries that have already adopted VAD legislation is a sobering reminder of how easy it is, once the legislation is in place, to broaden the scope of practice. I am not a great supporter of the slippery-slope arguments in this area or others, but I am a student of history. It is an immutable law of history that if we do not learn the lessons of history we are doomed to repeat the mistakes of the past.

CHAIR: Thank you, Mr McMahon. I am conscious of time. Welcome, Valerie Manning.

Ms Manning: My name is Valerie Manning. I am member of the DWD. I find it very difficult to follow the last speaker.

Death is a part of life. Why deny it? Why make it long and prolonged and painful when it is not necessary? I do not understand people who insist that somebody with a terminal illness must go to the very, very end before they are helped out and sometimes not helped out at all. Why is it so difficult to go gently when we must go in possibly the next days or weeks because our bodies are no longer capable of living a proper life?

My husband of 50 years, who was a good man, at 74 was diagnosed with acute myeloid leukaemia, and his final days were almost more than I could bear. They were so unnecessary, so pointless. Why did he have to suffer like that? In the few days it took him to struggle to die, I was left with something on the bed. It was a distorted, grotesque mask of the man I loved. One of his sons was sitting on the other side of the bed, and the two of us have been haunted by that image for 14 years. How could anybody insist that that happen? I do not understand.

My first experience of feeling like this occurred 35 years ago when I was 50. A dear friend from my teenage years had a terminal cancer and was being cared for by his brother in Bundaberg. They sent him home from Brisbane without an operation, because they just closed him up again. He was a very nice man. The brother had gone out to get some groceries. When he came back Des had put a gun in his mouth and had shot himself because he could not stand it any longer; but he was not yet dead. That was 35 years ago, and people to this day still kill themselves because they cannot bear to go on any longer with their lives. There is someone here who insists that that be so. I do not understand. Thank you.

CHAIR: Thank you. I just have one question at the present moment. I think you said that an extraordinary number of people benefit from palliative care.

Mr McMahon: Obviously that would be the desire.

CHAIR: Did you as a group of people articulate that that should occur in cases of cystic fibrosis, motor neuron disease?

Mr McMahon: I am conflicted on that issue. I understand that.

CHAIR: I just wanted clarification of it. I understand where you are coming from. We must respect everyone's views. I thank you all for expressing your personal experiences. They were all very difficult, but you are helping inform our committee.

Ms Lange: Can I just say one thing that I did not say? I am in a position where I have seen and heard of a lot of people suiciding. I do not wish this to happen. If we brought in this law, this would save a lot of people from making that dreadful decision to commit suicide. It is happening and it is happening underground. The government must know about this huge number of people who are dying alone and who are in such an insidious position that this happens. It is just horrific.

CHAIR: I can comment that the committee is working with the coroner's office to get a view of exactly what is happening.

Ms Lange: It is huge, and a lot of it is not even known about.

CHAIR: Thank you very much.

JENNINGS, Ms Jillian, Private capacity

PITTS, Ms Shirley Ann, Private capacity

RASMUSSEN, Mr Lionel, Private capacity

STANSBIE, Mr Sam, Private capacity

CHAIR: Welcome to the table. We will start with Sam Stansbie.

Mr Stansbie: My name is Sam Stansbie. I am just an individual. I support voluntary assisted dying. First, I have been truly humbled by some of the things I am hearing. I do not think that this committee will change everything. I think that after 12 months the finding will probably be ambiguous and I really have no faith that you will change anything. I certainly hope you do. I believe that the more people who say something, the more we can change things. I believe in people power.

Bill was a bushman, a family man whose passion was bush poetry and story telling. He would appear at country shows and mustering events. He was mid-60s and he contracted throat cancer. The diagnosis was that he would need an electronic voice box. His family knew that he was considering suicide. One of his brothers, my brother-in-law, spent five weeks with Bill and thought that he was okay. One week after he went home, Bill went down to the back of his property, called the police and then shot himself. Bill had to die alone. His family had to suffer the stigma of suicide. 'But he could have had counselling,' I hear you say. This was a man who did not want to live if he could not do what he had done all his life. That was his right to do that. As I understand it, palliative care has come a long way in recent years, but Queensland is a big place. In saying that palliative care will solve the problem, it may eventually take years before the funding and the resources are available. What happens in the meantime?

A very good friend of mine, Bob's wife, died recently of cancer. She was living in Bundaberg and had to go to Brisbane for care. Bob was lucky, if you could call it that. He was on the pension and had a son living in Brisbane whom he could stay with, because it took several weeks for his wife to die. I refer to advanced voluntary assisted dying. If the love of my life, if it ever comes to this—or one of my family members—is in a situation where she asks me to assist her in dying, no threat of prosecution, the law stops me from doing what she asks. Thank you.

