

JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
TUESDAY, 27 FEBRUARY 2018**

SESSION TWO

Members

**Ms A. Sanderson, MLA (Chair)
Hon Colin Holt, MLC (Deputy Chair)
Hon Robin Chapple, MLC
Hon Nick Goiran, MLC
Mr J.E. McGrath, MLA
Mr S.A. Millman, MLA
Hon Dr Sally Talbot, MLC
Mr R.R. Whitby, MLA**

Hearing commenced at 10.59 am**Mr WAYNE LAURENCE BELCHER****Chief Executive Officer, Braemar Presbyterian Care, examined:**

The CHAIR: Welcome, Mr Wayne Belcher, to the committee this morning. I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson. I am the chair of the joint select committee. I will introduce members of the committee. We have Hon Dr Sally Talbot; John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Col Holt; Hon Nick Goiran; Reece Whitby; and Hon Robin Chapple. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in Western Australia to highlight any gaps that may exist. It is important that you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege. However, this privilege does not apply to anything you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet.

Do you have any questions about your appearance here today?

Mr BELCHER: No.

The CHAIR: Before we begin with our questions, do you want to make a brief opening statement?

Mr BELCHER: If I may—and how long is brief?

The CHAIR: I will let you know.

Mr BELCHER: Except for five and a half years after I left a previous aged-care organisation, I have worked in the aged and healthcare sector since 1976. I am a Christian. I attend a Baptist Church in the northern suburbs, and in between retiring from one of those aged-care groups and recommencing in the aged-care sector, I was actually one of the pastoral team members at that church. My personal views, and those that I bring to Braemar Presbyterian Care, come out of an evangelical Christian faith tradition. Having said that, I am not the sort of person who is not happy to hear what alternative views are presented about a whole range of matters of life, including biomedical ethics, and leadership—management. I have been engaged as a CEO for many years. So even though I have some quite strong personal views, I am more than happy to entertain that not everybody is going to agree with my views nor those of our organisation. I hope that our submission, although fairly frank and forthright, gives enough of a view to say that we are part of a democratic society here in Western Australia. There are many aspects of the law that we may not be comfortable with, and we have to learn how to work and operate within those constraints as they may change from time to time.

The CHAIR: Thank you. I will commence with some questions around palliative care. Do Braemar facilities offer palliative care?

Mr BELCHER: Yes we do. In fact, we have two very clear strategic roles. We want to provide a palliative approach to care for all of the residents who come into our services, and we want to focus on care for people who are living with dementia and other cognitive disorders.

The CHAIR: Does it include access to specialist palliative care services?

Mr BELCHER: Yes, it does.

The CHAIR: Does Braemar utilise the metropolitan palliative care consultancy service?

Mr BELCHER: Yes we do. The south metropolitan service is used quite regularly, as we require.

The CHAIR: Can you comment on the level of quality of service and accessibility of that service?

Mr BELCHER: We actually think they have been very supportive and we are quite happy that we have access to them.

The CHAIR: In terms of on-site palliative care, what is on offer for the residents?

Mr BELCHER: When one looks at a palliative approach to care, one considers the whole range of physical, mental, emotional and spiritual requirements of care that people have. In fact, even if they are of no faith tradition, or certainly not ours, one of those things we keep in mind is the questions that people have about, “What next? I’m living with a terminal illness; what are those things we may need to talk about?” We facilitate care, discussion and activities related to people and try to offer a quality of life so that people can actually, while they are living with us, live with a measure of decorum and quality while they are with us.

Hon NICK GOIRAN: Is the on-site palliative care offered to your residents offered by palliative care practitioners employed by Braemar, or do you bring in external providers?

Mr BELCHER: We bring in external providers as and when we need to. Our aim is to improve our skills in the whole manner of a palliative approach to care. We have a clinical nurse on staff who specialises in palliation services, and those services are provided across the three facilities that we have. We hope to grow those as we are growing our focus on the palliative care services—to grow them from within. But we certainly recognise that we are not the font of all knowledge in these areas, and we like to bring in specialists as and when they are needed, determined by either the staff that we have—the nursing and care staff—or the general practitioners who visit their patients.

Hon NICK GOIRAN: Is the nurse involved in palliative care employed by you?

Mr BELCHER: Yes, she is.

Mr J.E. McGRATH: Just further to that, roughly what percentage of your residents would have their own GP visiting them?

Mr BELCHER: GPs supplied in residential aged-care services can be problematic. We have a GP either of the resident’s own choosing, or we recommend a GP if they have come from far afield. Every resident has access to a general medical practitioner. The response of those people is mixed, from time to time, depending on their preparedness for after-hours call-out or whatever, but every resident has access.

The CHAIR: In your submission you expressed concerns that, if legislated for, a GP might accede to a request for voluntary assisted dying from a patient that would be contrary to the family’s wishes and those of the provider. Does Braemar have concerns that a GP may accede to a Braemar resident, at the end of their life, requesting terminal sedation, in particular if this is contrary to Braemar’s wishes?

