

JOINT SELECT COMMITTEE ON PALLIATIVE CARE IN WESTERN AUSTRALIA



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
FRIDAY, 31 JULY 2020**

SESSION TWO

Members

**Mr Chris Tallentire, MLA (Chair)
Hon Nick Goiran, MLC (Deputy Chair)
Mr Zak Kirkup, MLA
Mr Shane Love, MLA
Hon Kyle McGinn, MLC
Hon Alison Xamon, MLC**

Hearing commenced at 12.05 pm

Mrs ROSIE BROWN

CEO, Busselton Hospice Care Inc, sworn and examined:

Mrs JENNIFER MONSON

Chair, Busselton Hospice Care Inc, sworn and examined:

The CHAIR: Welcome. Please take a seat. We are not going to come across and shake hands with you, but you are very welcome. Before we ask for the broadcast to start, I just want to advise you that if you have any confidential material, please keep it flat on your desk and that way it will not be picked up by the cameras. We can now start the broadcast. Before we go any further, you need to take either the oath or affirmation that is in front of you.

[Witnesses took the oath.]

The CHAIR: Thank you. You will have signed a document entitled "Information for Witnesses". Have you read and understood that document?

The Witnesses: Yes.

The CHAIR: Thank you. These proceedings are being recorded by Hansard. Please note that this broadcast will also be made available for viewing online after the hearing. Please advise the committee if you object to the broadcast being made available in this way. No objections? Thank you. A transcript of your evidence will be provided to you. To assist the committee and Hansard, please quote the full title of any document you refer to during the course of this hearing. Please be aware of the microphones and try to talk into them. Ensure that you do not cover them with papers or make noise near them, and if you can both speak in turn. I remind you that your transcript will be made public. If for some reason you wish to make a confidential statement during today's proceedings, you should request that the evidence be taken in private session. If the committee grants your request, any public and media in attendance will be excluded from the hearing. Until such time as the transcript of your public evidence is finalised, it should not be made public. I advise that publication or disclosure of the uncorrected transcript of evidence may constitute a contempt of Parliament and may mean that the material published or disclosed is not subject to parliamentary privilege.

Would you like to make an opening statement to the committee? We will then have a series of questions to put to as well.

Mrs MONSON: Okay, thank you. We will just make a short statement.

Thirty years ago, our organisation formed with a commitment to work with key stakeholders to achieve the best possible standard of palliative care in our local community. Our work has been based on the national palliative care standards and has championed the inclusion of dying people in the community. For 15 years, we offered an inpatient hospice facility. We also paid for the employment of registered nurses to work in the community and they also coordinated the care in the hospice unit, which involved 100 volunteers offering end-of-life care.

In 2015, the WA Country Health Service took over our model of care, but our organisation kept up its commitment, and we pay for the coordination of the volunteers in the hospice unit that is managed by the WA Country Health Service. We also offer a bereavement service, which is free of

charge, and complementary therapies, and we are now embarking on a community outreach volunteer program with an associated carer education program. We believe that this community volunteer support will provide a much-needed component of emotional and social support to families, and it will also help increase the awareness in the community of the clinical services. It will support those clinical services that are offered to the community.

One of our concerns—and I think this is a gap in services—is that, according to the PCOC study, only 40 000 of the 100 000 patients who are receiving treatment at end of life receive specialised palliative care services. We encounter this when people approach for assistance in our local community. A lot of people are receiving assistance and treatment from oncologists and specialists, and they miss out on being referred to specialised palliative care, and therefore they miss out on symptom management.

[12.10 pm]

We are very encouraged by the recent allocation of more clinical nurses in our local community. We still see a gap across the state in services, particularly to people under 65 who do not receive adequate end-of-life support. This has always been a concern of ours. We also think that any model of care that involves the use of volunteers adds an incredible amount to people at the end of life. It is enshrined in the services around the world and in the eastern states, but in WA there is no inclusion of volunteer services in the funded programs. We have been going for 30 years and we have never had any government funding. We are funded by the generosity of the local community.

The CHAIR: Any questions on the opening statement?

Hon NICK GOIRAN: If I can jump in here, Mr Chairman, and just say that that is very helpful for us to know, because there has been a lot of discussion in this inquiry so far around compassionate communities. One of the questions that we were recently trying to get an answer to was: how much funding has been provided to the Busselton Hospice for that particular program, particularly in the context of the pilot program that is now happening in Albany and the great southern. It does help us to know that, well, actually, no funding has been provided, at least at a government level, and that it is all being generated at a community level. Obviously, that is a great testament to the local community.