CHAIR: Thank you very much. Mr Rasmussen?

Ms Rasmussen: My name is Lionel Rasmussen. Experience of life is my experience. The last time I went to my GP he said, 'You should fill out this form,' which is a form about how I would like to die.

CHAIR: An advance health care directive?

Ms Rasmussen: Self-care, yes. I think every one of us here should talk to our doctor about that, because today my mind is sound but tomorrow I might have a stroke. I could be in a car accident and I could lose my mental ability. If I had not signed that document—and I suggest that people look at this document with their doctor because it is pretty hard to understand in terms of how you should end your life—before I stopped being a human in terms of being turned into a vegetable, I know that I would not want to be here. I think most people would agree. The biggest problem is that we do not know when or how we are going to die. If you want to die with dignity, you need a document signed in that respect. I do not know what the law is, but I think it is available now.

I have a brother who died at home with his wife. He belonged to a euthanasia group. I do not know too much about it, but I know he used to talk to them about it. He looked after his wife for 10 years. He was such a devoted husband and carer that his wife did not want to die in hospital. He did speak to me about it. I said, 'Well, I do not know the law but you have to be very careful with what you do.' Both of them died at home. He might have got the tablets from that euthanasia organisation, but as we know it is illegal. Anyway, because he did everything right, he took his own life and that of his wife. That was out of love, because he could not stand his wife's suffering. Years before, he had been run over by a four-wheel drive tractor and was suffering more than anybody knew.

I lost a son in Singapore. I do not know how he died. He could have died from suicide, accidentally or from foul play. At the time we were so emotionally upset, we did not realise. We thought he had died accidentally—and that is what is on his death certificate—because there is nothing that we could do about it. This is the problem for us all. When somebody is on death's bed and we are emotionally upset, we do not think straight. Also, there can be family problems where one family member might have different ideas but only two agree. Some children do not worry about their parents but some do. To stop all this, for goodness sake, we all should go to our doctor and get that form signed.

CHAIR: Thank you very much, Mr Rasmussen. You make a very good point. As I did yesterday in Hervey Bay, I commend the AMA, which presented in front of us in Brisbane a couple of weeks ago. They are trialling Fifty over Fifty, so 50 per cent of 50-year-olds signing their advance healthcare directives or advance care plans so that people's wishes, if they do become ill—stroke, motor vehicle accident, terminal illness—have at least been articulated. I did this yesterday, so I am going to do it today. I ask you by a show of hands: how many people in the audience have an advance care health directive? Well done, you! Well done! Thank you, Mr Rasmussen. You make a good point. I welcome Shirley Pitts.

Ms Pitts: Thank you very much for allowing me to be here. I am on the other spectrum in that I am not healthy. I have MS and there is only one other lady I know of in Bundaberg who is older than me who has it. It frightens me when you say, 'Anybody with these sorts of things should be terminated.' It also frightens me when you say that people with cancer should be terminated, because I have had cancer from the time I was 17 and I am now three years without cancer. I have battled through life with MS and it is extremely painful, but my family, my friends, everybody, loves me. Why? Because they say I have a happy, smiling face because that is the only way I can cope. You have my submission there.

CHAIR: I have read your submission.

Ms Pitts: My late husband believed in euthanasia, and he tried to kill me 45 years ago. All he did was smash my jaw and all my teeth came out and I lost my memory of English, so then I had to start all over again and learn to speak English again. I was very fortunate that a young man who knew all about me decided to marry me and care for me. That was 41 years ago, and he has been caring for me ever since. He has kept me alive for those 41 years and he said that he is so happy with me he does not mind being married to me for another 40 years.

There are a lot of things that I cannot do anymore because I am extremely handicapped. When I had my strokes I could not even open a door, so a friend of mine taught me to do teddies. The first teddy I did the head rolled on the floor because I could not tighten up the screws. After six months I was champion in the show. This happens by a person who is terminally ill, and I will tell you a little bit more about that in a minute. I also have another group of friends who teach me how to make blankets. I make them and then we donate them to various charities here in Bundaberg that need the money.

CHAIR: Well done!

Ms Pitts: My life is precious and my life is important for my family and my loved ones, and especially for the people in Bundaberg.

CHAIR: Thank you, Ms Pitts.

Ms Pitts: I need to tell you about palliative care.

CHAIR: We might come back to you on palliative care while you pack the teddy. How is that?

Ms Pitts: Sorry?

