



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
Ms JE Pease MP

Staff present:

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

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

TRANSCRIPT OF PROCEEDINGS

FRIDAY, 3 MAY 2019

Caloundra

MONDAY, 3 MAY 2019

The committee met at 10.32 am.

CHAIR: Good morning and thank you for being here today. Before we start can I request that all mobile phones are switched off or to silent. 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 are meeting today. Can I also thank the Caloundra Committee of Service to the Ageing, CCSA. I met with Margaret and some of the team. Thank you for allowing us to be here today and use your facility. It is fantastic to be here. With us today are Mark McArdle, the local member for Caloundra and our deputy chair; Marty Hunt, the member for Nicklin; and Joan Pease, the member for Lytton. We have apologies for the member for Maiwar and member for Rockhampton. I understand that we will have fellow member Chris Whiting, member for Bancroft, joining us later on.

The committee is a statutory committee of the Queensland parliament and as such represents the parliament. It is an all-party committee which takes a nonpartisan approach to its inquiries. The inquiry into aged care, end-of-life care, palliative care and voluntary assisted dying was referred to the committee on 14 November 2018. The committee is required to report on this inquiry by 30 November this year. The committee received approximately 5,000 written submissions by the closing date, 15 April. We are still working through the submissions but the majority of submitters expressed their views on voluntary assisted dying. That does not take away for a moment the importance of palliative care and aged care that we are looking at as part of this inquiry.

Today is the very first regional hearing for this important inquiry and I am glad to be in Caloundra to hear the views of people from the Sunshine Coast. This is an opportunity for everyone to share with the committee their thoughts and experiences on these issues. I ask that everyone respect the rights of others to hold and express their particular views. I also ask that witnesses take care when you are referring to acts of suicide or euthanasia.

The hearing will start with invited local stakeholders, of which we have many, giving their views on aged care, end-of-life care and palliative care. We will then open the hearing up to those who have registered to appear as witnesses to hear their views on those topics as well as voluntary assisted dying. There are a large number of people who have registered to speak to the committee today. We will try to give all people who wish to speak the opportunity, but this will be dependent on the number of people who wish to speak and the time available. I ask that those who do speak to the committee keep to their allotted time to ensure that others have the opportunity to speak. If there is time at the end of the hearing we will invite anyone who has not registered but who wishes to speak to make a short statement to the committee.

This public hearing is a formal proceeding of the parliament and is subject to the Legislative Assembly's standing rules and orders. The committee will not require evidence to be given under oath, but I remind you that intentionally misleading the committee is a serious offence. This public hearing is being recorded and transcribed by Hansard and witnesses will be provided with a copy of the transcript. All invited witnesses appearing this afternoon have been provided with a copy of the instructions so we will take those as read. If there are any media present I ask that you adhere to my directions as chair at all times. I remind members of the public they may be admitted to or excluded from the hearing at the committee's discretion. Please also note that you may be filmed or photographed and images may appear on the parliament's social media pages.

Before I start, given we are in Caloundra and the member for Caloundra is here, I might ask him to make a few short comments. He knows his community well. I think he knows just about every single person in the room. He has had many conversations this morning. I was speaking with members of the CCSA this morning and they tell me that their 40th year will be celebrated this year but that it will take a little bit of money to hold the celebrations. I told them they should speak to their local member. I now ask the deputy chair to say a few words as the local member.

Mr McARDLE: Chair, thank you. First of all, welcome to the hall. I thank you in advance for the words you are going to provide to the committee. I emphasise that when you do speak, please give your name first because Hansard need to record who you are then what you say.

Today we are going to hear in relation to very emotional topics. People may well get emotional. If you do need to have a break or sit down, please do so. We understand totally if you need to do that. We on the committee will also ask you a series of questions. Those questions are not meant in any way to denigrate your argument but merely to obtain more information or pose a different scenario for you to consider. They are not criticising you in any way, shape or form. You may also hear comments by other people in the audience that do not marry up with your own comments. Please understand that those comments are not attacking you; it is merely a different perspective on the same topic.

Finally, we all believe quite strongly that everybody, as the chair said, has the right to an opinion and this is the time and the place to express that and to express it in an environment that allows each of you to make a comment and put your point of view across. This is your day. From what you say to us we can take details and that will form, in part, the final report of the committee. This is your inquiry as much as it is ours.

CHAIR: Thank you, Deputy Chair. We have a range of invited stakeholders who will first provide us with some information.

COOPER, Dr Matthew, Palliative Care Advanced Trainee, St Vincent's Private Hospital Brisbane

ENDACOTT, Dr John, Geriatrician, Clinical Services Director, Community Integrated and Subacute Services, Sunshine Coast Hospital and Health Service, Queensland Health

FAWCETT, Dr Christine, Geriatrician, Acting Clinical Service Director, Medical Service Group, Sunshine Coast Hospital and Health Service, Queensland Health

LEADBETTER, Ms Barbara, IRT Home Care, Business Manager, Queensland

MANTON, Ms Sue, Business Manager/Secretary, Little Haven Palliative Care

MASON-BAKER, Mrs Sue, Chief Executive Officer, Sunshine Hospice

MOORE, Mr Alex, Cittamani Hospice Service

WALLIS, Professor Marianne, Professor of Nursing, School of Nursing, Midwifery and Paramedicine, University of the Sunshine Coast

WELCH, Dr Louise, Clinical Director, Palliative Care, Sunshine Coast Hospital and Health Service, Queensland Health

Ms Leadbetter: I am the business manager for IRT Home Care but today I would like to speak as a registered nurse. I have been a registered nurse for a very long time—38 years—and I have worked in the aged-care industry for most of that time. I have personally witnessed hundreds of deaths. I have never heard a person ask to be kept alive when they are in severe pain, leaking bodily fluids, agitated, not knowing who their family are, but hundreds of times I have been begged, as have other staff around me, to assist these people to go. Why do we need to get to this stage where someone cannot choose when it is time to go?

A little piece of doctors' and nurses' hearts die when we are asked that question and we cannot assist. I still to this day challenge the government as to why we cannot do this. I personally have had people—I hear those voices in my head still—begging to help someone to end their life and why could I not have done this before I got to this stage?

Currently in the home care space on the Sunshine Coast, just in our small company, we have two clients out of the 44 customers we service who want to end their lives. They are younger aged people with terminal diseases and they are sitting around knowing what is in front of them. They do not want to go through this. They do not want their younger children to see them like this. I am begging the Queensland government to please see fit to change the law. That is my opening statement. Thank you. Thank you for your time.

Prof. Wallis: I am a professor of nursing at the University of the Sunshine Coast. My presentation is on something slightly different. For the last five years I have been working with a team of clinicians, both in residential aged-care facilities and hospital and health services. We have run a Caloundra

number of research projects that have investigated and evaluated new models of care aimed at improving the outcomes for frail adults who experience a serious but non-life-threatening medical condition. This might be an acute illness or it might be an exacerbation of a chronic condition. My work has incorporated working with older adults living in the community and in residential aged-care settings. It has evaluated novel models of care in hospital and in those settings. I am also involved in some research into GP care.

With respect to my work in aged-care facilities, which was funded by the federal government starting in 2014, I can say that what we developed was a two-tier intervention model where we evaluated the introduction of a nurse practitioner candidate into aged-care facilities and we also evaluated a model of a physician championed, nurse led specialist service in the emergency department of the hospital. What we are trying to do with all this is deliver the right care at the right time in the right manner to the client. Hospitals can actually be dangerous places for frail older people. There are lots of lights and buzzers and noise and it is a difficult technical environment. People can become more confused, can injure themselves and can develop more complications. We are trying to work out the best way to give the right care.

With the RACF, we discovered that it is very difficult to do research in that facility because often the information systems are designed to put data in but not to pull data out. We could not actually, for example, work out whether or not the nurse practitioner reduced transfer to hospital because we actually could not get that data out of the system. What we did find out was that when the nurse practitioner was on duty there were fewer transfers to hospital; if people were transferred, they would have shorter lengths of stay in hospital; and a surprising finding was that we actually increased the number of residents with advance care planning in place. Initially, the organisation represented 23 per cent of residents. By the end of the year of the trial it was 75 per cent.

We also costed this and found that there were savings to the health service from a reduction in presentations; there were savings to GPs because the GPs did not have to leave their clinics and travel to the aged-care facility—they could liaise with the nurse practitioner candidate; and there were lots of savings to the Ambulance Service, but there were no savings to the residential aged-care facility. There is this interesting shift where the residential aged-care facility is paying for the service; they are seeing an improved quality of care, but the cost savings are to the other side of the equation.

We also saw that the nurse practitioner gave very similar care. We asked the GPs what care they would have prescribed, and the vast majority of the care was the same. We interviewed all of the GPs who service this facility afterwards and there was one GP who was still a little bit undecided, but the rest were all absolutely in favour of this model of care. The RACF staff felt they were well supported.

CHAIR: Thank you very much for that.

Dr Cooper: My background is as a GP working in Mapleton in the Sunshine Coast hinterland. I worked there for a 14-year period, with quite an involvement in palliative care within general practice. I have also been involved as a board member of Cittamani Hospice Service, I am a co-opted member of Palliative Care Queensland on state council and have been involved in GP education. At the moment I am undertaking palliative care training at St Vincent's Hospital in Brisbane with a view to gaining a specialist qualification. The hope is that that will allow me to play a role in advocating for and delivering comprehensive and coordinated community based palliative care, supporting both the generalist and the specialist approach.

GPs have a pivotal role in the coordination and delivery of health care. Palliative care is one of the more challenging areas, although no less critical, in which to practise this role with confidence and skill given the complexities of symptom management, care needs and advance care planning. For most patients, their palliative care journey begins with their GP, presenting with a symptom or concern that ultimately leads to the diagnosis of a life-limiting illness. The needs that follow in terms of delivering optimal care are extensive. The competing needs of GPs and the time-poor environment of general practice make this all the more challenging. This care will require a truly multidisciplinary approach in meeting the physical, psychological, social and spiritual needs of patients, their families and loved ones. Unfortunately, the competency with which these needs are met will depend on where the patient lives, the GP's comfort and skill level with practising palliative care and the support network the GP can access. Across Queensland the funding and resourcing of community palliative care, the access to these resources and the workforce capacity to deliver care are not universally consistent or available. In a fragmented system this creates somewhat of a lottery as to the care people receive.

As stated by Palliative Care Queensland, the way we care for our dying is a significant indicator of our society's values. In terms of their care, what do those with a life-limiting illness tell us? Statistics show that 70 per cent of people wish to remain and die at home and that 17 per cent of people achieve Caloundra

this. Of the people who do achieve this and access community palliative care services, most patients have a cancer diagnosis, yet the overwhelming and increasing burden of disease is non-malignant: dementia, heart failure, emphysema, kidney failure and frailty of ageing. Current service provision clearly does not meet the current needs of the community. The prospect of this improving without dramatic changes in priorities, funding and access to care is negligible.

All GPs at some point will have a patient with a life-limiting illness, yet not all GPs are or want to be experts in this field. Palliative care may not be an area of interest, GPs belong to an increasingly part-time workforce and remuneration is clearly a disincentive. In supporting GPs and their patients, there needs to be a broader view of palliative care beyond general practice. This may include roles for nurse navigators and nurse practitioners, thereby providing links and access to specialist services and care providers. The capacity of specialist services needs to be significantly enhanced. The statewide lack of palliative care specialists is well documented and the majority of these are hospital based.

Care provision requires access to specialist palliative care nursing, generalist nursing, allied health professionals and volunteers. Not surprisingly, this access need to be 24 hours a day. Overseas research showed this impacts significantly on improving the rate of death at home, reducing acute hospital admissions and—of note for government—reducing the overall cost of care.

Internationally, palliative care is recognised as a human right. Our challenge is: how are we going to respond to this edict? Death occurs at one end of the life continuum. What do we find at the other? Birth. What would we do as a community, a government, a society if 70 per cent of people wanted a birth at home? How would we respond in terms of mobilising funding, resources and access to care? What would we say as a society if only 17 per cent of people achieved this wish?

Dr Fawcett: I am a geriatrician who has been on the coast since 2002. I am currently the acting clinical service director of the Medical Services Group. I did not have anything broadly prepared to say. I thought I would more answer questions. I have a couple of points. Firstly, I am very glad that this topic is being looked into. I think we as a society seriously need to look at how we provide services for our older Australians. Touching on something that Matthew talked about—fragmentation of care—I think that the need for lined up care for people that goes from the primary healthcare setting into tertiary level, if that is required, and back out the other end of the hospital experience for those who require hospitalisation is something that we have a lot of work to do on. I am very pleased that we are starting to enable conversations about the end of life because it is there for all of us. I think that is something that we have neglected to do as part of the culture of our society. Anything that brings that up so that we are hearing the voices of everybody in that conversation is important.

I would like to touch on models of funding that allow seamless care and promote independence for older Australians, and personal choice is important. Any initiatives that are taken need to be underpinned by strong research. A good idea is a good idea. It does not translate into reality as a good idea unless you prove that. I think we need further research models around this such as the work that Marianne has been doing. Finally, I would make a comment on education of staff and ensuring that the people who are there to provide care for older people do that in partnership and are educated to levels that are appropriate. A particular area of concern in terms of accessing care would be people with dementia who suffer those severe behavioural and psychological symptoms of dementia. They can generate particular issues of care.

Dr Welch: I am the clinical director of the specialist healthcare service for this district. Thank you for the opportunity to speak with you all again. Because I have already been on this committee, I thought I would give you an understanding of what is supplied locally from our Queensland health service. We have what is called a level 5 framework service; it is one from the top, the top probably being Royal Brisbane and like services in Brisbane. Our service is actually based in the Caloundra Hospital and we reach into the other district hospitals in the area.

CHAIR: Is that Dove Cottage?

Dr Welch: It incorporates Dove. Dove Cottage is historical. We have the Dove Palliative Care Unit, which is our specialist ward, which we welcome you to visit this afternoon, our outreach or community based centres—our nurses and allied health work in the same building. To expand on that, our Dove Palliative Care Unit at Caloundra has recently been refurbished from 10 beds. We are now currently at capacity at 14, and that will be building up to 18 in the near future. We are in the middle of developing a new service with a model of care and planning for a four-bed day unit, and this will develop over the next three years. It is expected that this unit will offer a number of new facets of care such as a crisis day assessment, allowing our palliative patients in the community to enter directly from the community, and provide specific palliative care activities such as top-up transfusions

or minor clinical procedures which will take them out of the acute hospital system and able to come to a familiar group that is already providing that care. We are hoping that that will reduce some of the activities in the other acute hospitals.

Our community team is involved with supporting and educating, and clinical care of the whole district. We do this via home visits, residential aged-care facility visits and outpatient clinics at all of our hospitals in the district. We also provide telehealth consultations via videoconferencing directly to the patients' homes and to the other district hospitals for inpatient advice and consultation. Our staff includes specialist medical officers and our juniors, two nurse practitioners, psychologists, social workers, other allied health and, of course, our admin officers and volunteers. We are also responsible for a small amount of local funding for our domiciliary community funded providers for care in the home. This provides some nursing hours, equipment and consumables to keep people at home.

At the new Sunshine Coast University Hospital we have a small clinical team who provide direct inpatient and consultations to the patients in SCUH. We also provide support to the cancer care, multidisciplinary meetings and other complex patients. Our service is very busy, with a focus on patient centred care and working towards ensuring the best care to the right patient at the right time and the right place.