Mr BELCHER: We have a view of that. I think it is not a view that would be considered immediately, though, either by a practitioner or by a family. So, if a person is living in care, it would usually be some time, as most people facing death would ask a question about whether there is an alternative way out of this. Our hope is that the regime of care that we provide is sufficient that people actually ask about what is it we can do to assist you, even though we cannot provide an end-of-life choice at the moment. If the legislation indeed changes, that is another consideration for us, but we have concerns that, because we do not have a contractual arrangement with a general practitioner, there may be occasions when we are not aware that that discussion is happening, and that that could be problematic for a number of people and the organisation if the choice was made to end one’s life.

The CHAIR: How would Braemar currently respond to resident at the end of their life requesting voluntary palliative starvation?

Mr BELCHER: We certainly would respond to them, and in fact it is not an unreasonable question. I am not a clinician, but my understanding is that most people who are living with a terminal illness ask the question, “Is there an alternative? Can I be released from this in some tangible way?” The role of the nurses and carers that we have is to say, “Look, we can’t help you with this. However, what is it that would provide you with the best alternative in terms of hope, in terms of care, in terms of your life with us, that we can actually work together in delivering?” We are not frightened of the question. It actually opens the door to a greater understanding of where people are.

The CHAIR: How would Braemar responded to one of its residents if they were in a similar position to Mr Rossiter, and requested that the artificial nutrition and hydration on which they were dependent was withdrawn?

Mr BELCHER: We would honour that. We believe it is a person’s right to make that choice.

The CHAIR: Thank you. The Australian Institute of Health and Welfare reports a recent downward trend in the number of aged-care residents and admissions appraised as requiring palliative care, and states that this is likely to be influenced by changes in the application of the aged-care funding instrument. Are you able to provide any comment on the changes to the application of the ACFI for palliative care?

Mr BELCHER: Until about 2015–16, the commonwealth did actually provide for a palliation supplement to residential aged-care providers. Bear in mind, these were the years that I was not actively involved as a manager or administrator in aged-care services. Those supplements have largely been withdrawn. There is still a process in place whereby providers can use the funding instrument to receive some palliation top-up funding. However, my staff tell me that the complexities around that and the time within which that can be used, usually outweigh the time that the resident is in the terminal phase of life when those alternatives can be sought and provided.

We make no apology that we are choosing to improve our skills in an area where there is limited funding. But the reality of life is that 95 per cent of people who come into residential aged care in Australia today are going to die in care. So, in a sense, every resident who comes to a high-care service requires palliation. It is a matter of timing, and the time that they are living with us. So it seems to me to be, if I can use a crass term, a no-brainer that providers would focus on a palliative approach to care. We just have to do the hard yards—that is what we are there for.

[11.10 am]

Hon NICK GOIRAN: You mention that the commonwealth used to pay a palliation supplement. How much was it?

Mr BELCHER: I actually do not know.

Hon NICK GOIRAN: Would you have that data available in your organisation?

Mr BELCHER: I am sure we do and I am sure I can get back to the committee with that information.

Hon NICK GOIRAN: Can we take that on notice?

The CHAIR: Yes.

Hon NICK GOIRAN: Further to that, whatever the amount was for this palliation supplement, when it arrives at Braemar, how then is it allocated? Is it allocated on a per-patient basis and that entitles them to a specified amount of hours of palliative care? Can you just explain that?

Mr BELCHER: I would also have to take that on notice. The aged-care funding instrument is based on an individual's assessed need for services. There is specific criteria that weighs up frailty and behavioural issues and cognitive issues. There is a sense in which it would allow for additional services or treatment regimes to be provided, but globally it would come into the revenue for the organisation and each person's needs would be managed on a person-by-person basis.

Hon NICK GOIRAN: Can we take on notice the amount and how it is allocated?

The CHAIR: Yes. We will write to you with specific details. In relation to the Braemar facilities and the AIHW report, are you able to provide comment on the suggestion that the number of aged-care residents and admissions appraised as requiring palliative care has been trending downwards?

Mr BELCHER: It is an interesting outcome. I do not understand it, other than perhaps some of the difficulty in accessing funds for that purpose, so people are just saying, "Look, they are high-care recipients. We will just provide the services as and when we need without specifying." It is also interesting that until the last couple of years, the commonwealth, in one of their reports—again, I can take on notice to get it to you—actually comment that they did not specify length of stay by, say, dementia times of residents. The system is not necessarily as well finely tuned as hospital-type reporting and the international disease classifications and whatever.

The CHAIR: It does not take into consideration dementia patients who may, for example, stay longer?

Mr BELCHER: It does, not only just recently, and they have not split the type of dementia. It is just saying the length of stay of residents with dementia may vary according to chronic disease type. So there are those issues that we still have within the services.

The CHAIR: Just on aged care, in your submission you indicated that the average length of stay in a residential aged-care facility is now just 17 months. Can you clarify the source of this figure?

Mr BELCHER: Yes. I have had that comment confirmed by principals of a firm called StewartBrown. They are an accounting firm based in Sydney who do national benchmarking of the aged-care sector—residential and community care. Their benchmarking is over some 929 aged-care facilities. Their commentary around the country—they have confirmed it was in industry briefings—was that the average was now about 17 months for high-care residents, and many of the larger providers, they say in this email, actually believe it to be lower. I can provide that to the staff as well.