CHAIR: We might come back to you on the palliative care and invite Jillian Jennings to speak while you are doing that.

Ms Pitts: All right.

CHAIR: Thank you. Welcome, Ms Jennings.

Ms Jennings: Thank you for coming to Bundaberg and giving me this opportunity to speak to you. My name is Jillian Jennings. As have quite a few people today, I have had some family members who have passed away with cancer. Thirty years ago my mother passed away. Thirty years ago my mother died from metastatic breast cancer. Her last three months were spent in hospitals in New South Wales, so she had six weeks in Sydney with bones breaking and things like that. For her last six weeks she was back in Grafton in northern New South Wales in hospital because the palliative care option was to be in the local hospital. Basically, all her bones were breaking and disintegrating. Pain relief was not wonderful in that last couple of weeks—lots and lots of morphine—but my mother's life still had value.

Eight years ago my father died of cancer of the oesophagus. He had a feeding tube down his throat until such time as the cancer blocked that and then he was sedated and passed away in about 24 hours. My father's experience of palliative care in the lead-up to that was quite good. He was able to stay at home. My father remarried at the age of 76, so there is still life. My stepmum helped look after him—she was also that age when they married—and the palliative care came to their home in Wollongong in New South Wales and he had good care. He had a palliative care doctor who would come to visit him as well as nurses.

Now it is my turn. I now have metastatic breast cancer. I am younger than my mother was, but my journey is different to my mother's. When I was diagnosed with bilateral breast cancer at the age of 50, I thought, 'Well, my mum had it in one breast. I've got it in two. My mum died in under three years. I'm not going to have long.' I had chemo and I had radiation. I then started on a drug called tamoxifen. In the 1980s with my mum's turn, my mum was given tamoxifen near the end of her life. It was a very new drug. For me in 2012 it was standard treatment to start tamoxifen. I went through a couple of different drugs. I actually had six years of being well and then discovered that, yes, life has changed and I have it in lots of bones and lymph nodes. Yes, there is no cure, but it has been 18 months now. I have still been working—I have been at work today—but that is going to have to change.

I am on my second new drug. I have been very fortunate to have access to drugs that were finished trials but not yet available on the PBS and, with lots of negotiating, have been able to get compassionate access from drug companies for which I am truly grateful. I started on ribociclib, which did then come on the PBS, but it is no longer effective and my cancer is increasing in its activity. In the last month and a half I have started on the second compassionate access drug and within three weeks of being on that drug my cancer marker that had climbed to 673—a marker that should be below 30—has dropped to 377, as I said, in three weeks of being on this new drug which has just amazed me, amazed my oncologist and I guess will amaze the drug company. On top of that I also get Xgeva denosumab injections every month.

When I was diagnosed I had nothing wrong with me. I was not aware that I had anything wrong except my annual check-ups had indicated that things were changing and within a few weeks I started to get pain in my right hip. I started to think, 'My life's going to go like my mum's. I'm going to have lots of pain and my bones are going to break.' After having the Xgeva injections every month and the tablets I have been on, so far I have had no broken bones. I am not in pain. I am truly grateful for that. Life is changing. The medical capacities are changing dramatically and quickly. Whether it will change enough in my lifetime, I do not know. My chances of being alive in five years time are extremely slim.

What do I want? My life has value. I have value. I do not want euthanasia. I do want access to good palliative care. It is scary to hear of a friend of a friend—I do not know the particular lady, but my very dear friend is a close friend of hers—who in this last six months has passed away from metastatic breast cancer in Bundaberg and unfortunately her life took a bad turn on a Friday night. Palliative care arrived Monday morning, as did the ambulance, as she had passed away after being in extreme pain all weekend. While I see lots of advantages and changes and I see my life going quite differently to my mother's so far, I do have this fear as to what will happen to me at the end in Bundaberg and in terms of what will be available for me.

CHAIR: We will take that on board, Ms Jennings. We have just about doubled on time, but we do appreciate you and your resilience is amazing. Thank you for coming. We have no questions at this stage, so I ask for maybe one or two minutes on the palliative care issue that you wanted to add, Shirley.

Ms Pitts: Yes. When I was 56 I was in the base hospital and they said, 'You need palliative care, Shirley, but you're not getting it.' The doctor examined me—the GP—and he said, 'I'll send you down to the Sunshine Coast.' They sent me down there. They found out I had one month to live, so they quickly got me treatment and I was able to survive for the last 18 years. Three years ago I had a heart problem and the doctor said to me, 'We're not treating you because you've only got six months to live.' Then the GP sent me down to Brisbane to the Greenslopes hospital and they kept me in there and they examined me totally and then they showed me how to survive and how to have palliative care at home, and that is what is happening for me now. My husband is caring for me all the time. If I am in one half of the house and I start breathing funny, he quickly grabs me and takes my blood pressure. He keeps an eye on me day and night. I wake up in the middle of the night and I am getting my blood pressure taken, but he is keeping me alive and I appreciate it and I appreciate the preciousness of my life because I believe that every single one of us is an unrepeatable miracle.