We work closely and collaborate extensively with our local stakeholders. Our issues relate mostly to trying to get people home to achieve that 70 per cent goal of home care. Our inpatient ward and care in hospital is available for those people who cannot achieve home care and for those who have complex needs. Obviously, in order to keep sustaining community supports we need our service to be sustainable. I think we spoke enough about that at the previous committee meeting, so I do not need to go over that. We need to continue to empower our general practitioners and our community nurses and provide appropriate education ongoing for those groups.

Dr Endacott: I am a geriatrician and also the clinical service director for Community Integrated and Subacute Services with the Sunshine Coast Hospital and Health Service. I would like to thank you for the opportunity to participate in this inquiry. The guidelines that we have been provided for our participation in this inquiry tell us that I am here as a representative of the minister and also my hospital chief executive. That in turn means that I am also here to represent the service providers that my service group represents, which includes Louise's team in the Palliative Care Unit, Glenbrook Residential Aged Care Facility, the Transition Care Program, the Aged Care Assessment Team and CHSP, which is the community home support packages. This means that I am here to represent my HHS as a clinician and also as an administrator. I have not prepared any particular comments for this introductory piece because I did not want to pre-empt the questions of the committee but to respond to the questions. Therefore, with that preamble, I will not be presenting my personal views on any of these topics.

Mrs Mason-Baker: I am the managing director of Sunshine Hospice. Thank you for the opportunity to speak today. Sunshine Hospice wishes to make the inquiry aware of the challenges facing new and emerging hospices in Queensland and to offer solutions to some of these challenges. Sunshine Hospice is a local charity established in 2008 and an experienced hospice provider. We operated a six-bed hospice in Doonan between 2010 and 2015 caring for over 300 patients and their loved ones. Other than subscribing revenue, our hospice did not receive any operational funding from the Queensland government despite many years of lobbying. This made sustainability extremely difficult and ultimately impossible. We relied on revenue from our op shops, donations, bequests and fundraising activities supported by an army of volunteers. It was only through a couple of sizeable bequests that we could maintain operations for as long as we did. We were forced to close the hospice facility in December 2015 due to financial constraints.

Three years on, we have changed our business model. We have networked extensively with the South-East Queensland hospices, understanding their journey from conception to operation and learning from their experience and wisdom. Most significantly, we concluded our next hospice must be accredited and licensed, giving us access to revenue from private health funds, DVA and the government. Even with those extra multiple funding streams, as a charity we will have to raise 50 per cent of our annual operating budget.

We can advise that we have secured a parcel of land in Buderim on the Sunshine Coast subject to Sunshine Coast Council granting approval to build a six-bed residential hospice. The application to council will be lodged in the coming week. Our journey to date has not been an easy one but one worth fighting for. We know from firsthand experience the significant positives that a hospice can bring to a community as well as relieving the financial burden on the public health system. Let me share with you three stories to support that statement.

Our first story is about a motor neurone patient in his late 30s for whom we cared until his death. He spent approximately 180 days in our hospice free of charge. This patient simply had nowhere to go for care. He did not fit an acute hospital setting or an aged-care facility and had no family who were willing or able to care for him in the home. Our hospice became his refuge, his primary carer and his family. We celebrated his birthday before his death and baked him a cake. He had never had a birthday cake before. We allowed him to experience another first in his life, even when so close to death. We were able to offer him physical, spiritual and psychological support in a peaceful, home-away-from-home environment. Imagine the alternative if we were not there to offer shelter and care? What happens to members of our community who fall into the cracks? Consider how much money Sunshine Hospice saved the public health system for 180 days of care for just one patient.

Our second example is of a young lady in her late 30s dying of breast cancer. She had a relatively short stay in our hospice but her stay remains memorable. She decided to make the most of her last days on earth, inviting family and loved ones to embrace the little time that was left with regular visits. We honoured her wish to provide her with a living wake. The wake was held in the beautiful grounds of our hospice and it allowed her to celebrate her life with a large gathering of loved ones. She thought it was perfect and she died peacefully soon after.

Our third example is of a gentleman living at the back of Gympie who had no family or friends. He was referred to us by our colleagues at Little Haven—thank you, Sue. Upon admission, we discovered that he wanted his dog, a red heeler, to be with him. We could accommodate his wish to have his best mate by his side. In fact, his dog slept on the bed with him, as was their usual routine. There were no barriers allowing this to occur, no strict rules to follow. This is what a hospice allows. Our staff and volunteers would walk and feed the dog, taking him around the grounds, and once we secured a safe home for the dog his master felt that it was time to leave and he passed away soon after as well.

Having drawn your attention to some of the amazing work that a 24/7 residential hospice can achieve, I need to emphasise the enormity of the task in setting up a new hospice. Toowoomba, Hopewell and Ipswich hospices were all established in the 1990s and we are one of very few organisations contemplating a capital project to construct a purpose-built hospice. Our journey has been challenging, and we know we have many more mountains to climb before we open our doors. If hospices can offer so much to a community, why are more organisations not embarking on this same path? There are many reasons. Here are just a few.

No. 1—and this would have to be my favourite—is that it requires significant personal commitment and a strong belief in the cause. Having experienced many highs and lows during the last 10 years, our success to date is primarily attributable to a group of resilient, committed people who totally believe in delivering hospice care to the Sunshine Coast community and who simply refuse to give up. How many organisations would pursue a difficult and painstaking project year after year without guarantee of success? The second point is lack of information—

CHAIR: I am just mindful of the time. We have your excellent submission and I think we will just move on and then we can open up for questions. Sorry, thank you.

Mrs Mason-Baker: Thank very much.

Ms Manton: I am the CEO of Little Haven Palliative Care, a not-for-profit community based palliative care service in the Gympie region. I am also the state secretary of Palliative Care Queensland and a founding member of the Hospice Services Network, which represents the excellent models of hospice care that we have uniquely in the south-east corner of Queensland. I have been a very strident voice in this debate because it frustrates me that, despite 20 years of service, our hospices, which are delivering care to patients in the way they require—in their own home, with 70 per cent to 80 per cent of patients saying they want to die at home—and are meeting these sorts of criteria, have not had the political will to look into that. Time and time again we hear quoted international studies of palliative care when they are right here on our doorstep.

I welcome you to the Sunshine Coast, which has an excellent specialist palliative care service in two excellent providers of community based palliative care in Cittamani and Little Haven. It has a variety of very good generalist nursing services that work in collaboration with our services to provide the best level of palliative care that you can and we have a wonderful hospice. We still have the Katie Rose hospice as well, but we look forward to the Sunshine Coast hospice getting up and running in the near future.

With that in mind, my turning point was probably when I had to care for my own mother, who was diagnosed with a brain tumour about three years ago. I had the time to step outside of my community, because much of being a palliative care provider and an NGO is very time consuming. At the time, we were having to raise around \$600,000 a year in our community. I had a little time to stick up my head to see what the overall landscape was. When I moved into the much broader space—into a metropolitan south area—to care for my mum, I realised that that level of support was not available. There was not that lifting of the burden of care that I had come to expect for people in our community and the people in our community knew they had.

That motivated me to make multiple submissions to the Productivity Commission. I encourage the committee to really drill down into that information. I will not quote it here, but that is our model of care. That is the hospice model of care that has been recommended as the No. 1 recommendation on how to improve societal and economic benefits for patients at the end of life. I will draw you to that.

I have been reading every submission that comes through. I am obviously quite passionate about it, as are all of us here. It is heartbreaking to hear those stories. I think that, in the absence of proper care to relieve burden, to relieve symptoms, to talk people through what is going on, that is the outcome that you get—that people feel terrified, they feel a burden to their family, they end up in hospital undertaking futile treatments. If I have two minutes, I would like to share a story from my nurse in giving you an idea of what a good death could look like.

CHAIR: We did read that. It is a beautiful—

Ms Manton: A part of it?

CHAIR: Yes.

Ms Manton: This is just because there are a lot of people here in the room who are scared of what dying looks like. I am reminded of a patient in Boreen Point—a wonderful woman who was in and out of our sites for several years as her battle with cancer waxed and waned, a spiritual woman who had explored every twist and turn on this mortal coil. She went deep but, inevitably, she reached a point in the trajectory of her disease where the end of life was in sight. Her liver was failing and her body was saying, 'I'm done.' I arrived at the home with the knowledge that this woman was not long for this world—maybe weeks, maybe days—and that she wished to die at home. Boreen Point is remote in regard to swift response health care. You cannot even get bread and milk after 7 pm, let alone a doctor.

Her daughter and granddaughter had arrived and would stay until the end. Our patient was at this point mobile, alert and independent in her intimate care, but she was heavily jaundiced with marked indices. It would not be long until these blessings of ability to self-care would no longer be hers.

I entered the bedroom where our patient was lying in her bed. Her daughter and granddaughter were at her side and at her feet. I am struck with an image in my mind of three pale, frightened faces peering out from the bottom of a deep, dark well. It was heartbreaking. Everyone in the room knew why I was there. I am a palliative care nurse. I was there to talk about dying, and so we did. We talked about symptoms and how we would manage them. We talked about activities of daily living, like washing and toileting, and how we would manage them. We talked about equipment that would ease the physical burden of care that Little Haven would provide easily and at no cost at the next home visit. We talked about medications and how they relieve symptoms and how they would be given. We talked about paperwork and getting affairs in order. We talked about bodily functions and how they would respond to the dying process. Then we talked about emotions: love, fear, loss, love.

I returned the following day. The image of these pale, frightened faces peering up from the bottom of a well had gone. Instead, I am greeted by the same three faces—resolute and bold despite their fear to face the inevitable and imminent parting of their matriarch. I was honoured when the granddaughter voiced her gratitude for the conversation the day before and how they felt prepared and able to give their beloved the death experience she deserved and desired. If we can step people through that process, what an absolute privilege it is for families to care for those who have cared for us. Thank you.

Ms Moore: I am the director of Cittamani Hospice Service on the Sunshine Coast. We are a specialist home palliative care service providing 24-hour support to people who are facing a terminal illness. I have worked in community palliative care for over 25 years. I was involved in setting up Karuna Hospice Service in Brisbane and also Cittamani Hospice Service here on the Sunshine Coast, where I have now worked for over 20 years. My area of expertise is palliative care.

I knew that Sue would speak very eloquently about the value of our services, and I think you are aware of those. There is another issue that I want to raise today that has been really impacting on our team. We know, as everybody has said, that people wish to die at home. We know about the advantages of that: for the person who is dying to be in their own environment; for the family, if they can manage to be there to support that person; for the community, that we keep people within our community rather than shuffling them off when things happen that we find a bit difficult to deal with; and for the healthcare system in terms of cost. When costs are blowing out as they are, it is extremely cost effective. I am sure you are aware of that.

For people caring for someone at home—the carers—there is a huge burden involved in providing care for that person—a physical and emotional burden that people are willing to take on, and gladly take on. I am sad and frustrated, as is the team and as are many people working in the community, that I find that, after my 25 years working in this area, the amount of basic support for people dying at home is less now than it has ever been in those 25 years. It is heartbreaking. There are so many people feeling very despondent about it. I know that it is not the responsibility of the state government—the new My Aged Care system—and that there is increased demand, but people facing the death of someone they love need support now. They need to talk to someone. Many of them are aged. Even if they go on to the website to try to negotiate that and they are rated as urgently in need of assistance, they have a six-month wait. Most of the people we care for—virtually all of the people we care for—will have died before they can access the care they are eligible to have.

It is becoming more and more difficult. If the family member is providing the shower, even if they can see that that family member is exhausted, they cannot say that there is an unmet need there. The need is met, so they do not need any help. Even if they are urgent, they wait six months. It is hopeless. Caring for someone at home takes a huge toll, but if we can provide support—things like hygiene assistance and respite—then people can continue to do that.

The healthcare providers in the various services within communities—and I think the Sunshine Coast is a great example of that—work so well together. Louise's team, our team—all of the community providers work very well together. We have been totally disempowered. Communities look after their own. They are very resourceful and they find ways to provide care, but that option has been largely removed from our scope. Although within the palliative care area within the community we work together closely, in terms of working with the domiciliary agencies, that ability has been really decreased. If we are going to keep people at home then we need more funding for services that are responsive to the needs of the dying, and that is within the community's control, so that we can work to provide the kind of care that we want. That was the main point that I wanted to make, because it is taking a huge toll on care and on the carers.

In conclusion, having worked for 25 years in palliative care I need to make the comment that, from my experience, if people are provided with the kind of care that Sue was speaking of, very few people have ever requested me to end their life. They have found value in that end part of their life, but they need support if they are going to do that. If we do not provide them with that support and their only option is to ask for their life to be ended then I think we are letting down people in our community. Thank you.

CHAIR: Thank you very much. We are definitely going to go over time, but that is okay; we will manage that. As a fellow health worker—I have heard a lot about you and where you come from—I started in 1985 as an orderly in a nursing home—I am showing my age—and then joined the ambulance in 1990 until I was elected. I have worked with a lot of aged-care services and seen a lot of people suffering in that time, so I just wanted to give you some background on that. What we are hearing is that there are concerns about the models of care in aged care. I like that trial that you did. The outcomes are very interesting in terms of staffing. I want to see if we can talk a little bit about that. From the bottom of my heart, I want to say thank you to all of you for what you do. That is just an amazing array of expertise in looking after people in the community. As you said, there is no doubt that it is challenging.

We have an ageing population, and we are hearing from your submissions and from other stakeholders that the workforce modelling needs to be looked at. I want to quickly touch on the views of aged care—and anyone can speak to this—in terms of waiting times to get into residential aged-care facilities. I think you mentioned six months. What about the packages—level 1 to level 4? I want you to talk to the aged-care packages and also make any commentary on staffing models. Is there a view that if you put an increased staffing model in, as you suggested with the nurse practitioner, the burden will then be taken off the public healthcare system if you have a better clinical model in a residential aged-care facility? I must highlight that I was so impressed with Blue Haven in Caloundra

the Lytton electorate. There is a palliative care service set up by Queensland Health within the aged-care facility. I was very impressed with that model. Can anyone talk to the staffing models and aged-care packages to start with, briefly?

Ms Leadbetter: I look after home care packages in my role. We recently had the local member, Mr Ted O'Brien, come to our service. I called in the care staff who are nursing people until they pass because they have been waiting for a package upgrade or have no package at all and staff are doing it in their own time. I am appalled at the federal government in this current election. We are not hearing anything about My Aged Care or the royal commission. Nothing has been in the paper or on the news except dirt about each other. There has been nothing about My Aged Care and the lack of support for people with packages. Our hands are tied. I know of one man who died at home alone, waiting to have his package upgraded. We were only funded for two hours a week. He was palliative and he had been waiting 12 months. You can hear the agitation in my voice. I am very passionate about my industry and I am appalled at what the federal government is currently doing.

CHAIR: Thank you. I want to share with you that we are sharing this information with the royal commission. We are communicating with them. Of course they are taking a nationwide view on aged care, but we have assured them that we will be passing this information on to them before they come to Queensland. Thank you.

Ms Moore: If I can just clarify, the six-month waiting list I was speaking about was for in-home.

CHAIR: Right.

Ms Moore: If you are classified as urgent—the highest—it is a six-month wait. As you were saying, people do not get that care.

Dr Endacott: You are talking about palliative care rather than aged care; is that right?

Ms Leadbetter: It is both.