The CHAIR: Does Braemar receive public funding to provide aged care?

Mr BELCHER: Yes, we do.

The CHAIR: Does Braemar accept patients outside the Presbyterian faith?

Mr BELCHER: Yes, we do.

The CHAIR: And Christian faith?

Mr BELCHER: Yes, we do.

The CHAIR: Your submission describes Braemar as a values-based organisation and a ministry of the Presbyterian Church. Do Braemar's values and ministry restrict the scope of lawful services that would otherwise be available to its aged-care residents?

Mr BELCHER: Restrict the scope of lawful services? No.

The CHAIR: So there are no restricted services as such?

Mr BELCHER: No. We are able to provide services to all who choose to live with us—or their family, as the case may be.

The CHAIR: As an example, the refusal of life-sustaining treatment or terminal sedation or palliated starvation?

Mr BELCHER: If a client—a resident—or their endorsed guardian were to ask for withdrawal of food, nutrition, whatever, including medications, we would honour that request. I actually believe that Rossiter's case is quite firm. Rossiter asked, as I understand it, not to have his life ended, but to refuse the intake of nourishment and whatever. He requested that the PEG tube remain so that he could take medications. He was really seeking the right to refuse treatment. We honour that outcome. In fact, the church has a tradition—I wish the church today knew that—back to the 1500s saying that that was acceptable practice where treatment was futile. We would uphold that. There is some issue around autonomy and choice that we must uphold.

The CHAIR: I will move to Braemar's role and the Guardianship and Administration Act, which limits the capacity of paid carers, other than those providing home care, to be substitute decision-makers. What legal role do you think that Braemar has in oversighting residents' medical treatment?

Mr BELCHER: Braemar is not a hospital. Most aged-care services today in fact fall out of any state legislation with regard to health and hospital services. I think that happened in around 2007 when the health and hospital services act ceased to cover nursing homes because of the commonwealth coverage of their requirements. We are not hospitals; we are therefore not strictly clinicians. Whilst we have registered nurses and skilled carers that provide services, any treatment regime will always be at the request of a combination of family with their local general medical practitioner who visits them on an occasional basis.

Mr R.R. WHITBY: You mentioned that quite often there is a request from residents about refusing food, sustenance and medicines. How often does it happen that residents request that end-of-life option?

Mr BELCHER: I actually have to step out of Braemar to give an answer to that. I am actually married to a registered nurse who has recently retired as a palliative care nurse. My wife, Janice, would say to me that every patient she visited would at some stage ask that question. The issue for her was: what was the depth of feeling in sincerity around that that she could say, "I can't help you with that, but can we explore this to say, 'What are the issues and things that we may be able to work together on securing that can alleviate some of the stress and symptoms and suffering that you are experiencing?'"

Mr R.R. WHITBY: I guess often that issue is raised not as if it is a definite choice the person wants to make but as an option to be held in reserve sometimes—is that what happens?

Mr BELCHER: That is my understanding. I think that is a perfectly reasonable assumption.

The CHAIR: Stepping back to that oversight role, you mentioned that Braemar is obviously not a hospital so you do not have the same kind of oversight of medical practitioners. Do you think an aged-care provider should have management over a doctor's performance and clinical governance?

Mr BELCHER: What I think and what a medical professional might think may be two different things. I am not a shrinking violet. If I was concerned about a matter of medical practice, I would be speaking one on one with the doctor that we might be concerned about. Braemar is a smallish organisation. Whilst 218 residential aged-care places sounds big, actually by comparison with, say, Baptistcare or the Bethanie group—both of which I have been involved with in the past—it is small. Scale is an issue. There is a point at which my own management inclination is that you would engage with a medical practitioner to provide some of that medical advisory oversight of practitioners and therefore be able to get a much better relationship with doctors around those sorts of things involved in the issues around a palliative model of care and whatever.

[11.20 am]

My sense is, though, that the doctors we have are quite responsible, quite responsive and they would be talking with the clinical nurses around all sorts of matters of care of their patients, their respective residents, to ensure that the quality of care we are providing is at least up to standard, if not amongst the best in the state.

The CHAIR: Are you able to provide any examples for the committee of how that lack of oversight and management of doctors may have affected a patient negatively?

Mr BELCHER: Yes. I have not insignificant experience where local medical practitioners who, at the end of the day, are good practitioners, have families, and have lots of patients in different parts of their suburban coverage, just are not available on call to come and move one of their patients and deal with the crisis that they might be having. I have had occasion to say to families in the past, “Can we offer an alternative to the doctor that has been your choice simply because we feel that they’re not really servicing the needs of your loved one adequately in terms of responsiveness?” So it does happen. It is rare, but it does happen.

Hon ROBIN CHAPPLE: Mr Belcher, you say that 90 per cent of your clients who come into your facility will actually end up dying in the facility, so obviously there is a very, very close relationship with the end of life. With the medical professionals who come to your establishment or are provided by your establishment, there will be decisions made towards the end of life. What control does your organisation impose or have around some of those decisions? If you could answer that one more broadly, then I might go and test a few more angles.