Just following on from that, because there is obviously, as you will appreciate, some appetite to try to roll out compassionate communities across the state, are you aware of any other models other than what is happening in Busselton with a pilot program in the great southern?

Mrs MONSON: We are not aware of any others apart from the great southern program. I went to the palliative care summit that was held at the end of last year, and people were very interested in what we did. They had not heard of anything like that. There is something in the midwest, I believe, where there is some sort of community support given, but we do not know of anything like that. We have been doing the compassionate community work since 2000.

Hon KYLE MCGINN: Can I just ask to clarify? That is all three levels of government—federal state and local?

Mrs MONSON: Yes. Look, we have applied for small grants. We are on the lookout all the time. We have had a few small grants through the local government, but we have never had any funding through state or commonwealth funding.

Mrs BROWN: We are sometimes lucky to get \$1 000 here or \$5 000 there, but nothing that is going to sustain our service provision long term.

Hon NICK GOIRAN: Perhaps, Mr Chairman, just to conclude on this point from me about compassionate communities, if governments of any particular persuasion were desirous of having compassionate communities rolled out across the state, what type of funding would be necessary in order to coordinate that? We did have a dialogue with one of the earlier witnesses around the fact that in comparison to most mechanisms to improve palliative care services across Western Australia, this model is relatively inexpensive because it is so heavily reliant on the volunteers, but to the extent that there could be some value in governments providing funding, it would probably be around the coordination of volunteers one would think. Have you got any comments around that that might be able to assist the committee?

Mrs MONSON: Our annual budget is \$350 000 a year. The volunteer coordinator is employed 0.6, and that costs us just under \$100 000 a year, does it not?

Mrs BROWN: Yes, about \$70 000.

Mrs MONSON: Including that are a few other costs like training and things like that. But our total budget includes the extension of this program into the community—bereavement support. All of our services are free of charge to the client, and we are probably one of the few places that offers free bereavement service. It has always been important to us, because it is one of the hallmarks of a palliative care program that goes by national standards that we offer bereavement follow-up.

Mrs BROWN: I think the wonderful thing about the volunteer service is that although on the scale compared to clinical services it is a fairly small investment, what it does is provide that longer term care for families. We know that 95 per cent of a dying person's time is spent either on their own or with their family and friends. Only five per cent, whether they are an inpatient or whether they are at home, is in front of the health practitioner, so we need to make that 95 per cent the best it can be. Families see other regular members of the community who are not frightened by what they are facing and who are gracious and gentle in that space, and they think, "If you can do it, I can do it." When those frightening moments happen at end of life and some of the distressing signs of imminent death happen that are hard for laymen to understand, having a member of the community sitting with you, nothing more than sitting with you, gets people through that space, and it means they do not get on the phone to the ambulance in a panic and rush this person into the hospital so that they die on a gurney in ED. Instead, they die surrounded by the people who love them with dignity and grace, and the people left behind feel they have honoured the wishes of their loved one by achieving that they have the ongoing support of our volunteers through the bereavement and the complementary therapy processes, so everybody does better for the sake of a \$350 000-a-year investment. But in addition to that, the clinical services that the government is already paying for are enhanced by the collaboration with volunteer services, because the nursing staff know that when they can only go into that home for an hour, the volunteers continue the same message, they continue to support that family—they are able to sit and listen to the stories or whatever it is people need to get off their chest that they cannot necessarily do, but they know that volunteers are well trained to do it, so they have confidence in their skills and their abilities. So they are a professional volunteer service, and that means they need good management. They need robust recruitment, they need excellent induction and ongoing training, and they need support and management in the course of their duties, and you cannot leave that to another volunteer. That needs a skilled practitioner, because that person is also liaising with the healthcare team, so they are straddling the formal and the informal services.

The CHAIR: Just to clarify, the volunteer resources that you have got, they are provided to support the provision of clinical palliative care at the hospice unit, which is now located at the Busselton Health Campus.

Mrs BROWN: Correct. They do not provide any clinical services. The medical staff are there for that. The volunteers are there 12 hours a day. They work three shifts a day and 365 days a year. They will go and will just help someone to brush their teeth after a meal, they will help them to cut up a meal, they will sit and talk with them, they will support the family. A lot of the time, in fact, is spent supporting family as they come out of the room and they need to debrief with someone before they go back in. The families, even the ones that are really independent, take a great deal of comfort in knowing that the volunteers are keeping an eye on everything outside and they do not have to worry about that stuff.