Dr Endacott: I will provide some data that our local aged-care assessment team has provided for me. The current knowledge about waiting times for packages is based nationally. It is really hard to get a local, nuanced view of what our local population is experiencing. The advice that I have been given is that level 1 packages have about a three- to six-month waiting time whereas levels 2 to 4 nationally are a 12-plus-month waiting time. That is consistent anecdotally with what I hear my patients say in clinic. However, access to residential aged care is slightly different. In terms of available beds, I am advised that there is something like 100 beds currently available on the Sunshine Coast. However, personal preference is a factor in whether or not those packages are actually taken up, so that does not mean to say that just because you have a package approval the place that you want to go to is available.

CHAIR: Thank you for that. One of the concerns I have is hearing that we are putting a burden on our public healthcare system of vulnerable aged-care patients who are waiting to go into a facility. I think you have just articulated why, and choice and waiting for the packages underpin that.

Ms Manton: I just reiterate what Alex said. We used to be able to directly deal with the providers and cobble together services. Particularly for patients under 65, that is very difficult. A good number of palliative patients do not fit the aged-care criteria, so they are not getting services at all. There is a transitional care program which we can access, but it is really putting a lot more strain back on to our services to try and get these things in place. The other thing is that, when the aged-care package is in place, there is a big variation as to what service providers are keeping as an administrative or a contingency cost. I think there should be some standardisation for that. As we know, people are desperate. If they have been waiting 12 months to get their package, they are going to accept whatever comes and there is a big variation in what aged-care providers are providing for that package money. Thank you.

Mr HUNT: Barbara, I want to touch briefly on what you said earlier about your experience in aged care and the hundreds of people who made requests to you to end their life. Going from that to legislating for this change, a lot of the legislation we are seeing around the world relates to a diagnosis of a terminal illness. I imagine that a lot of the people who have made requests to you over time are not necessarily diagnosed with a terminal illness and maybe are experiencing mobility issues, loneliness and some of those broader ageing issues and loss of ability to care for themselves. What is the breakdown when you talk about requests in aged care? Is that broadly the people who are making those requests or is it more the terminally ill who do not have long to live?

Ms Leadbetter: I used to manage Youngcare apartments in Brisbane. I do not know if anyone is familiar with Youngcare, but it is younger people with multiple sclerosis and motor neurone disease. They all have a terminal illness and none of them want to be there and watch it happen. That I suppose

started me on my journey of trying to action this issue, hearing people ask, 'Can you just help me die, please? I do not want to end up like that person over there.' The palliative care services are fantastic, so I am not denigrating any services here on the coast or anywhere in Australia; what I am denigrating is that there are not enough of them. A lot of palliative terminally ill people end up in nursing homes because there are no places for them elsewhere. There is also a large majority with the end stage of dementia. That is the cruellest disease known to men and women. As someone else mentioned, that is the other set of issues needed for dementia and care of dementia end stage.

Mr HUNT: Do you have any other broader comments to make in relation to where the boundaries should be within legislation and who should be able to access voluntary assisted dying, for example?

Ms Leadbetter: My personal view is that there needs to be a framework and investigation to look at best practice. People say, 'I have a choice of having care at home. The government has given me that choice, but the government will not give me a choice about where I choose to die, so I should have that choice with a regulatory framework.' There is plenty of research around the world. There is plenty of medical research for people who choose that. I am not saying that everybody with a terminal illness wants to do that, but there is a large percentage of people who do, in my experience as a registered nurse.

Mr HUNT: Dr Cooper, in relation to your comments about the percentage of people who want to die at home and those who are able to, what are the main barriers to that happening?

Dr Cooper: In delivering that care there are two aspects. There is the aspect of addressing people's symptoms and their comfort. That requires expertise from a GP point of view, and that skill level is very variable. There are other services that are required to deliver that comfort care, and that means linking in with specialist services, which are overburdened. That is where I think the role of people trying to coordinate care and support GPs, like nurse navigators and nurse practitioners, is really important.

The other aspect of care is meeting people's care needs in the home, and that requires, as has been indicated previously, a coordinated approach of both specialist palliative care nursing, like at Cittamani and Little Haven, and accessing generalist nursing like Blue Care. That is supplied through care packages, and we have discussed the limitations of that. It requires access to volunteers. It is all about supporting those family members. I guess the barriers are the availability and coordination of that care. Having worked on the Sunshine Coast as a GP I appreciate that all services are under strain, but the Sunshine Coast is a very fortunate place if people want to die at home because there are exceptional services, and that can be a model of care for other parts of Queensland where that does not exist.

Ms PEASE: I want to echo the chair's words in that I admire and congratulate you and thank you for the great work that you do in the community, caring across the sector. I want to go back to some of the figures that Dr Endacott was talking about with regard to the wait times for accessing packages. From my understanding, the figures that you gave apply to aged care. Do you have any figures on people being able to access palliative care that do not fit into the aged-care barrier?

Dr Welch: I think there is a difference in how the packages are used. For people over 65, our service will look at the aged-care packages to provide in-home care. We do not have funding to provide long-term in-home care. The funding that we have available through Queensland Health is very short term. We do sometimes assist our nursing communities to have a small amount of that funding, and the NGOs such as Cittamani and Little Haven have their own funding with which they help in the community as well.

Ms PEASE: Is that for people under 65?

Dr Welch: Under 65 there is no aged-care packaging. They do not fit NDIS because they have an illness, so we sometimes have to cobble services.

Ms PEASE: I understand that, but what I am wanting to understand is how people access palliative care services currently.

Dr Welch: They can be referred directly by their GP, other specialists, allied health, other hospitals or aged-care facilities.

Ms PEASE: Is there a wait time to access those services?

Dr Welch: Our benchmarking for community is usually seen within one month or less. If they are in hospital they are seen within 48 hours or less. That is by our service. To have care in the home our agreements in this district are that as soon as possible when a patient is discharged from hospital Caloundra

there is a nurse within 24 hours or 48 hours, depending on what the care needs are. For example, if we ring Little Haven or Cittamani or Blue Care and say, 'We have Mrs Bloggs here who wants to go home desperately today,' if they are available to take on a new patient today we will get equipment out today, nurses will see them this afternoon and hopefully that patient will go home and maybe die on the weekend, or it may be, 'They're okay. They can go home today, but please pick them up on Tuesday.'

To actually get care in most cases in this district is short term for palliative. It is the care needs on the day-to-day, personal care that we do not have that supports the family in the home. The specialist nurses, the specialist care that Little Haven, Cittamani, Blue Care and Anglicare provide in the community is not the issue; it is the day-to-day needs, the respite, the person who comes in and helps clean the house, who does the personal hygiene when the carers are exhausted, having a respite person there for six hours at night. This is what brings people into hospital, because the carers who are 85 or 45 are exhausted.

Ms PEASE: There are no packages to assist those people if they are 45?

Dr Welch: None whatsoever. There is nothing for people under 65. There are short-term packages through CHSP and transitional packages depending on what has happened. If someone has come in with abdominal pain, they are operated on, their tummy is full of cancer, they are terminal and they are going home to die over the next two weeks, we may be able to get a transition-to-home package for that short period of time. Again, our discharge nurses and our social workers spend hour upon hour upon hour trying to cobble together needs packages for these patients to go home and be supported, whether they are over or under 65.

Ms PEASE: Are the staff who work in the sector, particularly with the HHS, specialist palliative care staff? I know that we have the doctors, but what about your support staff, your nurses et cetera?

Dr Welch: We have highly qualified and experienced nurses in our palliative care unit and in SCUH. We have specific staff who would be, I suppose, special interest in Gympie and Maleny hospitals. We have our own social workers and psychologists who support the whole district, so if there are problems brewing elsewhere the other services will ring our service. Gympie Hospital or our community services may ask us for more help to support people in the community, so depending on needs.

Ms PEASE: In your opening statement you mentioned that the new service that you are developing is currently at 14 and looking at going up to 18 beds. From my interpretation of what you were saying, the increase in those levels of service is to keep less acute cases out of the acute hospitals so that they can stay in palliative care rather than taking up beds in a tertiary hospital, for example.

Dr Welch: To a certain extent, part of our role is to take dying patients who may need discharge planning. They get expert discharge planning and go home through our ward. It may be that they have very complex needs that cannot be managed at a residential facility or at home. It also may be just that they live down in this area and it is a better place for them to be, closer to home. That is our inpatient ward.

Dr Endacott: Louise is talking about a specialist palliative care unit. The specialist palliative care unit does not necessarily look after all end-of-life care needs on the Sunshine Coast, which goes to a number of things that have been raised earlier here. One of my concerns in particular is about unidentified end-of-life care needs and whether or not in the context of voluntary assisted dying we are not paying due attention to those unidentified needs. If we did, voluntary assisted dying may not be such an issue or have a heightened demand. For me, it reflects probably at a community level in broad terms what is called death literacy. It is people's understanding of what it is to die and what are the options available in terms of having your needs met.

CHAIR: I want to get the views of those delivering palliative care on voluntary assisted dying. I have read many submissions where people are very grateful for the palliative care given to loved ones who have suffered, but there are also some who say that there is a gap at the end, where people are lingering and suffering and they are on drips and not eating. I know that you answered this, but in the palliative care space do you have some of the clients asking or wishing to die, to access something to die?

Ms Moore: As I said, my experience is that it has been a very rare occurrence. I think it is happening more as the whole issue of voluntary euthanasia is more in the news. All I can say is that from my experience there is not a huge need. I guess the push is coming for it to happen and if it is going to happen then it needs to be done in a way where people have access to palliative care so

that they are not being forced by circumstance into that position and where there are very, very clear guidelines around it. Personally, I think if people feel they are a burden to their family there might be pressure on them to do it. I see the value that people have from caring for a loved one at home. It is a very positive experience for most people if they are well supported and they feel good that they have done it. It gives them a chance to go through a process around dying. That helps them then to go on. That abrupt end and that lack of a process for people worries me, but that is just my personal opinion.

Ms Manton: I think very often in our admission interviews we have people expressing that they would like the right to voluntary assisted dying because they want control of their end of life and they do not feel that they have that control. I think universally where there is the right to voluntary assisted dying only a small percentage of people take it up. More often we see people wanting to pursue very futile medical interventions, because human nature is such that they want to live, not die. I think people should have control if that gives them a sense of reassurance that they are not going to be left suffering. As people say, they would put an animal down in this case. Even your favourite pet you want to keep alive for as long as you possibly could. In my mother's own case, when she was hours away from dying and I said, 'Mum, I think the end is near. How are you going?,' she said, 'I don't want to die.' Generally, you are dealing with a situation where people are fighting to live, but I am all about people having the right to choose, the right to feel in control of their end of life. Providing we are giving good care, I think very often that is not something that they will reach for.

CHAIR: In relation to health literacy, I am reading that people are not informed or do not have advance care health planning. I know Queensland Health has a statement of choices. Could we do better to get people to plan not at an emotional time, when they have been diagnosed with a terminal illness? What are the views on getting our community to talk about end of life and having a plan or a structure well before being hit with a terminal illness? Can you give some quick views on that?

Dr Welch: May I offer a simple answer? How many people in this room have done their enduring power of attorney? That is the first question. Even in a public venue like this there are an awful lot of responsible adults who have not done their own care planning. If we do not start it as examples and lead by it then it is very hard for the general public to do it. We need that death literacy. We need to talk about it more openly and honestly. Two geriatricians and a palliative care specialist and an excellent GP with palliative experience will all tell you that when we open the conversations with our patients and families they are very grateful. It is hard. It is sad. It is teary. We peel a lot of onions in our outpatients and our wards. We have lots of tears. Inevitably, the families come back nearly always saying, 'That was hard but thank you. Now we have it sorted out. I didn't know Mum or Dad felt like that. It is such a relief to have that in place.' It becomes much better to have that discussion when it is not a crisis, as you mentioned. I think the emergency departments would reflect that as well. Within the Queensland health system there are processes now where if those discussions have been held it is available for the emergency departments to look on one part of the computer and they can tell immediately whether that family member has had discussions somewhere in the state. It is improving but we have a long way to go.

Prof. Wallis: I asked Louise's question to a room of health professionals about 10 years ago and myself and the dean of Sydney Medical School were the only two people to put up our hands. While there is a need for health literacy improvement in the general community about how you go about the legal processes of enduring powers of attorney and advance health directives et cetera, I think there is a huge need for education of our health professionals. There is some work by Colleen Cartwright, who surveyed health professionals and patients about this issue, and it is the health professionals who are more frightened about the conversation often, particularly junior health professionals, than the patients are. I think there is actually a need at all levels in our health professional education to include this issue.

Ms Manton: If you have an advance health directive that you want to remain at home to die, there are very few places in Australia where that may come about. We need to do better at that. I think paramedics—and this has been brought up previously—need access to the Viewer so that they can see those advance care plans. It is the same for our community providers, like Alex and I, who upload our advance care plans but we cannot see them once they have been uploaded. I would advocate for that being more accessible.

Dr Cooper: In terms of the advance care planning, I am referring to prior to that point of crisis. I think general practice is the prime environment in which that is best to occur. Most patients do establish some relationship over time with their GP and their GP has that rapport and insight to facilitate advance care planning. That is the ideal environment. I think there is some work that needs to be done to put that into practice. There is some reluctance amongst GPs to engage in that process,

and that is based on their comfort with the issue, on their communication skills and on issues surrounding remuneration. I think that is one issue to be looked at. I think there is a role for having advance care plan facilitators in the community to support that process. Trying to look at that in a very broad context rather than at the point of diagnosis I think is helpful.

Dr Endacott: I mentioned the term 'death literacy'. I guess like all forms of literacy it is a function of privilege. I would be concerned about communities and population groups that would have low death literacy. If we think about the documents that are available that you have mentioned, they are kind of in my mind the high school certificate of death literacy. Western Sydney University is currently doing some research projects around looking at population based death literacy, supported by John Rosenberg at QUT. He is one of the chief investigators. For me, that would be a good indicator at a population level about where to start directing resources to improve those sorts of things. The reason I think it is important is that the fundamental question patients need to be able to answer is: does the system that we run have their back?

Mr McARDLE: Professor Wallis, you spoke about a five-year study that you had been doing involving nurse practitioners. You called it a physician championed nurse within the ED of each hospital. Does the nurse practitioner model incorporate the use of the RN as well or does that replace the RN?

Prof. Wallis: No, the models that we looked at were, in the nursing home, a position of a nurse practitioner candidate who supported the RNs. The RNs and the care workers all continue to do their job, but they have this additional resource of the nurse practitioners. It is really hard for GPs to get to visit people in nursing homes. Their business model means that clinic based care is the best and most efficient way for them to deliver care. To leave the clinic and drive to a nursing home, where you might have only two or three clients, is not an efficient way of delivering care. If they can liaise with someone on site who could prescribe certain things and who could order tests, it reduces their need to visit but it has coordinated care.

In the emergency department, we have specialist gerontology nurses who would have a physician champion—so an ED physician but with an interest and expertise in the care of the older person. Again, this nurse led service is an additional support to the primary care team in the ED. That means that if they have a frail older person who needs additional focus, who needs more rapid decision-making, who needs someone to get them through the ED quickly to where they need to be, that frees up the primary nurses to look after the other seven patients they are looking after at a time. We found that, even out of hours, even out of the time of the specialist team, the GEDI team who are involved in ED, the care of older people improved across the whole system because they were assisting the teams with the more complex cases and so the care of everybody else improved as well.

Mr McARDLE: Would you argue that having the nurse practitioner model in the broad sense that you have just explained to us reduces the number of aged-care residents going to an ED and that those who go to an ED are there for a shorter period of time, given that the gerontology nurse physician within the ED is in place to assist?

Prof. Wallis: We could not show, because of the problems with the data, that we reduced transfers to hospital. However, logically, you would probably think that was happening. We did see a reduction in length of stay, definitely.