Mr BELCHER: Again, I reiterate that I am not a clinician but my experience over many years working in health and aged care is that doctors and nurses actually have a very good relationship around important matters of care of their respective residents. In some respects, a good clinical nurse might be better able to discern the closeness of end of life—so that term or phase of care for a resident—than a doctor who is obviously visiting less often. They would still defer to a doctor for advice around treatments, whether there needs to be any breakthrough pain management or other symptom control. I think, generally, those matters are actually covered very well, very professionally and very caringly by both doctors and staff, not the least of which is that many residents—for some it is a shorter period of time, but even 17 months—become like extended family members for many of our staff and their families involve people. So there are a lot of things happening at that point in time, but I generally think they are managed very, very well, so the relationship can be quite strong between the professionals. Does that answer your question?

Hon ROBIN CHAPPLE: That helps. There will be determinations made by visiting medical professionals as to whether this person is likely to pass within the next two or three days. So, when it comes to it, do you actually have on your patients’ beds quite often the DNR aspect; and who places that, and under what conditions?

Mr BELCHER: I am actually not sure of the very specific answer to that, but we have them. Families are usually involved in that discussion. There is often a family request around end of life as well, so there is not just the “Do not resuscitate” but “Do not hospitalise”—do not send off to hospital in an ambulance. They have to be managed by the clinicians who are on staff at the time, in whose view if they believe there is a life that is worth saving and it is not a terminal phase of illness, they have to make a choice about whether they uphold the wishes or whether they believe there is a professional decision about care being made here. When we are talking about people who are terminally ill, it is not just a one nurse, one doctor decision; families are involved.

Hon ROBIN CHAPPLE: Following on from that, and I really appreciate your answers, they are very informative, if a decision is made at a particular time that one of your custodians—one of the people you look after—is terminally ill and there is no point in resuscitation, and that is a decision made by yourselves in conjunction with family and in conjunction with the doctor, what level of involvement is there with the patient?

Mr BELCHER: If the patient is cognitively aware, then they will be involved in those decisions.

Hon ROBIN CHAPPLE: If they are not cognitively aware?

Mr BELCHER: Then, clearly, informed advocates, which are usually family members at that stage—we do not want to be rushing off to a guardianship hearing to get guardianship or advocacy for affairs when a person is in the last two or three days of care. This is a matter of life. People do die. People die at home; they die at various ages. We facilitate—in fact, you could say we are actually facilitating people being prepared for a loved one to die. A lot of those things are well planned.

Hon ROBIN CHAPPLE: I commend you for that.

Mr BELCHER: I talk about the staff because, for example, we have a resident in one of our facilities now who was told by his GP that his prognosis was to die before Christmas 2016. He is still with us. Medicine is not an exact science. Some are pretty good; it is not one size fits all. He is still dying and is still in care and the family still visits, but to be able to work within that scenario can involve a lot of tact and care and lots of answers to questions and support and things like that.

Hon ROBIN CHAPPLE: Again, I am appreciative of what you are saying and I really appreciate what you are doing. Given that unless there is actually proper designation of guardianship, decisions about “Do not resuscitate” or other matters are left very much to the family and the medical practitioner, does that not, potentially, open you up as an organisation to the challenge of having facilitated the passage of a person as opposed to the legal process?

Mr BELCHER: Possibly. I hear what you are asking, and I think it is more than semantics, but in providing care, we will continue to provide care in spite of their perhaps not being DNR orders, “Do not transport” orders and whatever. There is still an occasion where a clinician must make the appropriate professional judgement. Does the absence of a DNR order mean that one should not provide resuscitation therapy? Sometimes we just need to let life take its course.

Hon ROBIN CHAPPLE: As I say, I am supportive of what you are presenting. I am asking from that technical, legal point of view. Thank you.

The CHAIR: I want to clarify some comments you made earlier, which is around there may be a “Do not transport” or “Do not resuscitate” order, but ultimately it is up to the clinicians to make a call in each circumstance?

Mr BELCHER: Yes. I would be interested to hear what the coroner would have to say about that, but if a clinician has a view that there is a life worth saving and does not quite think that the person has been in a terminal phase of illness when something happens and there is a life worth saving, then they have to make a judgement call based on their clinical skills. To not do that would mean they may be negligent; to do that might mean they are told, “Well, that was unfair; the person is elderly; they were dying”, or whatever.

There are some things in medicine where we still need to leave decisions to the professional clinician. That would be outside of any understanding where a person was living through a terminal phase of illness.

[11.30 am]

The CHAIR: You may choose not to answer this, but would that decision be a moral decision or a legal decision?

Mr BELCHER: Let me first say that I do not envy the professional clinicians who are in that role having to make that decision. I am not sure I can say it is one or the other, but I would tend to defer to them believing as a clinician there is something here that they must do to allow the person to be given the best chance of surviving. It is a professional judgement call.

Hon NICK GOIRAN: Mr Belcher, have you had to make that professional judgement call yourself?

Mr BELCHER: I am not a clinician. But with a family member, yes, I was asked to provide care for my mother where I actually knew that there was a balance here about controlling symptoms and the likely outcome that the medication that was provided, the sedation that was provided, may in fact lead to her death. That was the outcome, but she was in incredible pain. She was within the last 12 hours of her life and they wanted to take her for an X-ray to see whether her arm had actually broken. I said no. So, yes, I have actually made the decision as a layperson, as a family member, but I do understand the dilemma that professional staff, when they are faced with that decision, is which is their best judgement call as a nurse, as a doctor. I think we make it difficult when we judge one way or the other whether it was right or wrong.