CHAIR: Thank you very much, Shirley. We thank the panel before us and call on the next group of witnesses.

DOESSEL, Ms Loris, Private capacity

DUNNE, Ms Sandra, Private capacity

GERRATY, Ms Francine, Private capacity

HAWKINS, Mr Raymond, Private capacity

HERBERT, Ms Lucile, Private capacity

KILSBY, Ms Julie, Private capacity

CHAIR: I welcome our final group today. Thank you all for being here. Loris, would you like to start?

Ms Doessel: Thank you for this opportunity. I am from Mundubbera. Having observed the lives of loved ones and general community members, I have given considerable thought over the past 15 years to aged care, end-of-life care including palliative care and the need for voluntary assisted dying to be legalised within strict guidelines. I am a volunteer driver for patient transport, taking patients from their rural homes to specialist appointments, which is usually a full-day trip of over 400 kilometres. As an observer when collecting these people and being a sounding board for their various nervous, distressed and sometimes miserable stories during the trip, I have seen that they are doing everything they can to age in place, this being their home of many years, rather than move to distant towns to access possible aged-care opportunities. I worry about these people when I return them to their lonely homes that are generally not at all suitable for their frail health, having been built before the invention of indoor plumbing meaning the bathroom and toilet are often an add-on at a lower level rather than an ensuite.

It is my strong belief that a small settlement of suitable two-bedroom homes needs to be constructed in most rural towns for rent by these independent people to ensure they are not living at such risk but are also not forced into other supported accommodation before it is essential for them to do so. A caring community keeps an eye on their neighbour, enabling individuals to live at home if it is suitable for much longer. There are very limited aged-care spaces in rural areas but they do provide good care. I believe this could be extended to provide spacious, suitable access, purpose-built accommodation with large garden and pet areas for dementia sufferers.

I have observed that, at first onset, dementia is confusing and distressing for the sufferer, whereas once the disease has developed their confusion unfairly affects others living in their aged-care facility while they themselves do not know they are confused or aggressive, sometimes to a dangerous level, and it is certainly very depressing for all who surround them. The tendency of relatives to entrust the care of dementia clients to a general aged-care facility unfairly impacts all staff and clients. It is impossible to integrate dementia clients with non-demented clients without unfairly impacting quality of life and quality of work life for the carers. The use of warning buzzers when a demented client leaves their room—or, worse, walks out the gate at their accommodation facility—is not sufficient as staff are generally elsewhere doing other tasks and cannot drop everything to retrieve a wandering dementia patient. The integration of such clients into the general population seems to be caused by an attempt to balance the funding ratio and the staff-patient ratio. It is neither fair nor safe and ruins already limited quality of life.

My paraplegic mother is the longest serving resident at her assisted living accommodation which receives no government funding. Several times I have been called the 300 kilometres to visit her when she has been in a bad way—all the way considering how I am going to help her go because I know she wants me to. Fortunately, I have not yet had to do it.

The 12 years there have taught her a lot about living with a large group of people with varied health and mental abilities. It is obvious to her and her visitors that the staff are under ever-increasing pressure to look after a wide variety of clients with diverse care requirements. Mum is now at the stage where she must depend on staff assistance to put on and take off her socks and to treat a pressure sore which developed a fortnight ago. The prognosis does not look promising due to poor circulation. She will soon be at the stage of requiring assistance into and out of her bed and wheelchair and eventually to shower and toilet due to an extremely painful and frail shoulder. Given her recent experience with irregular dressing of her wound, it is not expected that the limited staff will be able to get there in time when Mum needs the toilet. She has no intention of resorting to nappies while she can manage to get by, but the expectation is that sooner or later this will be her fate.

Her mind is very clear and we all know that when the suffering is too bad she wants to pick her departure time. Mum has observed many miserable deaths over the last 12 years. She cannot travel to Switzerland or Victoria, so we appeal to you to enable VAD for her and others who are suffering with no hope of recovery. There is only one way out of that place.

CHAIR: Thank you, Loris. We will come back to you for final comments at the end. Loris has become a bit of a parliamentary inquiry junky. She has followed us from Toowoomba. We thank you for the job you do too—driving those 400 kilometres.