Mr McARDLE: What are the shortcomings that would assist you in the ED by way of data to come to a definitive statement about fewer people going to the ED? What do you need?

Prof. Wallis: That is the problem. It is not the ED data. We have the ED data; it is the data from the nursing home about how many patients were seen in the nursing home and how many patients were considered for transfer who did not then end up being transferred. It is really hard. We could not get access to that data because it just does not exist.

Dr Fawcett: I would like to make a comment about that model from the inpatient perspective. In the system where you have nursing staff doing comprehensive assessments on frail older people—and not just people from nursing homes but frailty in general—if that person did need to come into hospital—and the focus was trying to get that person back out of hospital with appropriate supports—we would have close relationships that meant that, because I was working within that team at the time, either myself, one of my junior staff members or our senior nurse could pop down to the emergency department and have a look at that person so that we could understand what their care needs were coming back into the ward and rapidly get that person out of the emergency department. For the frail elderly person, there are risks associated in staying in emergency departments for longer lengths of time. Their risk of delirium goes up, their risk of deconditioning, believe it or not, from just Caloundra

lying on hospital trolleys for hours on end, dehydration—all of these things—are far more compounded for that older person. The system helped people going back out into the community, which would always be the preferred option, but if that person did need to come into hospital then that process was smooth. I thought that was very valuable for those people.

Prof. Wallis: That model of care is currently being rolled out across 20 different EDs in Queensland by the current government.

Mr McARDLE: Can you advise if you have published a paper on your research?

Prof. Wallis: Yes, we have published multiple papers on this research. We published the findings particularly from the emergency department intervention at the end of last year. All the findings on that are available. The findings from the nursing home aspect are currently under review by a journal.

Mr McARDLE: Do we have the first paper with the committee?

Prof. Wallis: You probably do not.

Mr McARDLE: Could you forward that to us?

Prof. Wallis: I could send that to you.

Mr McARDLE: When do you think the second paper will be reviewed and published?

Prof. Wallis: I wish I knew the answer to that one. I am happy to send you a draft, if you would like to see that.

Mr McARDLE: We can use that internally in the committee?

Prof. Wallis: Yes.

Mr McARDLE: Am I right in assuming that in Western society we do not talk about death? We avoid the topic almost from birth to death. If we do not discuss death, we then face the problem that you mentioned, Sue, that when a patient comes to palliative care they have a very disjointed idea of what palliative care is, because they do not understand the journey of life to death. Is it important that people get a better understanding of palliative care as part of the decision to move to voluntary assisted dying? Is there a balance being struck between the two, or do we need to do a lot of work on palliative care and the issue of death so that people have an informed choice? I am not saying that one is right and one is wrong, but the sense I get is that there is an imbalance there. Would that be a comment that anybody would care to make a remark on?

Ms Leadbetter: I think you have hit the nail on the head. I think there is a lack of education about what good palliative care looks like. I appreciate all the work that the team at the end of this table put in—and the rest of the table—but there is no funding. A lot of people cannot access these wonderful services. In the meantime, the bulk of the people are falling through the cracks. I can get figures to the committee—and I will—on the number of people who are in residential aged-care facilities who could benefit so much more from having hospice services, and poor nursing staff, who are untrained and unskilled in the end-of-life process, are doing the best they can. I also question who is going to fund the health practitioner in the residential aged-care facilities, because the government presently does not even fund enough for some places for registered nurses, let alone a nurse practitioner. The funding models need to be looked at. That is one of the recommendations to the royal commission also.

Ms Manton: I think the real problem for Queensland Health—or for health in Australia—is that increased funding into palliative care is not changing the results of the number of patients who get to die at home in a supportive environment. That is really where we need to be focusing. How do we meet that outcome for patients to have support in the home, as they want?

Definitely, when we see the voluntary assisted dying videos on TV, or people talking about it, it is often people saying, 'I'm on my 80th bout of chemotherapy,' and you think you have some control around your end of life. If this is becoming too big a burden, we can look at just supportive treatments, or more qualitative treatments rather than things that are necessarily just quantitative.

CHAIR: I have one question on this issue of staffing and models. There is no doubt that workforce modelling is something that we need to look at in the aged-care space. In 2016 we mandated nurse-to-patient ratios in hospital settings. I am not saying that we are going to look at or put a recommendation forward about mandated ratios, but does anyone have a view of nurse- or staff-to-patient ratios for aged care? If we could land on a number, that would steer us in our report. What should we be looking at? Is it the prevention of falls? Is it the prevention of patient transfers because of incidents that are happening in aged-care facilities?

Dr Endacott: It would be very difficult for me to give you a number but, as some guiding principles, it is more than numbers; it is probably the skill mix as well—ensuring that there are clinical coaches, nurse educators—and creating incentives to look at the interface between the aged-care sector, primary care and the hospital system.

Although Marianne was not able to access the data, I can give you some data with regard to the Glenbrook Residential Aged Care Facility in terms of transfers. There are only 22 or thereabouts residential aged-care beds at Glenbrook but, for what it is worth, in the last 12 months there were only three transfers to hospital, only one of which was admitted, and they were all for falls. There were six deaths and all of them were provided with end-of-life care in their residence.

CHAIR: What was that facility?

Dr Endacott: Glenbrook. Glenbrook is the aged-care facility that Queensland Health runs on the Sunshine Coast. The point is that there are other models of care that are within that facility that, like Marianne was saying, I think lift the overall level of care that may not be available to private providers that run an aged-care facility.

CHAIR: That is a Queensland Health facility?

Dr Endacott: Yes.

CHAIR: What are the bed numbers in there and your staffing?

Dr Endacott: I think it is approximately 22 permanent beds, but it also runs the residential transition care program and a small number of mental health beds, which is separate from aged care.

CHAIR: How many nurses would you have on that ward with the 22 beds? You can take that on notice.

Dr Endacott: Yes, I think I might take it on notice.

Mr McARDLE: Could you give us the ratio, too?

Dr Endacott: The ratios are relatively favourable compared to other facilities. I have the specific numbers here, but it is very—

CHAIR: I only asked that question because we have been to facilities. There was one private facility that had one nurse to 50 or 60 residents.

Dr Endacott: No, nothing like that.

CHAIR: One was 125—in a private facility on a night shift.

Dr Endacott: My concern would be the skill mix as well as the other things.

Mr McARDLE: I want to go back and reverse the question that I posed. I posed a question about palliative care. Those who support voluntary assisted dying will argue that there are always going to be a number of people for whom palliative care will simply not assist. They get to a point that, whatever palliative care is provided, that is not going to ease the suffering and the pain. Does the panel accept that as a statement, because we will hear that?

Dr Endacott: Yes, I personally accept that. As a clinician and someone involved in the administration of a health system, my concern would be around the processes that lead to appropriately identifying those people and making sure that we are not inappropriately including people who would otherwise access palliative care and not get to the point of wanting voluntary assisted dying as well as supporting those people who are appropriate for that and ensuring that they access it in a timely manner.

Dr Welch: We always say to our patients that we never promise that we will completely relieve suffering in all cases—that would be quite unwise—but we tell our patients that we will try our hardest. Yes, there are always very few—not many, but very few—who will persist in their request to have their life ended. That will always be the case, I believe. I agree with John: we must protect those people who may be wavering between one or the other because of an unmet need, but there will always be those people for whom, for whatever needs, their suffering is not met by anybody or anything.

Mr McARDLE: I have one very quick question on that exact point. Could we just remove who you work for and look at your medical qualifications? Does the panel want to make a comment on this: if the question of voluntary assisted dying was to form part of the committee's recommendations or commentary, is there a model in relation to how that should be looked at? If you do not want to do it, by all means just say no. I am not asking you to make a comment in relation to who you work for

but as a medical specialist. If you are keen to then by all means do it, but if you do not want to then please do not do so. Because you are here today and given we have agreed that there is a gap there, is there something that this committee should look at?

Dr Endacott: It is not a direct answer to your question but more as a geriatrician. The issue of dementia has been brought up a couple of times here. It is around decision-making capacity. I think that, almost by logic, the patients with dementia are likely to be excluded from a voluntary assisted dying system. Regardless of what their statements are about their wishes, I would suspect that their decision-making capacity to make that decision would be deemed inadequate at the time of the request, and I would be very, very hesitant about whether or not an advance health directive would reasonably cover this topic.

Mr McARDLE: And good luck to the doctor, too.

CHAIR: Thank you very much. I thank the entire panel. We all leave here a bit more informed from your expertise about the care you provide in the communities to your patients. We thank you very much for your information, submissions and the feedback you have provided us today. It is invaluable for our work going forward. Before we take a break, I ask that we give these folk a round of applause.

Proceedings suspended from 12.06 pm to 12.16 pm.

BARKER, Mr Kevin, Private capacity

BOX, Mrs Veronica, Private capacity

BRIGHT, Mr Marc, Private capacity

CRAWFORD, Mr Philip, Private capacity

HALL, Ms Gillian, Private capacity

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

Ms Hall: I am the lead for Compassionate Communities on the Sunshine Coast. I am a community development practitioner who has been actively working in the community where I live for four years. We thank you for the opportunity to be here today. We are concerned that people in communities have been forgotten about on a topic that is often overlooked and/or stigmatised—ageing, caring, death, dying and grieving—and the related social problems, such as social isolation and loneliness. Since the launch of Compassionate Communities in this region in October 2018—

CHAIR: Ms Hall, I will pause you for a moment. Sir, we cannot film these proceedings.

Mr Bright: Okay. Sorry.

CHAIR: Please continue, Ms Hall.

Ms Hall: We continue to meet regularly and are demonstrating that there is an unmet community need we are addressing that is much bigger than we expected. People want to get together in engaging, interactive, fun ways with people of all ages and abilities and have said they will not come along to formal meetings. They want to be involved in robust discussions and contribute their ideas, stories and experiences about ageing, end of life, death and dying, to debate things like the language used and to share their frustration about the lack of information about death, dying, grieving and living well. Importantly, people want to take action and work on things that matter to them.

At our workshop in April a hot topic was planning. When the statement of choices document was raised, some people had no knowledge of the different documents and it can be confusing. Last year COTA, the Council on the Ageing, was promoting enduring power of attorney sealed packs while at the same time the local PHN, primary health network, was promoting advance care planning. Comments were made by attendees that, unless you have a good advocate, most of the documents are not helpful anyway when a person is in crisis and presents at the hospital emergency department. Sadly, representatives from services were not present to hear this and do not attend our monthly workshops. At our launch in October 2018 some did attend and it was a PD day for others—professional development.

A measure of community impact is successive network mapping exercises. The first map we created was in October 2018 and we revealed there are lots of community and health services in this region. However, most have a weak or no relationship with each other and people from communities did not add themselves on to the network map at all. This exercise has been repeated on two more occasions, as recently as this week, and there are changes. Compassionate Communities Sunshine Coast has a cluster of people with strong connections who also added their main interests, but that was not in the instructions. This is promising and suggests that capacity-building caring relationships are starting to emerge.

Relationships between community groups continue to grow and strengthen. However, there is no improvement with relationships with services and peak bodies that are our community advocates. Also, it is unclear what services provide and the scope of advocacy organisations to expose the gaps that we need to address. A comment from a group member was that people living with life-limiting, life-threatening conditions flounder and get tossed around from one department to another and that there needs to be clarity on who and where can support them.

The issues of access to information and resources for people with disabilities about death, dying and grieving are often raised. We were able to provide access to a webinar and some relevant resources thanks to the GroundSwell Project and our connection with the caring end-of-life team at Western Sydney University. We have projects ready to go and university and community groups ready to collaborate to improve death literacy, to change the views on death and dying, to create and celebrate choices about the type of end that encourages community ownership and caring and the planning required to achieve their vision. We can do this, but funding is holding us back. Innovation Caloundra

in how services are delivered is needed to respond to the challenges of growth and sustainability, and this requires a new approach. Instead of treating people as passive consumers, government and organisations should collaborate openly with us in this innovation process.

CHAIR: Ms Hall, I might just ask you to pause there in the interests of time. Thank you very much. You have given an excellent submission with the three recommendations that I can see here, but we need to move to the others.

Mr Bright: I am from Sunshine Coast Compassionate Communities as a private person. I watched my father die and my mother, who is 88, be involved with care. Her process is now close to my heart. Amongst my other involvement in the community, I have been a community engagement person working with youth, youth suicide and youth programs with all abilities and disabilities for maybe 25 years now and watched so many things happen with people in their truth in their heart and a sense of what they feel. This is a strong memory for me and it invokes lots of emotion. In the process of feeling the community and its needs referred back to me by various community story-harvesting events that I have been privy to whilst filming and taking notes and listening very carefully, I have been drawn to the group that is represented here with Gillian at the lead to show that there are options, to show that there are other possibilities that include everyone. It is inclusiveness that I sense is on the change, on the grow, on the wind. There is a new thing afoot and we are all part of this and I am excited to be sharing that kind of energy today. Thank you.

Mr Crawford: I am a banana farmer from Hunchy. I am a friend, EPA and carer of Mr Edward Alfred Ehm and this is concerning home care service providers. We both live at the same address. Six years ago I started a plan for Eddie's older age. Eddie sorted out his advance health directive and all of his funeral plans. We cleaned up the corner of our property. In 2013 Eddie helped me to build a banana stand to be able to sell all our produce from our own farm so I could be close to Eddie if he needed any assistance as he was getting older. I did not have to do any markets anymore. Now Eddie is older, I have put in place measures with Veterans' Home Care—he is a gold card holder with DVA—to come and do some cleaning. This started at the beginning of 2016. At this point Eddie was still cooking his own meals, right up until March 2018. When Eddie started to need more assistance, I employed some schoolkids and uni students to look after the farm so I could attend to Eddie 24 hours a day if necessary. Even though he is blind and has had some hearing loss, he is still capable of advocating for himself and getting himself a glass of water. He is still capable of good conversations.

I had an incident where I split my toes apart and I needed more care, so I got some respite hours from Veterans' Home Care. I engaged them to make meals for Eddie. I will not mention the service provider's name—you can ask me later if you wish—and I will not mention the names of the people involved either. I engaged them for three weeks to give my injury time to get better. Unfortunately, I disengaged integratedliving and I had to re-engage them as the infection came back. They were not being consistent with staff. There was always an hour time difference between their head office in New South Wales and Queensland which caused communication difficulties. On one occasion Eddie had a slight fall and grazed his knee. I had taken him to the doctor. An occupational therapist came out who had seen Eddie on a regular basis and had handrails in the shower put in place in Eddie's house and upstairs in my spare bedroom where Eddie could come because it was fully air conditioned.

One of the newer ladies noticed a scab on Eddie's leg and reported it to head office. I then got a call from integratedliving from a lady from Maitland in New South Wales who had never met Eddie before. She started to tell me how to do my job—I should take Eddie to the doctor, I should get handrails, I should do this, I should do that. I said to this lady, 'Excuse me, but who are you to tell me how to do my job?' Eddie is like my dad and I have cared for him very well. I had taken him to the doctor already and I had handrails put in place. I said to her, 'You are a third party employed to do cleaning and meals and I don't believe you should be telling me how to talk to my friend. I would like to talk to the supervisor, please, about this matter.' I talked to three different supervisors to try to explain to them that they are a third party and if there was a problem with Eddie I would appreciate being made aware first. Eddie has put me in charge of looking after his affairs, health matters and his life. If any decision about Eddie's health is to be made, I am to be consulted first. If any ambulances are needed to be called, I said that I would appreciate being notified first. After speaking to the last supervisor, I found out that she left text messages to the staff saying that in effect if Mr Ehm had an injury to call the case managers and not to notify the carer—me. I was very distraught and concerned about this. I complained to management. As far as I know, the text messages are still on the lady's phone today.