Mr R.R. WHITBY: Can you explain what is self-autonomous choice and why it is you are opposed to that?

Mr BELCHER: I have actually never said I am opposed to self-autonomous choice.

Mr R.R. WHITBY: Okay.

Mr BELCHER: I have simply said that sometimes I feel that the role of autonomy outweighs some of the other pillars that we have in terms of biomedical ethics. Autonomy is vitally important. Christian Rossiter's case is a prime example of the right to choice being upheld. He did not choose to have his life ended. He may have wanted that; I do not know, at some point he probably did. The poor guy was debilitated. You know the history of the accident that led to his situation. But his ability to have a court decision upholding his request to withdraw treatment, effectively, was profound for Western Australia. It had happened in other jurisdictions—Karen Quinlan's case in the 1970s or 1980s, whenever that was, in the US. That right to choose is quite important. In all of aged care across Australia now we are moving towards patient-centred care. Theoretically, the patient, the older person, is king; however, in practical terms it does not quite work that way. In health services planning in this state, for example, we talk about population health demand and growth of services and whatever. Whilst the individual has some quite significant rights, we will weigh up the planning of hospitals according to a population in a district and things like that. There are some balances that are important, but we should not lose sight of the right of a person to make choices.

But aside from autonomy as one of those pillars of medical ethics is beneficence—to do good—non-maleficence, to not do anything that will harm a person; and justice for all. That brings back the rounded thing that there is a sense of in any choice that is being sought: “Am I providing a scenario where no-one gets hurt in this? Is it the best thing for myself, my family, the place where I am receiving care?” Whatever. All I am suggesting is that sometimes we are leaning a little too much to personal autonomy without picking up the whole of this matter. In this instance, in this hearing, my question simply is that the right to choose to end one's life is fine, but is it fine for the whole of society to accept that as a norm; that we all should be bound by? Is there still place for a conscience-based decision about whether in fact a doctor can be exempted from the proposed legislation that will arise, whether a health service provider who has a conscience about wanting to deliver really holistic, highly skilled palliation services can be excluded from the legislation if they make other

alternative arrangements for their residents? That is the sort of mix that I am getting to, Mr Whitby. It is certainly not saying that there is no right of autonomy in choice; it just whether the balance is right and how does it affect the whole of our society.

Mr R.R. WHITBY: So the balance in your view would be accommodating exemptions and the ability of people to opt out?

Mr BELCHER: Where pragmatic. I think it is not a matter of if this law is passed, it will be when; whether it is this term of government or in 10 years' time. I think western societies are moving, in my view sadly, inexorably to that view where end-of-life choice will be available to people. Our view is that we believe that holistic high-level palliation services can provide an alternative to that. We continue to strive to make sure that even things today, where there is intractable intolerable symptom management, that within a handful of years I believe we will be on top of most of those things; that there will be a valuable alternative for people.

The CHAIR: I want to move to the area of futility of medical treatment. In your submission you state that you do not believe the practice of prolonging life with futile or burdensome treatment is morally acceptable. How and when is it determined that there is no realistic prospect for a resident to recover?

Mr BELCHER: Fortunately, it will not be me making that objective decision. That is an issue for the clinicians to really have significant case discussions with the person if they are alive certainly and cognitively aware of what is happening, but certainly with their families and their own GP if we are engaging specialists for that. I really believe it is important that we understand where people are at in their care pathway.

Hon ROBIN CHAPPLE: A supplement to that if I may. The families and people making some informed decisions—is there any ability for you to test whether those people making those decisions may or may not stand to gain by their decisions?

Mr BELCHER: That is a very good question and one I actually had not considered that might come up today. Look, I am sure there is. Because of the length of time that people live with us, we usually get a reasonable objective view about families and relationships and whatever. Some of them can be quite testy. Some of the complexities only arise when something goes wrong in care. So if there is a fall and the person might be taken to hospital for a repair of a fracture or whatever, and then someone comes literally out of the woodwork and says, "Look, I am really not happy about what happens here." But because of the time we have with people we are usually on top of those. We have to rely on the person who is listed as the next of kin, and the doctor to be our best guide as to where the information stores are, and the conversations with family happen. Every time there is a family member there will be somebody who is chatting with them, speaking with them, letting them know how mum or dad has been going—or aunt or uncle or lifelong friend—and if there is anything they can do or bring in that might be helpful to them, whatever. Those conversations are happening and where some things come out that will impact care they are recorded in our notes. There is a sense we know a lot. Whether we go to that extent, I am not sure. It is a good question.

The CHAIR: Are you able to provide some examples to the committee of circumstances when life-sustaining treatment has been withdrawn from Braemar residents or where residents have refused this treatment?