Ms Doessel: I actually went to the LNP conference. I am exhausted.

CHAIR: You should be. Welcome, Julie.

Ms Kilsby: I speak as an individual. I have been a nurse since 1972 and I have recently been medically retired. Over the years, I have formed the view that there really is a place for voluntary assisted dying within our community. With regard to the living will, it does not go far enough. It will say 'not for resuscitation'. I have not looked at it lately, but I do not think it says anything about voluntary assisted dying. I really think it should be incorporated in that so it can become a legal document that must be adhered to, regardless of what other people's thoughts and opinions are. People need the chance.

I have seen a lot of things over the years where people have asked me to help them die. 'Hit me on the head, Julie. No-one will ever know. Just hit me on the head.' 'Give me that extra needle. It will help me, Julie. Come on.' You know that these people are speaking from the heart but you cannot do it. You cannot help anybody. It is just not possible. If it was within the scope of a legal document, then these people would have ways and means at their fingertips if ever they needed it.

My mum was a great woman. I lost her about 18 months ago. She was a bush girl. Everything was black and white; it had no greys. 'I know what I want to do. I'll just go down the creek and I'll die down by the creek.' I said, 'Yes, Mum. Off you go. When you're ready.' She was not to have her way. She developed atrial fibrillation, where your heart just beats out of whack. When your heart beats out of whack and they cannot put it back into sinus rhythm, you tend to spit off little clots. Hers used to land in the brain. Each time we had a little event, we would lose a little bit more.

She came to live with my husband and me. There were the three of us then—and a bird we have been babysitting for my son for eight years now. I was working full-time, and my husband was at home and he would look after her. It got to the point after two years when we had this huge raging inferno one day. Mum wanted to light the fire and he said, 'No, it's not a good day. It's too windy,' so she snuck out—she really did—and we had this raging inferno going out the back.

It just got too much with him doing all of the day shift and I was working and doing the night shift, so we put her into residential aged care in Bundaberg, and I must admit that they were absolutely wonderful. It broke my heart to put her there. She did not want to be there. She said, 'They're all mad.' She hated it but I had no choice; we could not cope. When my husband said to me one day, 'You're going to come home and find me hanging from the rope,' I thought, 'I can't do this. What do I do?' It puts you between a rock wall and a hard place. She wanted to die but she could not and I could not help.

In the end she developed cellulitis in her legs. We ended up at the hospital, and I tell you the care there was just terrible once she got upstairs. I had to try and fight with the doctors to say, 'She needs this treatment. Let's give her this treatment. She needs this full course. We all know doing half a course of antibiotics doesn't help. She needs the in-line course.' I would say, 'Give her a little bit of sedation,' and I would tell them what to look for. 'If she sits there and she's got her arms folded and her lips pursed like a little cat's bottom, that's when she's thinking. That's when she's planning. That is when you sedate her, not when she is mad.'

I used to sleep with the phone by the bed, and I got a phone call at two o'clock one morning saying, 'Julie, come up to the hospital. We've got four security guards with your mother.' I raced up to the hospital and there were these four burly men with this little 87-year-old pinned down on the bed. She had great cuts to her arm. She was black and blue. She had tried to escape. She just wanted to get out. Instead of just letting her go for a walk and following her to keep her safe, no, they had to fight and wrestle her and of course she would buck and kick and fight for all she was worth because she just did not understand.

That is where we need palliative care not only for cancer folk. We need better care in aged care. Where she was living was good and I will sing their praises—she was at Meilene and the staff in there were just wonderful—but when you put them in hospital there is nowhere for a person with dementia of any sort to be. If you put them in a ward, they become disruptive. They are lost. They are at a total loss and we need to be better there.

CHAIR: Thank you, Julie. 1972—

Ms Kilsby: That is when I started nursing.

CHAIR: What, as a child?

Ms Kilsby: I was too young.

CHAIR: People say that to me. I started in 1985 in an aged-care facility before I joined the ambulance as a young tacker.

Ms Kilsby: I was 17. You had to be 18 and I was 17.

CHAIR: It is just remarkable.

Ms Kilsby: I have only just retired.

CHAIR: Can I say over 50 years of nursing?

Ms Kilsby: Forty-seven years.

CHAIR: Well done. Thank you. We will move to Sandra Dunne.

Ms Dunne: There have been so many horror stories and some of hope, which is always a good balance. I do not know if it was Shirley, the lady with the teddy bear, who referred to termination, but that is not on the page for anybody who is here. I think that may be a very poor choice of words.