CHAIR: Mr Crawford, we might come back to you on that, because I can see you have had to take your friend to QCAT at 98 years of age.

Mr Crawford: Yes.

CHAIR: We will come back to you, but thank you for giving us that information. I have your submission here and we will move to—

Mr Crawford: That is the most important part.

CHAIR: Yes. Thank you very much.

Mr Barker: I do not represent anyone but myself here. My comments today are about my own experience. In 1972 I came back to the coast and joined a medical practice at Maroochydore. Part of that job was to be an assistant to the police, and I held that job for 35 years. During this time, as you will appreciate, it was a farming district and every farmer had a gun, a car and a lot of poisonous stuff and this was the way some people—not many, thank God—would end their life. This was very traumatic for their loved ones—very. Eventually, things went on and a lot of the carers and family used to get very angry and very guilty that they did not recognise that this problem was going on and the way these people died was very obscene. Things changed and there were more and more doctors and a thousand times more people coming to the coast, and then we had the AIDS epidemic. We once had a cremation building or crematorium. One of my jobs was to examine people before they were cremated. I found that, once AIDS came, there were a number of people that I considered were doctor assisted suicides. It was absolutely different between the way they died and the way I had seen other people die. I held that job for 35 years and then I left and travelled around working in Aboriginal and Islander communities.

I worked in many nursing homes around Australia. Every nursing home had a lot of people in them who said to me personally that they would rather be dead. Because of the situation, they could still be there for all I know, because some people with multiple injuries or multiple illnesses can live for a long time. I would like to see voluntary assisted dying become legal in Queensland and I strongly support the idea.

Mrs Box: I wish to address the availability of palliative care in Queensland. I am the president of Catholic Women's League Queensland and represent 700 members from the Gold Coast to Townsville, Mount Isa and Roma. Our members are concerned about the availability of palliative care services. Personally, I have had very good experience of palliative care, caring for my husband here on the Sunshine Coast and sharing the care of my sister in inner-city Brisbane in their end-of-life phase because of terminal cancer. In my husband's case 12 years ago, I was so impressed with the care provided by palliative care at Caloundra Hospital and Dove Cottage that I wrote to the premier of the day, the Hon. Anna Bligh, extolling the excellence of the service.

Family were involved all along the way, from when I was taught by the famous Dr Fabio to administer injections and medication at home to when increasing pain necessitated his admission to the palliative care ward at Caloundra where everyone—from the specialist doctors and nurses to the cleaners and the ladies who delivered the meals—was dedicated to the welfare of its patients. It was truly a culture of compassion and care. His last days in Dove Cottage, which provided accommodation for me alongside him, remain a positive memory for our family. This was not a pain-free time, but the pain was meticulously managed and bearable. Family and our priest were able to visit at any time. My husband was able to spend time alone with each of his five children and with several grandchildren which gave him great joy. He told them that he would soon be dying but that he was not afraid.

The Premier did answer my letter and thanked me. She also informed me that the unit in Caloundra was to be enlarged. I think that happened in 2008. From what Dr Louise has told us today, I think Caloundra is still doing pretty well.

CHAIR: They have a good local member.

Mrs Box: I will not detail my sister's end-of-life time, except to say that the experience five years ago with St Vincent's Care Services in Brisbane was similar to that with my husband.

Before we made our written submission to this panel, we did a survey of our members throughout the state. Unfortunately, that tells a very different story from mine. In regional and remote areas it is very difficult to arrange palliative care. In many or most areas away from the major cities there is no direct access to specialist palliative care. When it is available there is serious understaffing. There are not enough resources and no beds available when required.

On a tour of our branches in the Mary-Burnett area, when I made our written submission available to the members for comment, palliative care was the main topic of conversation. I heard many stories of loved ones being unable to access palliative care. Often they had to remain in a nursing home or be admitted to a public ward if there was a bed available. I have been told that staff in nursing homes were not qualified to attend to their needs and families felt unwelcome when they

tried to help or intervene. If a bed could be found it was often far from home so that the ageing spouse often had to find accommodation, which could be quite expensive. State and federal governments must show, by more funding for resources, that Australians in the bush are just as entitled to good palliative care as those in the cities.

Although we do not agree with it, we do feel compassion for those who feel that VAD is the only option when pain becomes unbearable. Whether patients live in Chermside or Cunnamulla, Ascot or Augathella, red tape involving NDIS, My Aged Care, and Queensland Community Care—and I did not know that this was happening—must be cut so that they are able to more easily access a palliative care team with doctors, oncologists and GPs working with carers to ensure terminally ill patients receive the very best of care in their final days. Thank you for the opportunity to speak. I wish you very well in your deliberations.

CHAIR: I represent Townsville and that region. The seven funded organisations that I have identified and the Queensland Health representatives that I have had discussions with, or this committee has, are all based in South-East Queensland. In my mind, there is an absolute need going forward for more services for specialist palliative care. Mrs Box, for members of the audience can you define specialist palliative care versus palliative care?

Mrs Box: What I experienced at Caloundra where Dr Fabio, who probably retired long ago—he has not retired? As far as I knew, he was a specialist palliative care doctor, whereas in the bush there are not those people, I do not think. People try to provide palliative care. I am sorry, I did not answer that very well.

CHAIR: That is fine. Mr Crawford, it was disturbing to read in your submission that your friend Eddie, a 98-year-old, had to go to QCAT.

Mr Crawford: That is correct.

CHAIR: Why?

Mr Crawford: Could I continue reading my statement?

CHAIR: If you could provide an answer then we will open it up to others. How much more of your statement is there to go?

Mr Crawford: There are just two pages left.

CHAIR: Maybe that will answer the question?

Mr Crawford: Yes, it will. Eddie has been assessed for a level 4. He has received funding for a level 3 from My Aged Care. DVA services were finishing for the financial year on Sunday, 16 December. I tried to organise a service provider to put a package in place by 17 December. A customer relations manager visited us on three occasions. She met Eddie for a total of about 20 minutes. She rushed to put things in place before Christmas. She told me that it would start on 19 December and I would be covered for the 17th and 18th.

On Monday, 17 December nobody came to cook a meal. I complained. No-one would answer their phone. I left a message saying that I would change the package and get another service provider if they could not get their act together. That opened up a can of worms. I never got to speak to this lady again. She called the ambulance and police on 21 December and tried to take Eddie away. They said it was duty of care. The ambulance found that there was nothing wrong with Eddie. They questioned why they were there. She then reported a lot of lies and accusations to the elder abuse hotline. None of them were proven to be true.

On 2 January 2019 I received an order from QCAT, the Queensland Civil and Administrative Tribunal, that my power of attorney was to be suspended and the Public Guardian was to take over on 9 January. The customer relations manager was trying to take all of my powers away and put Eddie in a home. Life was made very stressful and hard for four months. The Public Guardian that was to look after us could not get their act together. The left hand did not know what the right hand was doing.

The new service provider has still not started. I have had to look after Eddie all of the time since Christmas. Now I have a full-blown hernia and I am still recovering from a quadruple bypass that I had not quite two years ago. I have been doing everything for Eddie. I had help from the Aged Care Quality and Safety Commission. Lisa Wadham has been marvellous. She has received and passed on three letters of apology but they were considered very poor. The ACCC is still investigating. The people from Aged Care Advocacy are really nice. Annette Awoski helped us a great deal and represented Eddie and me.

On 2 April I had to take Eddie, a 98-year-old, to the tribunal where we are guilty before proven innocent, with no evidence whatsoever and a lady only knowing us for 20 minutes. She did not even ask any of the staff who came to visit us what went on. I have some beautiful letters here from some of the staff about my assistance to Eddie. The accusations and lies that the customer relations manager told QCAT in order to put this in place, when she did not know us, need to be looked into so that this does not happen to someone else. When you look at all of the evidence, this person has done this out of spite and has tried to cause maximum stress and discomfort to me and Eddie.

CHAIR: Have the QCAT proceedings been finalised?

Mr Crawford: Yes. The member basically said, 'Why are you here?' The lawyer from the service provider felt very embarrassed. She retracted all of the accusations and the case was all dismissed. It was a waste of public money, as was the ambulance being called. This lady still works for this company. They knew that I had had heart attacks, shoulder operations and things like that. They did not care.

CHAIR: Thank you, Mr Crawford. Thank you for sharing that.

Mr Crawford: You are welcome.

CHAIR: I acknowledge the member for Bancroft, Chris Whiting MP. Thank you for coming along today. Mr Barker, as a former government medical officer, were the suicides that you talked about in relation to terminal illness?

Mr Barker: Some were in relation to terminal illness but not all. Some of them were people who were depressed or had motor neurone disease or early cancer. When AIDS came to the area it was a terminal illness, as you remember. We had the grim reaper. People acknowledged that they were going to die and they wanted to shorten their time to die, I imagine.

CHAIR: Gillian and Marc, thank you for your submission. The recommendations talk about collaboration between PHNs and HHSs and the state. You mentioned in your opening statement that there were two—I did not write it down quick enough. The PHN was promoting advance care packages—no, advance health directives.

Ms Hall: There was a package with COTA which was about the enduring power of attorney and the PHN were promoting advance care planning, and neither knew what the other was doing at that time.

CHAIR: So better collaboration is needed?

Ms Hall: Yes.

Mr HUNT: Mrs Box, thank you for your submission and for providing a stark contrast between what can be very good palliative care and what the challenges are as you move further away from densely populated areas. Often people are saying to us that they need more resources, more funding and proper funding, but in a state as big as Queensland—and as you get out of the populated areas distances between people get quite large—what do we do with that extra funding? What does a model of care look like that provides good palliative care, as you described, to people in remote areas?

Mrs Box: I do not think I am qualified to say what it is. When someone in Childers, which is not terribly far away from anywhere, fights for resources but then I also spoke to people in Mundubbera, and that is a good way away from anywhere—even Gayndah, their nearest big town, is not very big and probably the hospital is not very big. I really do not know what it is. Whether you need a flying squad of palliative care, I do not know. I think it needs to involve doctors, oncologists and GPs. GPs are really the starting point. When I think about how easy it was for me—my husband had his operation; he knew he was terminal; he went to the GP; he rang Fabio; the next week we had the conversation with Fabio and everything was in place. I understand that that does not happen now. That was 12 years ago and how far back we seem to have gone. I did not know that all of these things like the NDIS, My Aged Care and Queensland Community Care were involved in getting your package, but that is the way it is now. I am sorry I did not answer your question properly.

Mr HUNT: That is okay. The difficulty is that it is not an easy answer, is it?

Mrs Box: No, and I know it is not easy.

Mr HUNT: Thank you for your insights and the contrasts you provided in those examples.

Ms PEASE: Thank you very much for coming and sharing your experiences with us. It is really important that we get to hear from everyone so that we can have a very good understanding. One of the things that I am hearing from everyone is that it is about choices. Veronica, you have just said that what happens in one place might not necessarily be the right fit for everyone. Therefore, it is

about the ability to have a choice—and we are talking about palliative care and end-of-life care but we are also talking about voluntary assisted dying. I note your comments, Veronica, that, whilst you and your organisation do not necessarily support VAD, you are compassionate to those people and understand the position that those people might have. Kevin, thank you for sharing your experiences as a government medical officer. In your time when you were practising, did you ever come across the advance health directive and access to those sorts of documents?

Mr Barker: Yes, I did. They are fairly recent. It was probably only 20 years ago when they first started. They are a great idea, but they are still lacking when it comes to dying. I am in a men's shed and we discuss things. We all know that we are dying, but it is the way we die that worries us.

Ms PEASE: That leads me to the next point I would like to make. Would anyone like to comment on health literacy or death literacy? The people who were here before would have heard the conversations around those two things. I guess it is about education and letting the community know how to access the myriad different services. Veronica, you said how difficult that is. The two things are the literacy issue and accessing the services.

Mr Barker: The attitude of people is changing, which is exemplified by our meeting here today. Also, once upon a time when you went to a funeral, everyone would wear black and you would cry and you would weep. Nowadays, at the funerals I have been to, you go along and you can wear colours, and they celebrate the life of the person. It is a totally different mental attitude to mourning the death. I think the people I know and we all know are changing their attitudes to dying and death.

Mr Bright: Regarding literacy, one of our passions is to harvest conversations and listen a lot. We talk to a lot of people and record them for a documentary we are doing called *The Last Breath*. One of the other aspects of that is if they wish they can come along to a Dying to Know Day and participate in our dying to celebrate aspect of it. This has been brought home to me by everybody I have spoken to, just like the speaker before mentioned. They want to celebrate life as fully as they can right to the time just before they die. That was my experience with my father and many other young ones I have met. As much as they were under all sorts of medications and in various states—delirium, whatever you want to call all those situations just before death—they wanted to enjoy their time and they had a sense of humour. It is a bit like the Australian way with humour. There is a humorous way about death. It has been talked about in army situations and war and things like that where they have a black humour. It is actually the Australian way which puts a different approach to it. They like to talk of that. Those stories provided to me—and I imagine to a lot of the carers and people involved with it—offer a balance or a perspective over our condition as humans and their experience of death.

Ms PEASE: Philip, I am sorry about the experiences you have had with regard to your friend. I hope that things are being resolved. You would have been one of the people who put their hand up who had an enduring power of attorney, so that was a good step. Have you spoken about an advance health directive or a statement of choices for Eddie?

Mr Crawford: We have had one in place for the last six or seven years. We have had all of that in place.

Ms Hall: I would like to speak about death literacy. Compassionate Communities has the GroundSwell Project. That is a national organisation and that is really what they are trying to do—that is, improve death literacy so that everybody knows what to do in caring, dying and so on. We see there is a great gap. There is a lot to be done in that sort of space. We find it confusing. Palliative Care Queensland and people like that are trying to do the best they can, but we read things that say 'education' and 'community capacity building' but, to be honest, we do not see them here. I think they are coming up here next month. Since we have begun, we have not met. There has not been one conversation.

As part of the National Compassionate Communities Practice Forum that we are a part of with Western Sydney University, we have access to the death literacy index. Dr John Endacott from the previous panel did mention that. We would like to be able to get a big sample from the Sunshine Coast to actually understand where we are at with death literacy so we can make better use of resources and our different roles and responsibilities in that area. At the moment, we are fighting pretty hard just to get money to have a website, just to be able to put together a communication strategy to roll that out. We have networks in place so that we can make sure we can reach lots of people. We just practically at the moment cannot do that. That index can only be used by the eight GroundBreaker communities in Australia at this time, so that is an opportunity we have to do something constructive about death literacy.

Mr McARDLE: Thank you for your time here today. Mrs Box, Fabio is alive and well and doing some wonderful work in private practice. He was indeed and is a wonderful doctor and did a lot of great work at the hospital. Mr Barker, you made comment that in your 25 or 35 years—I apologise; I cannot recall exactly—you saw a number of assisted suicides. Can you put a figure on it?

Mr Barker: No, I cannot. It was a small number. It certainly was not usual, but for a number of years after they built a crematorium at Buderim I would have to see everyone who got cremated.

Mr McARDLE: Would I be right in saying that, when you say you saw the outcome of the assisted suicide, it was a medical assumption you made to come to that?

Mr Barker: Indeed, yes.

Mr McARDLE: You are all here about palliative care and the necessity to expand upon that and educate the public. Would anybody here care to express a view on voluntary assisted dying? If not, that is fine.