Mr BELCHER: I cannot describe the examples but I can tell you that there have been some and there continues to be some. What our usual process is is to honour that respect, but too—I would say regularly, but more likely occasionally and then how often it is I cannot tell you—occasionally check back in with them that it is still their request and that is a practice that they wish to continue. We

do uphold a person's request for withdrawal of nutrition, of treatment. Our manner of providing care for them is then to make them as comfortable as possible whilst they are living through that phase.

[11.40 am]

The CHAIR: Are you able to explain the difference between supporting someone's decision to withdraw life-sustaining treatment and their decision to end their life through voluntary assisted dying?

Mr BELCHER: For me there are two simple things: one is that in order to assist oneself of voluntary assisted dying, you need to have an agent—there has to be another person who effectively provides you the means, or if you cannot use the means yourself, some other way of delivering that outcome. For me that is a step too far. The second part of that is that when we are talking around issues of terminal sedation, palliative sedation and other things in that end-of-life phase, it is about intent. If we are intending to treat and manage symptoms and there is an adverse outcome that a person's respiratory system slows down and as a result they die, for me that is not assisted dying—that is simple caring for a person, treating the symptoms and allowing them to endure what nature provides and delivers. If the intent is to end their life, that for me is a completely different outcome that is not an acceptable part of a care practice. That is the problem.

The CHAIR: In relation to voluntary assisted dying, in your submission you stated that pain, suffering and distress are existential. Can you expand on that for us?

Mr BELCHER: Yes. I do not want to make light of everyday circumstances, but there would not be a person in this room who at some stage in their life has not endured some pain and suffering, whether it is because they could not meet their council rates that year or whatever. It is how we suffer as people and we suffer differently as people. There may be two residents in our facility who for all intents and purposes have exactly the same condition that will lead to their death, and one handles that much differently from the other. One lives with intolerable, intractable symptoms, when nothing that the staff can do seems to get on top of those things and there is a request that comes out that says, "Look, just help me end my life"; whereas, the other one, for whatever reason, seems to be able to live with what is happening—it is not comfortable but their experience is entirely different. That is what I mean by pain and suffering being experiential. We all experience those things and we experience them individually. This goes back to the issue about autonomy and choice. It is complex.

The CHAIR: Your submission also states that the desire to end one's life is based on existential circumstances, with perhaps the view that there is little hope for any future improvement in one's outlook. Can you elaborate on what "future improvement in outlook" a patient who has a life-limiting illness or is approaching the terminal phase might expect?

Mr BELCHER: We like to refer to people choosing to live with us; not to say that they are coming to us to die. That might be the public perception, and that is okay, but we are striving to make the last weeks, months and years of people's lives as high quality of lived experience as possible, bearing in mind that we know that 90 to 95 per cent of the people who live with us will actually end their lives. That is perhaps the wrong choice of words—will actually die with us whilst they are in care. It is being able to work out whether an individual and/or their family, what are the lived experiences of what actually brings life and purpose to them. We believe, actually, there is a significant amount. Funding does not allow us anywhere as much as we would like to do, but the experience people have is sadly too often today just completely discarded as being valuable. The lived experience of the people in this room, and if your parents or older relatives are still with us, is huge. To be able to share that with staff, volunteers and family members, to be able to share the lived experience of

the joys, loves, struggles, conflicts and whatever, actually brings meaning to life. Simple sharing that story and being able to do that regularly is a simple activity that can add value to life. We just want to make that a much more prominent feature of what we do and believe that is a hope that lives within all of us if the opportunity is given.

The CHAIR: Your submission also indicated that you would seek any relief from any proposed legislation that adopts physician-assisted suicide. If this were to occur, what would be the process for removing such a resident from a Braemar facility? What would happen if an alternative facility was not available?

Mr BELCHER: That is a good question because it is not currently law, so I guess I do not have to explore it to its full extent. But it would be difficult. I know there is a follow-up question in the list that was provided. But I believe there will be some services that will, obviously, not have too many difficulties with meeting the requirements of the legislation. There will not be the same issues around conscience. It will be up to us to find who those are and come to some arrangement with one or more, I suspect, facilities who will be happy to take in people from our services for that terminal phase of care. We will actually be disappointed with that. We believe we have something to offer. But we believe we will have an issue of conscience in living with permitting assisted death in our services. We want to do it the right way. There is a question about security of tenure; it is difficult—very difficult. But we believe there needs to be a capacity for a conscience choice to be able to work through those things and we will be striving to do that as best we can.

Hon COLIN HOLT: Can I follow up on that. Does Braemar only operate in Western Australia?

Mr BELCHER: Yes.

Hon COLIN HOLT: Knowing that aged-care providers are well networked, Victoria recently passed a bill around voluntary assisted dying, yet not fully implemented, have you looked at how some of their aged-care providers and some of the ones of Christian faith are going to work within their laws that are coming along and how you might adopt some of those? I would be interested to know what you think or how they have gone about it.

Mr BELCHER: So would I, Mr Holt. I have asked several, including a law firm that constructs the residential care agreements with the one of the peak bodies—I have asked for their opinion; the extract is actually what I proposed to them—and they have not got back to me.

Hon COLIN HOLT: Do you think there is gap there?

Mr BELCHER: Yes, I think there is a big gap there and there seems to be little response. I think people are struggling with where they go, actually, is the issue. I would love the answer if you have got any friends who you can ask.