In Gladstone in 1996 I had a friend who was diagnosed with terminal cancer caused by a melanoma that had started many years before. He was only in his mid-40s. The specialist gave him three to six months to live unless he had half his tongue cut out, half his throat removed, massive doses of radiation and then there was only a 25 per cent chance of success. He chose not to take the chances. The odds were not what he believed to be stacked in his favour.

In May, we got down to pureed food, which he was having trouble swallowing. Then we moved down to Sustagen and liquid morphine. He turned into a skeleton with just skin draped over him. I would lie in the bed with him. He did not speak very well, but he cried an awful lot.

In June I called the ambulance as he was deteriorating so rapidly. With his family, we asked the doctor to just keep him comfortable. The doctor's response was, 'I'm the doctor. I'll decide what's best.' They put him on a drip. They sent him home to me two days later. A couple of days after that I called the ambulance. We took him back to the hospital. The same doctor said, 'All I can do is keep him comfortable.' I could have smacked his face. I really could have. The same doctor only a few days before had said, 'I'm the man. I'll decide.'

He was dead within 36 hours after he returned to hospital. His parents were elderly and frail. No parent or friend should ever have to watch someone they love. It is that person's decision. It is not our decision. It is our decision for ourselves, but his torture could have been ended. He did not have to suffer, but he was allowed to.

CHAIR: Thank you for sharing that with us. Lucile Herbert, welcome.

Ms Herbert: Hello. I firstly would like to say to all the people who have shared today—I sat up the back and wept—the pain and suffering in people's lives, the heartache, is horrendous, but I am a Christian and I do not agree with assisted dying. I do not say that in any way to judge, because I had been an enrolled nurse years ago, hospital trained, worked on a medical ward with cancer, with heart—with all sorts of diseases—and I also nursed my own mum in the last few weeks of her life.

I have done aged care. I stepped away from aged care. I originally started as a nurse when I was 18 in aged care and I went back to it in my 50s. I stepped away from it because I was absolutely disgusted. I was here in Bundaberg. I watched untrained, hard people caring for aged people and showing no compassion. They really could not care less whether a person stank of urine or was fed properly or not. At the facility that I was working for at the time, Sunday dinner was a scone that had been baked in Maryborough. It came here and it was like a rock cake. I was expected to feed that to an elderly person.

A regular meal each week was cheerios. My mother hated cheerios. Most elderly people do not like cheerios, but if you were incapacitated and could not feed yourself, you were given cheerios—and this is only in 2006 or 2007—that had been blended. This facility has stoves, kitchenettes and kitchens in which food could be made, but for some stupid reason we were getting it from Maryborough.

I tell you that this city desperately needs more jobs available. Why the blazes we could not employ a few decent people who did not have to be chefs but who could make soup and give food to people who deserve our respect and honour I do not know. I left. I walked away. I could not do aged Bundaberg

care. I could not when you were counting how many nappies that facility could afford and you had to make sure a person stayed a little longer in that urinated nappy because there were only so many allotted and allowed. It was a good facility, but many of them stink of urine because products to properly clean and remove smell are not used anymore.

I really have compassion and my heart breaks for what people are suffering, but I believe that we need to change a lot of things in our society. We need to extend the ability of palliative care. There are some great hospices available but not here in this city. I think one closed in Brisbane years ago. They can be a tremendous facility where there are properly trained staff.

I do not say that every person I worked with in aged care in 2006 and 2007 was hard and harsh, but many of them were not trained. I had been an enrolled nurse. I was no longer an enrolled nurse, but I went back to it with the thought that I would go back into nursing as my six kids had grown. I could not believe what I saw.

There was one particular patient who had only lost the ability to speak. She could walk and she could feed herself, but she was shoved in high care. That woman had a rash around her vagina—sorry, guys—but she could not get a tube of cream. It was a fungus that she had. I went home, bought some and took it in and secretly applied it to her, because she could not get a voice. Somebody did not have the time or compassion to find out why that woman was suffering. This goes on because our elderly people are no longer treated as valued.

CHAIR: Thank you very much, Lucile. This is why we have aged care as part of our inquiry. We need to make sure that we have adequate levels of care. There is also a national snapshot, with the royal commission looking at this as well and we are sharing this with them. Thank you for sharing that with us. We need to make sure that we look after those most vulnerable. Welcome, Raymond Hawkins.

Mr Hawkins: I am going to jump around a bit, and I apologise for that. Firstly, I would like to cover home care. My wife and I have experienced problems with this in Bundaberg with her parents, who are now both dead. Her mother was the first to go. We could no longer look after her in their local retirement village and she ended up going into a hospital, but in the hospital we were told that the medical insurance companies place a limit on the total length of time they can stay there at once. My wife desperately looked around everywhere in Bundaberg trying to find nursing home accommodation for her and there was absolutely none available. We were getting to a crunch time when this maximum time limit at the hospital was expiring and she still had nowhere to go. Luckily, she died a night or two before. That story is basically to say that I believe we have a shortage of accommodation in Bundaberg for nursing home aged care—at those late crucial stages.