The volunteers will also manage the visitor situation, so that the family do not have to be telling people, "Now is not a good time to visit." The volunteers can be the visitor police. They serve a really important role. They get to know the families even more intimately than the nursing staff because they are there the whole time. They are able to say to the nurses, "Now might be a good time to shower Mr Jones because his family have gone and he's really wanting it." They work very closely with the nursing staff but do not actually deliver any intimate patient care.

[12.20 pm]

The CHAIR: Your submission notes that there is no dedicated palliative care staff position at the Busselton Health Campus and palliative care is provided by generalists with varying degrees of expertise in palliative care. Are you aware whether this will change as a result of the recruitment that the WA Country Health Service has got and the idea of the district-based multidisciplinary teams? Has this improved since the funding announcement made in 2019?

Mrs BROWN: Certainly, the clinical services have had an uplift for the nursing care, which has meant that the clinical nurse specialist in the community is able to spend a little more time in the hospice unit. But she is not the coordinator of the hospice unit and the patients coming in and out and may not know all the patients that are admitted into the hospice unit because they might not be referred to her care. The hospice unit is an extension of the ward, so the nurse unit manager generally has the responsibility for the hospice unit. Whoever the allocated nurse is who is the shift coordinator for a shift is responsible for the allocation of the nurse who works in that unit. I believe that the Busselton Health Campus has now appointed a number of nurses who have expressed an interest in palliative care who will, when they are on duty, mostly work in the hospice unit. However, they will not necessarily be palliative care-trained nurses. They will be more under the supervision of that clinical nurse specialist who is able to be a bit more present in the unit on a day-to-day basis. That is an improvement. It also means that the teamwork between the nurses and the volunteers is better able to be facilitated because they understand what the volunteers can and cannot do. They can work more efficiently together as a team, which is better for everybody as well.

The CHAIR: It is a very important role that the volunteers are playing. How do you manage to train the volunteers?

Mrs BROWN: Each year we have a new intake. We have a recruitment drive. We usually train about 18 and we are blessed to have more people apply. We usually have about 40 people express an interest and we take on about 18. They undergo five days of training to be palliative care volunteers and then they start to work in the hospice unit. We also do ongoing training for them, keeping them linked in to the reasons why they are engaged in this kind of work and educating them about current practice, what is happening in other places, and different aspects of death and dying, even if it is what happens in different cultures, so that they broaden their understanding of the whole field of palliative care.

The CHAIR: You touched on the numbers that are coming through. Are those going up or down or stable?

Mrs BROWN: It stays at around about 100 volunteers. Some of them work as frequently as one shift a week. Others work one shift a month. Most of them are in Exmouth at the moment on holidays. We have the grey nomads, as they call themselves, that go away. At times, staffing the unit can be a bit spotty. Having said that, as the previous volunteer coordinator, I used to send out an email to them all and say, “We need somebody to fill in this shift”, and invariably someone would step up. They are quite extraordinary people. I am ever so impressed by them.

Mrs MONSON: Can I just add to that? We have got volunteers who have been with us on shift for 20 years. There is incredible experience they have. One of the things I believe they do is to hold the sacredness of the space in the hospice unit. What happens is as they come through and are exposed to the philosophy of care that we are very careful to share with them, they can, in fact, help the nursing staff and sometimes the doctors understand what is important, how things need to be done and what things need to be respected. I see them as custodians of that space because they are really imbued with the philosophy of care that we believe is important at the end of life. It is not just a clinical ward.

Mr R.S. LOVE: We have heard from a number of other people about the difficulties of navigating care and what is available in the palliative space. Would those volunteers—I know they are not professional providers, but would that experience be valuable in being able to guide patients that “this is available” or “that service might be suitable for you”, without necessarily setting themselves up as being an authority, but just gently guiding and helping people through that navigation of services in the local area?

Mrs MONSON: Certainly. One of the things we teach them is the people skills and how to be present in very difficult situations with people who are very vulnerable. That is one of the priorities for our training and ongoing training of the volunteers. Those conversations are not easy. A lot of the medical people find it hard. It is an area that is underdone, I believe, in the health system and, particularly, in palliative care. What is different about our volunteers is that they provide that emotional, social, spiritual support for people. They can help alleviate a lot of the distress at the end of life and there is often distress. There are difficult family situations—people are not talking to people. All these sorts of things go on in that hospice unit. They are there to help navigate those relationships in the unit.

Mr R.S. LOVE: The relationship between you, the volunteers, the health campus and the individual GPs who may have placed the patients, can you just describe how that all works in practice?