Hon COLIN HOLT: That is a useful answer, do not worry.

The CHAIR: That is an answer in itself.

I want to move on to advance care planning. We have touched on it a little. Does Braemar assist or encourage residents to complete advance health care directives, enduring powers of guardianships or advance health care plans?

Mr BELCHER: We encourage them. We take the view that for us to be involved is a conflict of interest so our involvement is very simple: we encourage residents and/or their families, or whoever they choose as advocates on their behalf, to make sure that they are in place so that we have as much description, including resuscitation orders and transfer orders and things like, as much as we can, available for each individual.

The CHAIR: Does Braemar ensure that it identifies the relevant substitute decision-maker when a resident is admitted into care?

Mr BELCHER: Yes, we do.

The CHAIR: Do you use the hierarchy of decision-makers?

Mr BELCHER: We strive to do that, yes. It is not always possible because some relationships have already fractured by the time people come; we strive to do that.

The CHAIR: The inquiry is looking at all aspects of the law in end-of-life choices. Are there any specific areas that have not already been addressed that you think require change or improvement?

Mr BELCHER: Not specifically; I just have a philosophical question or issue around the right to choose to end one's life: do we provide for a corollary that there is always the right to choose to stay alive? I think that is the important balance and one that should not be forgotten in any drafting of the legislation. My fear is that in our services, in services where these discussions will tend to arise, is that many of the people—most of the people, probably, are in a vulnerable situation; they are in care in whatever circumstance it is for many of the people. I would hate to see our society sink to a level where people who are elderly and frail, perhaps receiving care at home or in residential aged care service or in a hospital, feel that there is a subtle pressure on them that they are old, they are worthless and that they should be dead.

That will be as perception, but as people grow more frail or whatever, I think it is a perception that many older people feel is very relative. We just need to keep things in balance if and when this legislation is promulgated in the future.

[11.50 pm]

Mr J.E. McGRATH: Getting back to the person you said, I think, was told they had a life expectancy to the end of 2016 and is still with you, I have heard similar stories. That is one of the biggest issues with this. If someone, as you said, might be vulnerable, elderly and have a condition, the prognosis is not good. A lot of people would think that that would be a waste of a life if that person is allowed to end their life, which would be premature by 18 months, maybe more. As you said, the world is changing and we are moving towards more choice for people as to what happens at the end their life, is this one of the key planks that governments need to look at with regard to end-of-life-choices—that is, the fact that we do not want to see some people coerced or in a state of mind that they feel they should end their life when maybe there is more time to come—or should it be left to the very last stages when there is no hope?

Mr BELCHER: That is a very big issue. It is a big issue in other jurisdictions—it has not quite got here—in the Netherlands and in Belgium, for example. I think in Belgium now a child at age 12 can request to have their life ended. In the Netherlands there was a set of twins who at age 45 were either blind since birth and had also become deaf or other the other way around and had requested to have their lives ended because life was no longer worth living. We need to be careful about how we may open a Pandora's box—I am not talking about a slippery slide here, I am talking about a descending set of stairways that seems to have happened—and that we are very cautious about the circumstances we permit in any legislation. The difficulty for medicine is that it is not an exact science. It is good, and even the advances made in the last 30 or 40 years—I would not want to be around 40 years ago, given the things that are happening today. Some of those advances are great, but prognosticating about the time when the terminal phase of life is upon us—it is not there; it is not a pure science. Correct me if I am wrong, but I think the legislation in Victoria is six months, or it might have gone to 12—I know there was some debate about the prognosis of death. It is a hard number to get a hold of and be really safe, and I am glad I am not the group that has to make the

decision. That is one that I can safely hand back to the select committee, but it is a very difficult decision to make.

Hon ROBIN CHAPPLE: If I may, and following on from that—and I do not want to put words in your mouth—but one would assume that if legislation were to be brought in—I know you are not a supporter of the legislation—and it dealt with pain and suffering and emotional, that would be an absolute no, whereas if it was to do with a terminal condition at the very end of life, that would be more acceptable. I am sorry, I do not want to use —

Mr BELCHER: I hear what you are saying. My preference, my opinion, is that we should just say no, because I understand from even the palliative care physicians their own struggles with administering palliative sedation in that very final phase of life, those last two or three days, because, you know, I talk to them and they say, “Wayne, we know it helps in most instances.” I am trying to recall comments from a physician couple of years ago. I am sure he said it was only like two per cent of all of his patients required that, so it is a small number, but he said, “Am I actually making the final prescription and administering the drug that is causing them to die rather than alleviating their symptoms?” And it is a struggle, clinically it is a struggle. I know that if with the kind heartedness of those physicians and their skill at managing those symptoms it bothers them, I am bothered by it. I am confident that it will become law—I see it just from reading the times—but I am bothered by it personally. I do not like it at all.

Hon NICK GOIRAN: Is there a cost differential between a resident at Braemar with a terminal illness and one without one?