Moving on to my father-in-law, who ended up dying six months later, he was still at home in his retirement village. I spent almost all day, every day looking after him there—going home to Moore Park Beach each night but being available on the phone should he call. He had had a stroke. He could not speak coherently so he could not tell me on the phone what was wrong. I just had to have the phone ring, hear his grunting on the other end, hop in the car and break the speed limit all the time driving into Bundaberg to see him.

My wife ended up putting him into a nursing home under one of the Blue Care facilities here against his will, but my wife said to him, 'I'm sorry, Dad. I've got to do it. I'm not doing it for you; I'm doing it for us, because we just cannot bear the strain anymore.' That did not work out. The staff were absolutely wonderful. While I am at it, I would like to pay tribute to all nursing staff—

CHAIR: Hear, hear!

Mr Hawkins:—and care staff in institutions, people at home who are caring for family and for ambulance staff. I love you all. You are absolutely wonderful.

The people in the Blue Care nursing home—the staff—were wonderful. They did the best they could with their limited resources, but there were lots of problems. The administration basically just fobbed us off. They were not interested in our issues. Part of the reason we tried to force some issues is to help the system, to help everyone, not just for our own individual system, but it was basically ignored. My father-in-law hated it so much my wife ended up bringing him out, back into his retirement village and I went back to my full-time caring role almost.

The day after she brought him home we got a phone call from Kepnock Grove retirement village here, or nursing home—my wife had applied at every single place—and they said, 'We've got a place we think will suit your father. Will you come in for an interview?' We did not know how that would affect him, the sudden changes, but we went in and were blown away by the wonderful, wonderful people there. A lady called Jo was the manager, I do not know if she is still there. Within a couple of

days my father-in-law was admitted and it was absolutely superb. When I talked later on to in-laws about it, it seems the facilities they provide there are state-of-the-art—like cutting edge for good nursing home treatment at the moment. This is in the context where I had read in the local paper really bad things against Kepnock Grove at the time. I love the place.

One of the big problems we had with the father-in-law at the Blue Care place was what I think Lucile was saying, which is that they had a kitchen there but they did not do any cooking. He had really specific dietary preferences. We told them all of that in advance. Once he moved in there they said, 'It will take a couple of weeks before we can implement those because the food is all done somewhere else.' Someone told me later on it was Rockhampton, so similar to you in Maryborough. It was just disgusting what happened with him with food. Suddenly he went to Kepnock Grove. They have a kitchen and they cooked proper food for him every day. From the word go they could cope with all of his dietary preferences. He died a couple of weeks later with an aneurism, but it was wonderful, it was nice and quick, no pain. It was a couple of days before Christmas and because our family could not come to spend Christmas with him we had had a family Christmas a week or two earlier there with him. He had his family around him. It was wonderful.

Sorry to take up your time. I will try to be quick. The next one is voluntary euthanasia, which is what I really came to speak about. I am very much in favour of it. Like someone else said, I disagree with Shirley's phraseology—not her story, for herself, but her phraseology insofar as we are not trying to force anything on anyone. It is for us as individuals to have our own autonomy and to be able to make a decision for ourselves. I am in my 70s. I am the start of the baby boom. We have problems now with aged care, palliative care, people dying. It is going to get worse as my generation ages.

CHAIR: I will probably have to pull you up there. I think you are making your point. I will comment on this: we are looking at demography for aged care. By 2026, seven years from now, we will have nearly a million more people aged 65 and over in Queensland. By 2050 it will be millions.

Mr Hawkins: So, yes, please let us kill ourselves. It will save society a whole lot of money.

CHAIR: We might go to our final speaker. Thank you very much, Raymond. Welcome, Francine Gerraty.

Ms Gerraty: Thank you for coming to Bundaberg and letting us all share with you our thoughts on these issues. My first job was as a nurse's aide, nursing and washing priests and nuns in a nursing home in Melbourne, where I am originally from. I have been a carer for both of my parents for the last five years: Mum with early onset dementia, the Alzheimer's variety, and my father with COPD on oxygen 24 hours a day.