Mr Barker: I am quite comfortable with that. I feel that this will be allowable in Queensland, maybe not in my lifetime, and I would like to see it decriminalised. At the moment it is still a crime—from my understanding; it was the last time I looked—but I would like to see it decriminalised.

Ms Hall: Compassionate Communities does not have a position. However, we just need to do it all better anyway, so I take on board the comments that were made by the previous panel and people like Alex Moore from Cittamani, which is our local hospice. Until we do a whole lot of things a whole lot better, I do not actually know that that is where we want to be right at this time.

Mr Bright: That has been the subject of the same inquiry I have done with everybody I possibly could in the last three or four years now, interviewing and harvesting questions. That is going to be the subject in our *The Last Breath* movie about the percentages of people saying they would prefer dying than living at a certain time and when that was in relation to how they felt. There are some really deep, amazingly powerful interviews.

Mr Crawford: Eddie has been a member of Dying with Dignity for 20-odd years. We have met Philip Nitschke on several occasions and find him a very caring person. When you hear a lot of the stories that are generated about someone's spouse dying really nastily and in a lot of pain, then assisted dying could be brought in to save a lot of suffering with their families and the person involved. I think it is a great idea.

Mr McARDLE: If we accept voluntary assisted dying as a topic that we have to deal with and we have to come to a conclusion on, and if this committee comes down and says there is evidence to support a model in the community, we then come to the model and there are a myriad models. There is the gentleman who left for Switzerland at 104 years of age. I understand he did not have an illness and he was not in incredible pain. You have that particular model. You have the model whereby you are in excruciating pain, or words to that effect, which is the Victorian model and is quite restrictive. Does anybody have an idea of what the model should look like if we start to debate that? The committee will have to address that question in some manner.

Mr Barker: Do I have any understanding of what it should be? No, I do not. I will leave it up to you and the others who sit in parliament to fiddle it out and work it out. It will be impossible to get any sort of a ruling that appeals to everyone. It will either be too severe or not severe enough. I think the public is heading in that direction and I think the very fact that we have a meeting here today means that the politicians are coming that way too. If you ask me what the regulations should be, I really have no idea. It is too complicated for my simple brain to work that out.

Mr Crawford: Each case should be assessed on its own merit and individually looked at. I think that would be the fairest way.

Ms Hall: With trust at an all-time low with public institutions, I just wonder whether it is the time to be actually talking about that at this particular moment, particularly when we have so much more to do to improve death literacy and things around death and dying. I think if we can rebuild some of the trust in our public institutions and get a few other things working right, perhaps this could be a conversation for a later time. It is actually something we should not be deciding until we have fixed up some of the things we know quite clearly are not working.

Mr McARDLE: Ms Hall, can I ask you this question then. Given your last commentary, do you think we are not at a point—I mean this respectfully—of maturity to have that debate?

Ms Hall: That is an interesting question. I do not think we have actually had a conversation that involves all stakeholders. I think community definitely has not been involved in this. There have been assumptions made about community. We have been viewed as passive recipients of services for so long and now we actually have to try to shift that and change that. As for 'mature', maybe we just need to be evolving and looking at doing things differently.

CHAIR: Thank you to the panellists for your time today.

JACKSON, Mr Neil, Private capacity

NORRISH, Ms Linese, Private capacity

SAUER, Mrs Denise, Private capacity

SMITH, Mr Brian, Private capacity

WRIGHT, Mr Ron, Private capacity

CHAIR: We welcome to the table our next panel. Thank you all for being here today. We will continue with the same format. I ask you to make an opening statement limited to about four minutes so we can go to questions. We will start with Mr Brian Smith.

Mr Smith: I am speaking as a private person from Maroochydore in Queensland. I will somewhat change the beginning. I would like to ask each and every one of you, lady and gentlemen: if I could guarantee you a 70 to 80 per cent primary vote at the next election, would you be happy?

CHAIR: We will keep politics out of it.

Mr Smith: I would like an answer, please.

CHAIR: Our questions will be to you.

Mr McARDLE: Mr Smith, with all due respect, this is our inquiry. We would ask you—

Mr Smith: It is not a trap question.

Mr McARDLE: No, it is not a trap question.

Mr Smith: I do not want a politician's answer.

Mr McARDLE: Correct.

Mr Smith: I would like a person's answer.

Mr McARDLE: So you cannot ask me. I am a politician.

Mr Smith: That is right.

Mr McARDLE: Please, just make an opening address. We are trying to learn from you what you want to achieve.

Mr Smith: Every survey that I have seen over the past 20 years in Australia asking about voluntary assisted death has had 72 to 80 per cent in favour of. I cannot understand that in South Australia and Victoria recently, with those same statistics, going to the top of their lawmaking facility in the Senate and the upper houses, how it comes down to one and two politicians deciding what is happening. We expect that our politicians, if they had an 80 per cent majority on building a railway line or whatever, would carry through on it. This does not seem to be reaching the situation.

The reason I am so strongly in favour of this is that I watched my mother die an excruciating death from cancer—absolutely terrible. A very kind doctor in a hospital assisted her to go at the finish after months of agonising. We had to go and visit her and sit there for two hours waiting for her to come out of a coma from the injections. I watched that. I also watched my father die a similar death from cancer and in agony. He was in a nursing home. They tried to treat him there and he was just in tears the last time I saw him. I had to travel to Victoria to see it.

My brother has a terminal cancer diagnosis at the moment. He is in remission, thank God. I recently visited a friend for the last time in Brisbane. He had pancreatic cancer. I had a conversation with him some months before he got critical. He said to me—and I am not bringing religion into this for any spiteful reason; he is a Catholic—'Brian, what would you do if it got too bad?' I said, 'I know what I would do. The simple way out is to take your car, hook a pipe on the exhaust and go to sleep. That is less traumatic for anyone who has to find you.'

I say this because I spent many years as a policeman. I went to many shocking deaths. Some suicides I would not even try to describe in front of mixed company here today. In my experience, for the relatives who remain, including parents of a 12-year-old boy who shot himself with a rifle—a suicide—quite a few in those days were pretty sick. I believe that is the reason they did it. I am sure there were many relatives who helped those people suicide because of that.

I had another friend in the caravan park at Maroochydore. I nursed him for a month. The nurses would come in. They decided that he perhaps should go to hospital, against his wishes. He said, 'Brian, don't leave me.' He was terrified. He went to the hospital. I was on my way up and I got a call

that they had taken him to the two little cottages down here at Caloundra Hospital. I was there when he arrived, luckily. He grabbed my hand and nearly broke it. He said, 'Brian, I'm scared. Don't go, please. Stay with me.' They put him in a room. I went into his room. A nurse came up to me and said, 'Brian, say your goodbyes to Eric.' I said, 'What are you talking about?' He said, 'We're going to give him an injection. He'll be unconscious and he won't be back again.' I nearly fell off the bloody chair. I could not believe that. I sat with him for two days and two nights holding his hand, listening to his labouring breath until his son came down from North Queensland.

That, to me, summed up palliative care. I am afraid that smelly flowers and pretty music is not palliative care as far as I know it. I could go on. I will keep it short, because you are well over time—I am aware of that. I am so far in favour of assisted death it is not funny. I have seen it. I have broken my heart over it. I have sat with relatives over it. People will not face it. They think that palliative care is fine to a stage, but when you are writhing in agony, screaming in pain, there is only one way and that is where they inject you to unconsciousness. To be very short and to the point, I wish you had answered my question. I would have loved to see your face—

CHAIR: Thank you very much, Mr Smith.

Ms Norrish: I am the chapter leader for Exit International on the Sunshine Coast. It is a voluntary role that I have held for eight years. I work with the previous chapter leader, Bron Norman, who is sitting over there. We work together. We hold meetings and they are very well attended. Our members love to come. Bron and I often will visit a new member who is unable to attend one of our meetings and we will speak to them, offer comfort and give information.

During my eight years in this role, many members have chosen to end their lives, not by hanging or jumping in front of a train—although one woman did jump from a high-rise Brisbane building. Not all had a terminal disease but were suffering to the extent that they no longer had what they considered to be quality of life. Being consigned to a nursing home was not and is not an option. They consider this to be a fate worse than death.

Our requirement from our elected representatives is access to an Nembutal prescription known to us as the peaceful pill, although it is not a pill, to be ingested at a time of our choosing and also for terminal patients to be given an injection, should they require it, of what is given to animals to end their suffering. We understand that not all medical practitioners would participate in this practice, but there are some who would.

We respect those who choose to receive palliative care and the wonderful palliative carers whom we have heard from this morning, but that is not how my members wish to spend their last days. The people I have known in my eight years—many of whom have departed—in meetings are strong-minded individuals of full cerebral capacity. Therefore, unless we are run down by that proverbial bus, we ask for the right to leave this overcrowded and climatically challenged planet when we decide that, for us, enough is enough. Thank you.

Mrs Sauer: I live at Mooloolaba. I am here with a personal story but also as the coordinator of Dying With Dignity Queensland for the Sunshine Coast. We run meetings covering Caloundra, up to Noosa and up into the hinterland. I will go and conduct a meeting at the drop of a hat anywhere—wherever a group wants to.

I am here in regard to the upcoming bid to have voluntary assisted dying become law. The rights of the terminally ill should be of paramount importance. Forgive me for saying this: I personally do not even think that politicians should be the deciders of this important issue. It seems a no-brainer to me, as it is only fair and just. If one for whatever reason desires to end their days in pain and agony, good for them, but they have no right to inflict the same painful end onto others. Even palliative care people have admitted that they cannot always alleviate all forms of pain. Palliative care is wonderful for those who desire it—and I am not against it; it is great for some people—but it is not for all, especially me. I also consider that being kept drugged and in a coma to alleviate pain is doing harm. That is not for me.

We conduct these meetings where we promote Queensland government advance health directives, for everyone to have an EPOA spelling out their wishes and to also talk it over with their family members well in advance of anything happening. Let us face it: the results of reputable poll after poll are always over 80 per cent in favour of one having their own choice in end-of-life decisions. No-one has the right to deny another individual a peaceful end. It is a matter of personal choice. My life, my choice; your life, your choice.

I do not believe that it is up to the politicians, but this is where we are at right now. I think it should, frankly, be a plebiscite for everyone in Australia, but that is just me. I personally have chronic lung disease, so I know what my end will probably be. I do not look forward to drowning in my mucus

at the end of life and gasping for air. I will not go out that way. I absolutely will not and no politician is going to tell me that I must not end my life when I choose. I am not for resuscitation or for any more major surgeries. I have lived my life. I have had the most fantastic life. I have enjoyed it—I am still enjoying it. That money should be spent on the young who have futures ahead of them. If I am in pain and distress at the end of my life, I would like to leave the world with my loved ones around me with a humane, kind physician's help. If an accepted medical ethic is to do no harm, I believe that keeping a person in pain against his or her wishes when they have a terminal illness is doing harm. It is not even decent.

Dying With Dignity has delivered its submission stating that, with safeguards in place, end of life can be delivered safely. In the countries where voluntary euthanasia is already law, the statistics show that suicides do not increase. Dying With Dignity Queensland's submission has graphs showing quite the opposite, as often people are comforted by knowing there is a way out, if needed, and they continue having a productive and happy life. Also, there would be no pressure on the individual, because that individual must have approached two doctors without family or friends around them, so there is no coercion, and, if that person is asking or begging for a peaceful end, it must be adhered to. The doctors do not have to agree if it is contrary to their personal views, but they must contact a doctor who has already put their names on the list of those humane doctors who shall assist a dying person. There are plenty of caring physicians willing to do what is best for the individual and now would be able to do legally what others have already been doing in the past.

Mr Wright: Good afternoon. I am going to give my own private view on this matter of voluntary assisted dying. Today we are having a rational discussion about voluntary assisted dying. Rationally speaking, and being the kind people we are, we could easily conclude our discussion with an 'all systems go' for VAD. We do not want to be causing anybody pain or unnecessary suffering. However, we are individuals with free will, being distinct from other creatures on the planet, and many people have used their free will to go ahead and commit suicide. I personally believe that we do not have the right to take our life or make an arrangement to have it taken under special circumstances.

At this point you could question me and say that I am talking irrationally. Pretty much that is how it is. I will continue. I say that voluntary assisted dying should not be an issue for us as it is not an option that we have a right to mess with. We do not have the right to take our life, or anybody else's life for that matter. We do not have the right to have another person take our life, even if we specifically have requested that.

I am also concerned about voluntary assisted dying, if legalised, being easily accessible to young people who have not reached mature adult thinking. Voluntary assisted dying leaves them vulnerable. When voluntary assisted dying was not passed in Tasmania, some people said that was being cruel to vulnerable people. We have palliative care to look after people who are suffering physically near time of death. For people suffering mentally, do we advise them to seek VAD or do we include them also? People may not be protected by legislation if VAD is made legal.

I myself volunteer with an organisation that has been helping people living in pain and suffering because of their mental and physical situations and very poor financial circumstances. I have had 40 years experience in doing this. In the past, some of the people committed suicide. Currently, one 14-year-old that our group of volunteers is seeing has attempted suicide four times. I will not be suggesting to people I visit that they could get things 'sorted' by seeking legal voluntary assisted dying—if it becomes legal. We are not like our much loved pets—our dogs or cats—that we take to the vet to be humanely put down. We are destined for something better. I do not endorse VAD. Thank you, members of parliament, for the opportunity to speak today.

CHAIR: Welcome, Mr Jackson.

Mr Jackson: I have already rehearsed this twice this morning with Channel 9 News and the ABC. Can I stand? I do not just owe it to you; I owe it to all the people in the room.

CHAIR: We will try. If Hansard cannot record it we will have to get you to sit back down, sorry.

Mr Jackson: I will become a real celebrity after this, I assure you! My name is Neil Jackson. I wrote some notes last night but my printer died. I had photos I would have liked to share with you. I know that I have four minutes, but it is probably down to 20 seconds. My wife was a primary school teacher. She was the mother of four daughters. It was like I had five children. My youngest was 16 when she lost her mother. It is very close to my heart. I do not know whether any one of you has shared the experience of losing your best mate. I met her when I was 20 and she was 18, when I was in my apprenticeship to become a plumber. My four daughters are very humble. My eldest daughter writes and directs short film. She won a prestigious award from Lexus Australia in Sydney in 2017. She wrote a film calling *Fitting*, which was based on a woman who has breast cancer. She was getting

dressed and finding a bra and lingerie to wear to her daughter's wedding. It was based on my wife's mother, who had breast cancer. Her sister was getting married and she has just delivered my first granddaughter, Leila Nicole.

I had a plumbing business. It was easy for me because I was a perfect candidate. I am a big guy, I have broad shoulders and I had five beautiful women to look after. I was the man of the house. We were based in Samford. My wife taught at Samford State School. Her first year was in 2010 and prior to that it was McDowall for 12 years. She taught at infant level. She was an inspiration and proved that at her funeral: she had over 600 people there including past students who are now in their late 20s.

It is all about being happy and calling the shots. I understand that every case is different and we all have our belief and faith. I get all that. In 2015 I was invited by the Royal Brisbane & Women's Hospital to give a talk, which I have shared in my submission, which you have read—partially, but you should read it all. It took me three weeks to write. I probably cried about 20 times each day and six times the day I went and delivered it at the Royal Brisbane & Women's Hospital. A friend of mine who is a physiotherapist was there. I have a lot of friends who are medicos, including my eldest son-in-law, who is a doctor and is studying psychiatry now.