Mr BELCHER: Intuitively I would say no, but again it would depend. If we did an activity-based study on the cost of care delivered in the last two, three or four weeks of life of the resident, we may well find there is an out of balance cost, but it is one that I continue to support. It is just in the scheme of things we are dealing with people who are dying. If you have a 50-place facility, on average, if we are down to now 17 months of life, you have got those 50 people coming and leaving within 18 months. We are providing a form of palliative care and it matters to me not one iota who gets the most this week versus another one; it is based on the care needs of the residents at the time.

Hon NICK GOIRAN: Is there any pressure on places at Braemar?

Mr BELCHER: Well, we are full. I think in Western Australia there has been a demand for places because during the boom that we now do not have the cost of capital was too difficult to access, so we are actually about 3 000 places under where we should be, so demand is regularly higher. Respite is the biggest problem, and for people who are caring for somebody at home with palliative care who actually need a break, it is difficult to get respite. Most residential providers could provide residential respite as a form of palliative care, but there are no places available. It is really difficult. So, if the state could influence the commonwealth in some of those things, that would be nice, but I know, good luck!

The CHAIR: We try to influence them in a number of ways!

Hon Dr SALLY TALBOT: Mr Belcher, you have obviously looked into the whole question of voluntary assisted dying in a lot of detail. You have given it a lot of thought, both professionally and personally. Are you aware of the figures from other jurisdictions that suggest an extremely low number of people who have a plan to avail themselves of a voluntary assisted dying option, how few of them take that option when they are actually in the terminal stages of the illness?

Mr BELCHER: I am not aware of the stats. I have it from feedback, which is why we respond to questions, so help me work through this with you. What are you feeling; how can we help.

Hon Dr SALLY TALBOT: What I am interested in is that let us say that Braemar is able to offer the best standard of palliative care available anywhere in the world. Would you be reducing that standard of care if people were coming to you under a new statutory provision in which they could access voluntary assisted dying? Would you reduce the level of palliative care offered to them?

Mr BELCHER: No, that would be a complete anathema to my understanding of healthcare and my responsibilities.

Hon Dr SALLY TALBOT: I rather thought that might be your answer, but I thought you might like to elaborate on that.

Mr BELCHER: We will meet the needs of people as they present, so if a person is—I will not say fine—frail and elderly for six months of their life with us and then take a sudden deterioration and became really terminal in their life, we can meet their needs as they arise and provide more when we need to, to meet those needs.

Hon Dr SALLY TALBOT: But you cannot see yourself as being able to do that if there was a change to the law?

Mr BELCHER: No, we will continue to provide the highest level of care we possibly can. What I am suggesting is that we will make a choice between continuing to provide high-level palliative care, but not condoning a voluntary assisted death of our resident. In terms of care provision I do not think one is exclusive from the other.

Hon Dr SALLY TALBOT: It was tricky. The Chair asked you the question about what would happen if somebody wanted to go down that path and, in a legal sense, it was available to them. What would you do? How would you advise that person? Would they have to leave?

Mr BELCHER: That is the issue that I have raised. Our preferred position would be that we find alternative accommodation for that person, having advised us that that is the decision that they want to make. That is the struggle—how, where, when? How does that all work?

[12.00 pm]

Hon Dr SALLY TALBOT: I can see it would be a struggle.

Mr BELCHER: It will be. Do not hold me to that, because I may not be able to if it is part of law. We have potential jurisdictional issues. Braemar is an approved provider of the commonwealth for residential aged care. Every resident that comes in is an approved commonwealth recipient of care. We do not fall under the state jurisdiction in terms of health and hospital-type care. Does that present any jurisdictional issues in this whole matter anyway? I do not know. If the commonwealth department of health and ageing took it upon themselves to say, “This is not something we are supportive of”, where does it all fit? It is complex for us, because governments can simply say that is the rule, these are the regulations, and these are the laws. These are complex matters and we are trying to work through these as best we can. We uphold the value of people and our responsibility to care well for them. We are not comfortable with having somebody in our services want to have somebody end their life. That is the struggle we face.

Hon Dr SALLY TALBOT: You said earlier in answer to a question from the Chair that you do accept residents who are not Presbyterians, but also not of the Christian faith.

Mr BELCHER: Sure.

Hon Dr SALLY TALBOT: Are you permitted under your federal funding agreements—would you be able to enforce that ban so that you would not take people who did not share the same faith?

Mr BELCHER: No, we do not. We do not restrict entry.

Hon Dr SALLY TALBOT: Would you be able to if, as an organisation, you decided to?

Mr BELCHER: It is interesting. Within the discrimination on the basis of sexual identity, for some reason there is an exemption for commonwealth approved aged-care providers—not churches and not schools, but in the regulations and the legislation there is an exemption for commonwealth aged-care providers. At some point in time, somebody is likely to do that. I can take this back to our gospel perspective. We provide chaplaincy support. If I were to not open the doors to all who needed care, I would be defying the injunctions of the gospel. Hear me right on this: I am not doing this to proselytise people in their last days of life to become members of the Christian faith. I am doing it because we care about people and want to care for them in their last place of life. For us to discriminate on colour, race, sex, or creed is completely inappropriate, and I challenge my colleagues about that occasionally.

The CHAIR: Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days of the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. The committee will write to you with the questions taken on notice during the hearing. Thank you very much, Mr Belcher, for your appearance today.

Hearing concluded at 12.03 pm