With the issue of Alzheimer's, to try to find respite as a full-time carer is a great difficulty. Especially in Melbourne, with the climate, I would send them to Queensland every single year, normally to Bundaberg or Coral Cove or somewhere like that. Then I needed to ensure they were followed up with their blister packs and they would take them, that they would not fall over in the bathrooms in the motels or the hotels or the Airbnb and that they were also eating sufficiently. I was not able to travel with them at that time so that is what I planned for. It was not simple to plan that. Now that they have the Blue Nurses a bit more Australia-wide it is a bit simpler to follow it through, and with the My Health website it is easier to transfer your pharmaceutical records.

Putting them into respite in Melbourne, they would often separate them into two separate rooms, which meant Mum's memory bank was moved and that would cause great angst. That is an issue with the elderly, whether in Queensland or Victoria or anywhere. What I have found is that if you cannot find exactly what you are wanting, you go out and try to figure out a financial way to do it that will work. I think we have to look at aged care very differently. We do have a large population coming ahead. For my parents to be in an individual room in aged care in Melbourne is a \$600,000 deposit, and they were self-funded retirees. They have been taken to court by their four sons for their whole estate—it was in a trust—and they were in the Supreme Court in Victoria for 11 days. They won the court case without a barrister and without a solicitor and I prepared their defence. That was because no legal assistance is available to people who have a trust or a company. You are able to be defended if you are an individual. I think that is a big issue when it comes to financial abuse of the elderly. I just want to note that. Therefore I come back to the issue of advocacy.

It is really important. If there is no advocate and if you are going to go down the avenue of assisted dying, there have to be enough protections in there to ensure that financial bullying or emotional bullying or withdrawing grandchildren is not going to be one of the coercive issues. We tend to believe that many qualified people are the most qualified people. However, an accountant will always have a disclaimer, a lawyer will always have a disclaimer, a doctor who can diagnose someone with a mental illness can then turn around and be bullied by another family member to

rewrite a power of attorney. These happen. ASIC is not an all-safe entity. The saddest issue I saw was attending ASIC and not being able to speak to another human being with my father in his 80s and meeting other people there who were in their 70s and 80s saying, 'My children have stolen my assets, my home, and I cannot speak to anybody. I've had a stroke. I can't write.' Who do these people go to to be protected?

It then comes back to the nursing home. I said, 'Dad, you've won. You've been in the Epworth now. They've given you three days or three weeks to live. What do you want to do?' He said, 'Okay, I want to go to Moree and soak in the hot springs.' No problems. Off we went. We then came to Bundaberg. We stayed in this particular hotel here. The young receptionist was a CF sufferer and my father burst into tears with his oxygen machine and said, 'You are never going to experience childbirth, making these choices, because you're not even 21 and your life is already so compromised from your health.' They sat there in tears and shared their empathy together.

My father's name was Frank, and every now and then he was a bit of a cranky Frankie person. We ended up sharing his will with some of his best friends up here and going through things and then we spoke to a local real estate agent and found a house. It was a modified house from a young gentleman who apparently had motor neurone. It had disabled bathrooms, disabled toilets, a stair lift and it was \$600,000. We bought it. We moved in there. We got Dad into the base hospital under the palliative care team and they were brilliant. I just want to say that there is a way of doing palliative care which is perfect. The house has seven rooms. It would be a perfect butterfly home. It would be a perfect place for that type of environment. It is designed without white sheets. It is designed with colours on the walls. It has curtains that can be changed for blue or green or yellow or red. They can be child-like or they can be family units. You can actually have two units which are completely independent and separate. We have to look at how we want to be cared for. We want to know that we have a Skype room available, that if we have an Apple TV it is going to work. We have to work towards planning this now.

CHAIR: Thank you very much, Francine. I think we have got the perfect person to drive such a thing. That is a great note to finish on. In our travels leaving Brisbane we stopped at Katie Rose Cottage on the Sunshine Coast. It is very much a community-driven palliative care space. I think you have the perfect advocate to try to drive something like that with that particular property that you have. They are community driven.

We have taken so much from today. What a wonderful contribution from every single person who has attended today. We thank you for sharing your stories with us. You will help better inform us with your considerate, kind, compassionate, caring views on aged care, palliative care, end-of-life care and voluntary assisted dying. We cannot do it without you. We express our thanks to you. Loris, I know my two colleagues did not hear you before. Do you want to make a final statement?

Ms Doessel: On behalf the rest of Queensland I would like to really express our appreciation for the work of the committee, for the dedication and for the empathy and the concern and the obvious care they have to make the right decision. Thank you for all you have done and I do hope that you do not all need Valium to help you sleep at night because it drives us mad just thinking about it and you have had over a year of it.

CHAIR: Thank you very much. I declare this public hearing closed.

The committee adjourned at 3.25 pm.