Mrs BROWN: The volunteers, while they are our responsibility to recruit, train and manage, when they are on duty in the hospice unit, they are WACHS volunteers. They operate under a job description. They operate under the policies and procedures for volunteers. They also have our policies and procedures and whatnot. They take direction from the clinical team, who know how well-trained they are and have come to rely on them. In fact, they delayed reopening the hospice unit until Monday because they gave us time to retrain and re-educate, particularly in relation to COVID-19 precautions, our volunteers before they open the unit because they really missed them, which is testament to what a big impact they have as part of that multidisciplinary team. I think in New South Wales they have done a recent review statewide and they have actually established a palliative care volunteer program that they are funding now because they recognise the contribution of volunteers in meeting that gap of the emotional social support and the longer term bereavement support.

Unfortunately, I think our volunteers may be an endangered species because we are really struggling to raise the money to continue our services. Just this week I approached a major corporate potential donor. He asked some really good questions—similar questions that you are asking. He said, “I think

it's going to be hard for us to fund something that should be funded by the government." We struggle to get money from the public purse and we struggle to get money from the private purse, so we are caught on the horns of a dilemma. We anticipate that post-COVID, we are going to be busier than ever. We know suicide rates are going up. We know people are not being screened, so cancer rates are going to go up with late diagnoses, seeing more people dying. We know that people are struggling with this grief legacy from not being able to attend funerals, not being able to attend important events like weddings and births of new family members who will be two before they see these people.

These are all things people will grieve about and it will weigh on them and then it will overwhelm them and they will come find us, as they do now; and to keep our doors open, we need to support.

[12.30 pm]

Mr Z.R.F. KIRKUP: I appreciate that in the work you continue to do in Busselton and the surrounds, I guess, in that case. Given what you are faced with, have you approached the state at all for any funding contribution?

Mrs MONSON: Yes, we have. It has been declined.

Mr Z.R.F. KIRKUP: May I ask how much you sought from the government?

Mrs MONSON: One hundred and fifty thousand dollars.

Mr Z.R.F. KIRKUP: And they would not put \$150 000 in?

Mrs MONSON: No. That was half our operating costs at the time, so we asked for half our operating costs.

Mr Z.R.F. KIRKUP: And what would that have gone towards funding?

Mrs MONSON: The whole organisation.

Mr Z.R.F. KIRKUP: Across the board?

Mrs MONSON: Yes.

Mrs BROWN: Yes. That pays for our IT and phone—probably our biggest expense—insurance and then the cost of our volunteers is our coordinators. We have a coordinator for the hospice volunteers, who is 0.5; we have a coordinator for the bereavement service, who is 0.5; and we have a coordinator for the community outreach service, who is 0.4. Then we have an administrator. We have myself—I am 0.6. Our admin is 0.6, and we have one day a week is our finance operator. So we run on the smell of an oily rag.

Mr Z.R.F. KIRKUP: You do. You do.

Mrs BROWN: I mean, I know everyone is going to come and ask you for money, but I just wonder how many of them are representing this volunteer group and how often you will hear about volunteers as part of the solution to our best end-of-life care that we can provide. I suspect not that much and I think it is because we have not seen a lot of it so it does not come to mind that they are an amazing resource. We had a nurse come from Amana care for two days to learn what it is we do, and I believe in one of the residential homes under Amana care, they have now initiated a pilot project to have "no-one dies alone" on the basis of an adapted version of our model. We would love to see our model replicated in lots of rural and remote areas because they have great volunteering traction. That is how regional areas survive—with volunteer groups. So I am sure that where they only have one clinical nurse specialist in palliative care, her work is going to be made so much easier—or his work—if they can fund a small group of volunteers who will help them; it just means that the state get so much better value for every dollar they spend on palliative care clinicians.

Hon ALISON XAMON: Can I just get clarification. When did you ask for that money and when was that rejected?

Mrs MONSON: Late last year.

Mr Z.R.F. KIRKUP: After the passage of the voluntary assisted dying legislation?

Mrs MONSON: It was around the time it was going through. Yes, it was before. Because that was January, wasn't it?

Hon ALISON XAMON: So the money, you were requesting it for this upcoming financial year?

Mrs MONSON: Yes. We had a visit from the Minister for Health. He came and met with us and was interested in what we did, and so he invited us to send him a submission, which we did, but then we got the advice that it was declined.

Hon KYLE MCGINN: Can I ask what further advice did you get on why it was declined?

Mrs BROWN: I do not know that we did.

Mrs MONSON: We did not get —

Hon KYLE MCGINN: So when you say you submitted for \$150 000, was it under a specific grant?