My talk was for an hour and I used every part of it. I had my eldest daughter there. As I said, she is a writer and director of short film. I had 70-plus physios and professionals in there. The director of physiotherapy was there. I wrote this talk and I delivered it with pride and dignity. I felt very proud and honoured that I had that opportunity to tell the professionals in the medical sector my story, because everything about it was true. I do not need to write anything out now because I am telling it from the heart. I shared my story with those people and afterwards, out of 70-plus professionals, I saw that a third of the room were in tears. I had physios on the floor. No-one spoke and the director of physiotherapy said to me, 'You could have heard a pin drop on the carpet.'

No-one wants to talk about motor neurone disease, but I thought it was important for me when Nicole told me in the car park of the Mater Private Hospital that she had a bulbar palsy. She went to my GP after her 48th birthday in August 2010; I had just turned 50. She said to me, 'I've got to go and have a CT scan because the doctor is thinking that I may have had a mini stroke or a brain tumour.' I thought, 'That sounds fine.' I was a bit worried. She rang me up and said, 'No, it's all good, but I have to go and see a neurologist. I may need to have an MRI to further the investigation. I have to do it in about two weeks and I'd like you to come.' I said, 'Okay, yes I will.'

That day, 30 September, is a day I will never forget. My whole life changed. If you could be more humane and understand my situation of pain 6½ years on—and I still suffer. There is not a day that goes by that I do not feel for those who are suffering now. Friends of mine have passed since my wife and I know people who have this condition. You cannot just treat them as a guinea pig.

On that day when I was in the car park with my wife, she googled her symptoms and told the specialist, Dr Staples, what she had. He was gobsmacked and I thought, 'What the hell is MND?' I never knew. One of my closest friends is a specialist anaesthetist, Doug McEwen, who works at one of the hospitals in Brisbane. Even he did not know what motor neurone was. I think education is so important. When she told me that, my whole life changed. I was going to be out there and start a journal on this.

I know I only have a couple of minutes. I understand this, but you guys were speaking earlier and we had to listen to you. This is so important. All I am saying is: you cannot treat them as a guinea pig. That is what I was saying when I gave my talk. Every case is different. Whether you like it or not, we are in the 21st century. We can do the right thing for our pets, and they are our family. I have two Labradors. They are my best buddies. I would not be here today if it were not for my pets. All I am saying is that I looked after my wife until the very end, like the vow we made: in sickness and in health. All my wife needed was to have the key to her own salvation. At the end of the day, would you like to know that you are going to choke on your own saliva and there is nothing you can do about it? My two younger daughters and I witnessed it four times and there was not a thing we could do. All we could do was sit and watch.

You go against the fact of saying—you do not have any right. Quality of life? What you are telling me is actually crap. You have not lived it. Unless you have lived through it—I did it for 23 hours a day and ran my business, too, and supported my family. If it were not for a good friend of mine, Dr Jenny Brown, who works in oncology at one of the Brisbane north private hospitals—she was a friend of mine from before all this; I have known her for a number of years—where would I be? Where would Nicole have been? She was going to be in a bed and not a thing. She had all her faculties: her Caloundra

eyesight, her hearing and her brain. What are you going to do? Are you going to say, 'It's okay. She's only going to choke on her own saliva'? Would you go through that? I do not think so. I honestly do not think so.

You have to think very seriously about this. I went on to Rebecca Levingston's program on 5 April. It is so important that you do not treat people as a number or as a model. Each case is individual and everyone has feelings. The most humane way is for them to have full control and do it in their own space at home. You do not have the right—and I understand we have to be law abiding; I get that. Seriously, you are going to have to make a change.

CHAIR: Thank you very much, Mr Jackson. Thank you for sharing your very deep and personal story. My one question to you would be—I do not think it is a question actually—that you thoroughly support the introduction of voluntary assisting dying?

Mr Jackson: I do. I would like to say thank you for giving me this opportunity to speak.

Mrs Sauer: I would just like to mention that Dr Jenny Brown, who you mentioned, is actually the vice-president of Dying With Dignity Queensland. She is a very well respected lady.

CHAIR: In the interests of time—we have audience members who want to come forward. We do appreciate everyone's contribution. I think there is one question from the deputy chair.

Mr McARDLE: Earlier when Dr Endacott was discussing the issue of voluntary assisted dying he made the comment about dementia and there was a reaction from the audience. That is probably one of the most difficult areas to discuss, because it is normally inherent that the person has capacity at the relevant time to make the determination. We know that a person can make a pre-dementia directive. That person then loses capacity. If voluntary assisted dying is to come into effect, how do we deal with that, or can it not be dealt with? Again, this is for the committee to understand what the public are saying.

Mrs Sauer: I went through it with my husband. He went in for major surgery and he had an advance health directive. He was a strapping guy. After the surgery I got back a four-year-old child with frontotemporal lobe dementia and doubly incontinent. My career stopped that day to look after him for four years before he went into an aged-care facility. He would have been horrified. He had an advance health directive which he signed and had witnessed while he had full capacity. That should be a legal document. If you have an enduring power of attorney who will support it, that person should be permitted to take over at that point.

Jack did not know who he was at the end. He went from a 135-kilo, 6½-foot guy down to a 68-kilo shell of a man, partly because of being in aged care. Aged care is wonderful and they looked after him so well—I have such admiration for those people in aged care—but they do not have 30 minutes to sit there and feed him food at every meal. They just do not have the staff to be able to do that. He eventually died of malnutrition and dehydration, obviously.

If a person has made that legal thing—had their doctor witness it and had a legal representative witness an advance health directive, which is a Queensland government form—that should be the legal document, regardless of whether they develop dementia down the line. Frankly, at this moment I would probably be in prison if I had the time again with Jack because I would have helped him out at home. He would have helped me out.

CHAIR: Thank you. Mr Smith, you wanted to say a quick word?

Mr Smith: Yes. I will be very quick. My sister died five months ago in a local nursing home—and I hate to say the words—a dribbling specimen of an ex-human being for 18 months propped up in a chair. She had made a directive. She begged me when she could to not let her finish up in a nursing home like she feared. She had a properly signed directive. It was ignored by her daughter. I do not speak to her daughter anymore. You cannot do any more than that—have a person's wishes granted in preparation for their death. I think they should be followed.

CHAIR: Thank you all very much for coming up and giving your views. It is informing the committee as we progress forward. We do have some audience members to invite forward. Thank you very much for your contributions.

CRAWSHAW, Ms Julie, Private capacity

GIBBS, Ms Ali, Private capacity

HEAP, Mr Graeme, Private capacity

NAGEL, Mrs Sheila, Private capacity

ROBERTSON, Dr Marguerite, Private capacity

TRAILL, Ms Enid, Private capacity

CHAIR: Would you like to give a three-minute verbal submission?

Ms Gibbs: Thank you to the committee for the opportunity to speak today. I am here on behalf of my family. Eight weeks ago my 93-year-old aunt, Joy Taylor, was living an active life, living independently at a retirement village in Brisbane. Then she was diagnosed with stage 4 ovarian cancer. This is a terminal illness. There is no cure, no treatment due to Joy's age and the advanced stage of the disease. When she received her diagnosis Aunt Joy was given advance health care directive forms and statement of choices forms to complete and was then admitted to a palliative care unit. The forms had been confronting and extremely distressful for her to complete. No-one at the unit seemed to have sighted these documents and the staff knew nothing about Aunt Joy, her background or any of her wishes. Why bother putting her through this distress if the information is not going to be used? What can be done to make sure it is used?

The questions in the statement of choices are too general and do not apply to everyone. Why would you ask somebody with a terminal illness, 'What are the outcomes you would find unacceptable?' Aunt Joy was taken from her home and everything familiar to her to an unfamiliar and daunting place. More facilities that provide independent living and nursing home options should provide palliative care. This would enable people to feel less isolated and cut off from friends they have made in these independent living facilities because the friends would be able to visit more easily. If the people were in the same geographical location they would be more at ease, with familiar surroundings and staff, making the changes less daunting and less stressful.

While palliative care staff catered for my aunt's physical needs, not enough was done to address her emotional and mental needs. Staff rarely looked in on her. Also three full meals a day, totally inappropriate to her condition, continued to be delivered to her room as she deteriorated despite not having touched a meal in days. With no cure and no treatment options available, Aunt Joy was left to deteriorate with nothing to do all day but think about her impending death. Family visits provided brief respite. Although there were TVs, movies and books available, Aunt Joy, like many others in her situation, was unable to make use of these distractions due to her declining health. What happens to people who have no visitors? The impact on Aunt Joy's family has been devastating, particularly on her 87-year-old sister—my mother—knowing at her age she has limited time left herself, knowing that any one of us could end up in palliative care and asking, 'Is this the best the system has to offer?'

Needless days of waiting for the inevitable, feeling terribly ill, miserable, anxious and utterly hopeless, could have been avoided had Aunt Joy been allowed the choice of ending her life with dignity, without having to suffer the indignity of a drawn-out, cruel and horrible death. She asked daily why she had to endure these last weeks of her life knowing that her health was declining and that she had no hope of recovery. She pleaded many times to end her life. Had a voluntary assisted dying law been in place, at least she would have had the choice of when to end her suffering when everything else had already been taken from her.

Joy Taylor died last Saturday—six days ago—after suffering needless cruelty. We are not saying that she should have been assisted to die; we are saying that she should have been empowered with a choice. We are here today to advocate for the Joy Taylors of the world, to give them a choice about when they end their lives. It is time to end this unnecessary suffering. Please, I ask you to legislate for voluntary assisted dying so that others have the choice not to suffer in the future.

CHAIR: I offer my condolences on the recent loss of your aunt.

Dr Robertson: Thank you very much for this opportunity. It is a bit like a variation on 'the dog ate my homework': I actually did do a submission but I had a break-in at my home on 8 April and my laptop was stolen, including the words of wisdom that I had for you. You will have to bear with me

because I did not even bring notes today; I could not find them. I am a palliative care specialist. I have been for the last 30 years. I have been almost 50 years as a doctor and had 30 years of palliative medicine practice. Some of the people who have appeared before your committee—Louise Welch, Carol Douglas and many others—have actually been my pupils.

I spent the earlier part of my palliative care days in Brisbane. I moved to the Sunshine Coast in 2012. I worked with Louise from that time. For about the last not quite a year I have been unemployed. I would be very happy to be continuing my work, but Queensland Health do not have the money. There you go. That is true.

What I wanted to very briefly touch on was to do with not my opinion about assisted dying or euthanasia, because I agree with so many people that it is an individual decision—it is not for anyone else to take—but just a couple of things that have stuck with me over those many years. I do not really believe that doctors should be the people involved in assisting anyone to take their life. I think that is totally contrary to the oath that we take and also to the manner in which we practise. I think it is a very, very complex area and something that is too difficult an ask—to pretend that you can both alleviate the suffering of a person and at the same time be willing to end that life. I think there are huge ethical areas involved there. That is not to say that I do not agree that there are times where I think it would be totally appropriate for this person to die.

On that note, in the nineties I was involved in a bit of research with the department of psychiatry and we looked at the reasons terminally ill people would want to take their life. That was a very intensive study and it has been written up. It was interesting listening to the stories that I have heard today. The perception is always the horrible pain that people are left in or the indignity of how they are left, but really what we found was that the driving force behind wanting to take your own life was to do with lack of social support, isolation, loneliness. It was not to do with the physical things. I think that is well worth noting.

CHAIR: We are out of time. We might come back to you.

Ms Traill: I come from a background of aged care over a period of 35 years. There has been a lot of conversation today about home based palliative care. That is vital, but equally so is palliative care and end-of-life care in residential care. My experience has shown that there has been very little training available in those particular areas. Often if it is available it is not accessed. It is not mandatory to be accessed.

I have come from two different experiences. I worked in a nursing home where palliative care was addressed very positively. The staff were encouraged to undertake training to deal with it. My experience in that particular nursing home was a very positive one with regard to end of life.

CHAIR: Was that a public or private facility?

Ms Traill: It was a Blue Care facility. Unfortunately, my mum was in a nursing home and I experienced the opposite pole as far as her end of life was concerned. None of the staff had any training whatsoever. They were not interested in the training. When my mum's care was critical she was basically ignored. I knew what was possible. I knew what could be done and what should be being done and it was not. I found it very frustrating and very disillusioning. As a consequence, my mother died a death that I would have not have wished on anybody and that I had promised her beforehand would not happen. I had guaranteed her that when her time came she would not be suffering and she would not have pain. Unfortunately, it was beyond my ability to convince the staff at the nursing home that more was required for her care. From my perspective, I think education must be provided in both residential facilities and the community to ensure people make an informed decision about their end of life and how they would like it to be.

Ms Crawshaw: I want to talk about my aunt's passing. I feel that the last few days of a person's life should be dignified, pain free, calm and comfortable. Care needs to be person and family centred, as each person has differing needs. Monitoring by an end-of-life specialist trained supervisor or nurse practitioner should occur. Adequately trained on-site staff should be caring for the end-of-life client. There should be ongoing consultation with family regarding decision-making and also medical assistance should be available. I feel my Aunt Kath was not allowed much dignity when she was passing away. Kath had lived a full life and nearly reached her 102nd birthday. Her nursing home let her and her family down. Her care was inadequate. Her family had to watch over her in a very distressed state. She was on oxygen, she had had a reaction to the morphine and she was not adequately sedated by other medication.

Kath was unsettled, physically disturbed, agitated and very vocal, calling loudly for her mother. Her organs were failing. Her body became more and more toxic. This went on over a weekend. The family made frequent requests to the on-site nursing home staff that were available and were told Caloundra

often that they were too busy to attend her. The personal carers were emotional and not very professional. The other residents of the nursing home became unsettled. When the doctor did attend, my cousin Karen suggested he check her patient chart. He told her that Kath had only received her necessary medications intermittently. He also inferred that the on-site staff had other responsibilities to the other residents in their care. Karen managed to contact a palliative care nursing specialist at the PA Hospital. She arranged better care and within 48 hours my Aunt Kath passed away relatively calmly, much to her family's relief.

My points are that there need to be better models of care for end-of-life clients. To achieve this, company management needs to be made accountable for care of end-of-life clients at their nursing homes for this short period of time. End-of-life clients need 24/7 monitoring. On-site staff should be adequately trained to understand the needs of end-of-life clients. There should be enough staff on site to appropriately attend to the needs of these clients while also caring for the needs of other nursing home residents. On-site staff need to have backup trained personnel who can come in when necessary. Medications to enable end-of-life clients a dignified passing should be available at the nursing homes. I believe that a position within the management team should be created—that is, a specialist or nurse practitioner palliative care supervisor or coordinator should be available. This person should be trained to monitor the care of end-of-life clients and train on-site staff to have the adequate skills and education to care for these clients when and where necessary. This role could be an on-call position so that on-site staff at the residential complexes can access this resource during weekends and holidays.

Mr Heap: I am a resident of Golden Beach. In my former life I was also a doctor working at the General Hospital in Nambour, so I have had some contact with life and death. I have enjoyed today's discussion. I think it starts very well with the word 'inquiry'. 'Inquiry' infers that there are questions and there are solutions and there is putting them into action—and that is what many people have suggested—but not all of the inquiries and solutions have been the same. As someone else said, 'My life, my choice. Your life, your choice.' That is how the land lies, but there is a legal factor which has not been mentioned at all today; that is, consent for an action or a decision must only be made with the patient's full understanding and consent. That is fundamental to this whole document and it is not mentioned, and there is this fog of uncertainty as to which way actions should go. There are those who say that death should be accessible to all and sundry and others who say that in no way should it be accessible and it only can be decided if it becomes a choice of the person concerned, and it must be legal.

Somebody said, 'Who represents the old people? Who represents the Eddies of this world?' Well, I am here to represent them. I am one of the 74.1 per cent mentioned at the top of page 4. Unfortunately, my risk of being disabled—I am in the 85 to 89 age group—and my possibility of being a bit gaga is 74.1 per cent, so that is up to you to judge.

Mr McARDLE: You are okay in my book, Mr Heap.

Mr Heap: However, I do see some decisions that this group ought to be looking at. The first one is: what is the wish of the patient? The second one is: what is the wish of the treating doctor? The third one is: what is the information that the patient has about the disease he has and how it will take shape in later years? I do not think you can make an informed consent without that view. It is no good waiting until the patient is disabled and unable or, as somebody put it, untrained and unskilled in making that decision.

Someone else said that literacy is the solution in terms of a good education of the population, and that really is the point I want to come to. I personally am having great trouble in obtaining a training in computer language. Everything is on the computer and it is there for me, but I cannot access it. That is a practical thing that I would hope this committee addresses. Thank you very much.

Mrs Nagel: Good afternoon, Mr Chairman and committee members. Thank you for affording me the opportunity to speak today. My focus is on voluntary assisted dying and palliative care. I have already made my submission to the inquiry with attached photographs which speak for themselves. It is based on my own experience of my mother during her final days and years with what could only be described as a demon called PSP, progressive supranuclear palsy. It has been the catalyst for me supporting the right of an individual to request medical assistance when there is no cure for intolerable suffering and pain which leads inevitably to death. I have no intention of going into royal commissions, referendums et cetera regarding LGBT, abortion laws and so many others, but the statistics show undoubtedly that roughly 85 per cent of all communities agree with the right to choose our life ending.

I have firsthand information of aged-care facilities, but my four minutes will not permit me today. I would like to share with the committee that I am from a strong Catholic family but hold the view that religion and politics have no place in this debate. Voluntary assisted dying is not about ending life; it Caloundra

is about ending intolerable suffering and pain. There is more to life than the mere act of breathing. I do not know if there are any medical or nursing professionals here today who have had experience with PSP. It is an uncommon brain disorder that little is known about. Symptoms vary from person to person at its onset, and diagnosis takes a long period of time as a result. It is often misdiagnosed as Parkinson's disease in the early stages. The most common deaths are due to choking or inhaling food or liquid into the airways—aspiration—which can then develop into pneumonia and death.

This is my story. My mother was a healthy 80-year-old when she began falling backwards, splitting her head open on numerous occasions. Next came immobility, at which stage we were unable to bath her and the blue nursing service were only able to visit three times a week. The indignity of that was only minor when compared with what was to come. We were finally able to find a placement in a nursing home for her last three years. During those years the disease progressed. There was the incontinence, inability to sleep restfully, inability to speak, loss of eye function, total rigidity of her whole body and depression, to name a few—and obviously pain, which she could not articulate and medication did not control. Her eyes told that story.

She could only blink for 'yes' and 'no'. She was no longer weighed when she got down to 30 kilos. She could no longer swallow. Tube feeding was suggested, but that was only going to prolong the agony and pain. As a Catholic I contacted the Catholic ethics section in Brisbane. After numerous questions, which I answered in the negative, I was told that tube feeding was not at all on the agenda and we just had to keep mum's mouth hydrated and wait for the morphine to do its job. For over two weeks that is exactly what we did 24/7 so that she did not die alone. Palliative care was no answer in my mother's case. The regulated morphine dosage did not help her. Too little, too late. She kept breathing in that shocking state.

I am sure many here have followed Flora's story in the UK. The photographs of Flora say it all. I have looked at those photographs and said to myself, 'That is my mother.' In cases like my story, it is impossible to look into that crystal ball. The medical profession cannot determine whether patients like my mum will keep breathing for six months, one year or four years. This is what has to be addressed very carefully. By the time a final diagnosis was made on Mum, she had lost her ability to speak or write, though she was one of the unfortunate ones who still had her faculties until she died. Those were her blinking eyes. I strongly believe that if you can make a will which dictates how your estate is to be managed after your death, that will and advance health directive being active should be able to include requests for voluntary assisted dying made long before loss of faculties and strict guidelines set out for the medical and legal profession. My mum did eventually pass away in 2008 at age 85. She starved to death. She had also, while she still had her last little bit of slurred speech, asked, 'Will you please get me a tablet?' Thank you.

CHAIR: Thank you, Mrs Nagel. It must be incredibly tough. If you have any other information, feel free to write to our committee.

Ms Nagel: Yes, I have put in a submission.

CHAIR: We will consider that. Thank you. Are there any questions from any members? Your thoughts and contributions are all very much appreciated. I did have one further question for the doctor. We heard from some Canadian doctors who are practitioners involved in voluntary assisted dying in Canada. They are of the belief that if you are on a journey—this might counter your statement where you said that you do not think that, ethically, doctors should be the ones who do it. I understand that that is your view. Their observation was that they had built a relationship with the patient. It was very much family orientated, with the support of the GP. I thought I would give you the view of those doctors. They have been doing it over there for a number of years now, too.

Dr Robertson: I am aware of the statement that you have just made. My argument is that that is precisely why doctors should not be involved. If you are properly looking after this person, you do have a very complex and intimate relationship with not only them but their family. I find it extraordinarily difficult to differentiate my own feelings from those of the people I am caring for. We are all affected, particularly in this area. As a palliative care practitioner you look after I cannot tell you how many people dying each week—it is certainly more than one a day. Obviously there are some families who touch your emotional centre more than others. To then put yourself in a position where you think you are making a good decision in helping to take that person's life, that is what I argue we are not capable of doing. It is just expecting too much. I am sure that there are plenty of doctors who think they can do it, but I question how much training they have actually had and how much life or death they have actually seen.

Mr McARDLE: Doctor, thank you very much for that. You would argue that there should be a third person who should make that determination or a third person who should put in train the process. I would have thought that the person who puts in train the process has to be trained to make the diagnosis.

Dr Robertson: Yes. I am not saying that the specialist or the GP who is in a direct relationship with that patient or family does not have a role. They, of course, have a role in determining at what point that person is, but we doctors get things wrong notoriously often. It is lovely to think that we are close to God. I can tell you that after so many years of practice I have made so many mistakes in trying to predict when somebody would in fact die. I have been shown to be quite wrong. In other words, the timing of somebody's death is—

Mr McARDLE: Let me rephrase the question. If not a doctor, who?

Dr Robertson: I am sorry?

Mr McARDLE: If not a doctor, who would make the final call and in many cases has to inject or get the patient to inject? Who would do it?

Dr Robertson: From people I have spoken to, and I am talking about professional health people—

Mr McARDLE: Yes.

Dr Robertson: The ones who are the most outspoken advocates of assisted dying are actually nurses. I understand that too, because they are the ones who are there often 24/7. They are the ones having to do the very difficult intimate caring of a person. They say, 'Doctors do not really know what is going on.'

Mr McARDLE: Dr Robertson, with respect—

Dr Robertson: What I am suggesting is that maybe it is a role for somebody—we talk about nurse practitioners, and they are extremely good because they have been trained to do that. I do not know whether there would be such a role. I just do not think it is a medical doctor's role.

Mr McARDLE: The flag that is raised in my mind is that I do not know that there is a registered nurse who would take on the obligation at this current point in time.

Dr Robertson: Precisely.

Mr McARDLE: You then have to train somebody up to a level akin to a doctor to make the call. I am fuzzy about where you go with your argument.

Dr Robertson: Why does it need to be a doctor? It does not take a particularly long time to know what medication would achieve that end. It does not need to be a doctor.

CHAIR: Dr Robertson, I know that you are talking particularly about the procedure itself. What are your views on having two specialists, as in the Victorian model, work with the patient and family to go through that process before the delivery of the medication?

Dr Robertson: I think it is essential that there be two medically trained opinions. I think that is absolutely essential. As far as the Victorian model is concerned, we do not know at this point how successful that is.

CHAIR: It starts next month.

Dr Robertson: Yes. From what I have read regarding the Canadian model and what happens in the United States, in the counties or states where this has been brought in it has stimulated the growth of palliative care. People have thought, 'If this is the only alternative, we better do something about this.' If that is what it takes in order to get that going then maybe that is what happens. I do not know whether that answers your question.

CHAIR: Thank you very much. I thank all panel members for coming up to the table and for giving your contribution.

HOWELL, Ms Kerri, Private capacity

VONTA, Ms Yana, Private capacity

CHAIR: We are well and truly over time but, in the interests of trying to accommodate everyone, we are going to give both of you three minutes to give a verbal submission to the committee.

Ms Vonta: I come from a little bit of a different angle. This is a reference to my mother. I was her daughter and friend—everything, basically. We were very close. When it came to her care, I was there for her all the time. In the last nine years when she needed to go into a nursing home, because I was a carer prior to that, I thought I would be able to get on with my own life a little bit. She had dementia—Alzheimer's they called it. Dr Fawcett, who was here this morning, diagnosed her. It was at Nambour Hospital, and I cannot speak of them highly enough.

I looked for the best nursing home on the Sunshine Coast, or so I thought. She loved swimming. The nursing home had a swimming pool. It was beautiful. It looked like a dream and a place of serenity for my mother, and I could get back to my own life. To my biggest surprise, the system failure is amazingly terrible—the whole system failure. I am talking about from the government and from the managers. It all started in the first year she was there.

I am not sure whether you remember but there was a woman on the Sunshine Coast who was bashed. I was on the front pages of the paper then and, again, I was on the front pages of the paper when they killed my mother. The nursing home used to belong to Profke's and then it changed to ACSAG Japara. While it was under Profke's, my mother was bashed, attacked and bitten in her own room, because they have dementia people and other people all together. They all walk into each other's rooms. Of course they are sick. My mother was not that sick, but they did not have a place to put her that was somewhere in between.

To cut a long story short, there is a system failure beyond comprehension. Nursing centres that are now privatised abuse the system. I did not even know this, but my mother had access to all of these extra things—physiotherapy and this or that. She hardly ever got it until the end, yet the nursing centre was claiming it. When the director of nursing found out that I knew all of the ins and outs, he lied to QCAT and said that my mother only had one daughter. I have all of this evidence. He signed a statutory declaration—his name was Stephen Leggett—to say that my mother had one daughter and that enduring power of attorney should be taken away from me. Sure enough, it was—\$15,000 later I went to court to fight it.

My mother was still mentally able enough to attend the court in Brisbane. Can you imagine how stressful that was for her? Eventually I got enduring the enduring power of attorney back. QCAT apologised to me and said, 'You can sue us. You have every right to because they have made a mistake.' Of course I was not going to have the time to sue them. My mother was sick. This was just the beginning of the horror of my mother being in a nursing home.

CHAIR: Sorry, Ms Vonta. Thank you very much.

Ms Vonta: I know you are running over time but this is in your interest.

CHAIR: We will take a written submission, if you want to write to the committee.

Ms Vonta: Yes, I have. I went to the manager. I went to the nursing centre manager. I went to the state manager of Noosa Nursing Centre. I went to the general manager of the Noosa Nursing Centre. I went to the quality manager of the state. I went to QUADA, which is a waste of time and money. I went to the aged care complaints authority. I went to the *Sunshine Coast Daily* with the pictures of my mother having been bashed up.

CHAIR: Did you go to the Health Ombudsman in Queensland?

Ms Vonta: Yes, I went to the Health Ombudsman. I went to the solicitor. My doctor, Dr Ramaswamy, wrote—

Personally in 34 years of being qualified it is the first time I have witnessed such an event. To hear the sound of her skull cracking on the tiled floor is absolutely horrific. To be honest, the image and sound still haunts me.

No matter how many letters we wrote—I wrote to the CEO of ACSAG Japara. He earns \$960,000 a year, with \$500,000 in bonuses. Since it has been privatised, the money does not go into the correct resources for our families. My mother should not have had to go to hospital and should not have had to go through these horrifying events.

CHAIR: Thank you, Ms Vonta. I am terribly sorry that we are out of time.

Ms Vonta: Sorry. It is thanks to Bill Hoffman that I am here today. I did not know even you were going to be here.

CHAIR: You have it on the record now, so we thank you very much.

Ms Vonta: Can I give you this paperwork?

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

Ms Vonta: Thank you so much and thank you for the time to be able to talk to you.

CHAIR: You are very welcome. We will move on to Kerri.

Ms Howell: I promise I will keep mine brief.

CHAIR: You literally have three minutes. We are so far behind.

Ms Howell: My name is Kerri Howell. I am a nurse. I am also a government aged-care service provider. I own a company that deals with home care packages and DVA community nursing. We specialise in palliative care in the community. We have had a really enduring time in the past five years trying to get funding for palliative care. What I see the majority of the time with us as service providers is that we have an awful lot of money sitting there that does not get spread around in communities for the likes of the poor guys who make jams and crochet towels just to get enough money to drop RNs into somebody's home to educate somebody so they do not phone the ambulance and say, 'I can't do this anymore.' None of the big service providers will actually broker their services to them because they keep their own money and funds to themselves and put basically personal carers in the space without proper clinical care planning when somebody is palliative in community and wants to die at home.

For that reason—it has been doing my head in, I guess, because I am so passionate about it—we have joined USC. I am on clinical council for PHN. I am deputy chair of PHN as well. We have gotten together to try to organise a drop-in centre that is free and is in the community so anyone can go and get transparent, informed decision-making ability. They can go in there and say, 'Hey, look I've just found out I've got cancer'—or mum or the person next door or whoever it may be. They actually have a group of people who are not doing it to try to make money. I think this is going to help a huge amount when it comes to end-of-life choices.

I do see that the majority of people want to end their life because they are scared it is going to hurt or they do not understand. I see that the majority of informal carers—family members and loved ones—who call ambulances or admit mum or dad to hospital or to a hospice do so because they cannot cope anymore. I think we are missing the ability to help people at the very beginning, when they find out they have a terminal illness. We get them at the very end and it is really difficult to try to help them then.

Advance health directives are just not being done enough. I think it should be mandatory that, when somebody gets a home care package assigned to them, part of our assignment note from My Aged Care is that they have an advance health directive and that is mandatory in order to receive funding. Make it mandatory for service providers in aged care to actually broker to the little hospices that are the jewels of our community that get no money. These things could happen now. Some consumers have unspent funds in their home care package of \$20,000 and \$30,000 because of the consumer directed care, but they never, ever offer the opportunity to actually use someone like Cittamani and poor Alex. She can only take on 23 clients, so we are constantly saying, 'Hey, do you have any?'

A lot of things need to change in our local community. I am at the coalface of it every day and I am quite passionate. That was my little thing. I certainly would like to see if there are any MPs around who would give us some space. We have three days a week from 10 till one to share with the bridge club at Yaroomba community centre. If we could have a spot—and we will do it for free—anybody can come in and access free, transparent information on how to get funding, how to access palliative care. We can talk to ACAT and we can get their packages brought forward quicker. I am on the clinical council of PHN. We can defragment community.

CHAIR: Thank you very much, Ms Howell, for your contribution and for what you do.

Ms Vonta: I just want to say one thing. I strongly support voluntary euthanasia because my mother died in my arms and for four weeks was on a Niki pump. One thing just to help you guys: I think your directives should be made easier to write out. The one you have in place right now is very hard to understand. Thank you for your time.

CHAIR: Thank you very much. I now declare this public hearing closed. I thank you all very much for staying here and for your contributions today.

The committee adjourned at 2.23 pm.