Mrs BROWN: No.

Mrs MONSON: No, it was not. It was just because he had paid us a visit and we were invited to put up—you know.

Mrs BROWN: He mentioned the extra money that was going to be made available for palliative care —

Mrs MONSON: Through VAD.

Mrs BROWN: Yes—and suggested that a lot of that would probably go to the WA Country Health Service, and I suspect he may have thought that the WA Country Health Service may apportion some of it to us, but that is not what happened.

Hon KYLE MCGINN: Okay. And have you applied for any federal streams?

Mrs MONSON: Look, it has been interesting. There was one opportunity for federal funding that we looked at, but it just was not going to be appropriate for us because even if we put up the submission for the funding for a program like ours, it could not be a one-off thing; it had to be something that was going to be implemented across the state at the same time, so it was out of our ball game, if you like.

Hon KYLE MCGINN: Sorry, when you say—you are talking about expanding?

Mrs MONSON: Yes. It came under a program —

Mrs BROWN: I do not think we meet the criteria. So we will look at any opportunity, but for various reasons do not meet the criteria, so the doors are often closed to us to apply for funds.

Mrs MONSON: They did not want a one-off sort of submission; they wanted something that could be rolled out across the country for the benefit of all, and that is not something we could do.

Mr R.S. LOVE: I think I know the fund you are talking about. It was actually for a pilot study. I do know a couple of groups who got funded. Have you tried the lotteries COVID relief fund?

Mrs MONSON: Yes, we have. Look, we have had funding from lotteries at different points. They do not fund operating costs.

Mrs BROWN: No, they do not. That is correct.

Mrs MONSON: They will fund equipment.

Mr R.S. LOVE: I think that might be with respect to —

Hon KYLE McGINN: Sorry, I was going to say that. That has all changed now, and particularly your donations and fundraising would have been affected. Lotterywest is designed for you now to apply.

Mrs BROWN: On my to-do list when I get back to Busselton next week is to look at the latest release of COVID-19 lottery relief funding because I had seen that. So we did not meet any of the criteria for the first round, but I know I have just got an email last week about the second round that has opened so there might be some —

Hon KYLE McGINN: I think you definitely, definitely should have a look at that one.

Mrs MONSON: Is it going to be ongoing or is this like a stopgap?

Hon ALISON XAMON: It is a stopgap.

Hon KYLE McGINN: I think you should apply for what you can —

The Witnesses: Yes, we do.

Hon KYLE McGINN: But I would find it interesting that there would not be any other federal streams for opportunities, but it is something I could look into.

Mrs MONSON: Well, we are certainly on the lookout all the time.

Mrs BROWN: One of the difficulties we have with a lot of these funding situations is that they ask you to demonstrate sustainability, so we fall at that hurdle.

Hon NICK GOIRAN: You have been doing it for 30 years, though.

Mrs MONSON: Yes. We have been in business for 20 years. At the moment we have got enough for two years, so it is difficult. As Rosie said, it is really difficult—you see, up until we handed our model of care over to the WA Country Health Service, we had this steady stream of donations from the community. When it was located within the WACHS campus, the perception of the community is “the government is paying”. Now, we have done everything we can to overcome that. We have employed someone to write press information. We have got Facebook. We do everything we can to overcome this barrier, but it is difficult, and so there is this now hurdle. There is also a lot of competition for the corporate dollar, for fundraising from philanthropic sources. We are up against it.

The CHAIR: Does WACHS have a role in relation to the volunteers—for example, oversight or training?

Mrs MONSON: No, we do that.

The CHAIR: You do all that?

Mrs MONSON: That is our job. We pay for that.

Mrs BROWN: They do provide the emergency procedures manual and manual handling training as part of the mandatory training that all the staff receive, as well—that is part of their duty of care to the volunteers—and they pay for their police clearances. That is about it.

The CHAIR: Okay. Thanks. Your submission talks about the dedicated multidisciplinary team for palliative care in the City of Busselton and the coastal area, and the community service professionals for palliative care are drawn from the generalist staff of the community service team. Could you explain what you mean by that community service team?

Mrs BROWN: So up until recently, if an inpatient needed a social work referral, it was not a palliative care social worker; it would have been a social worker from the community department. The nursing staff are the nursing staff on the ward, of which there is that varying mix of experience and willingness to work with end-of-life patients.

The doctors who attend the patients each day would be the doctors that are rostered on for the ward, so you do not have a dedicated, identified team of people with palliative care experience who then come together and make all the decisions about the patients that are in the hospice unit.

[12.40 pm]

Mrs MONSON: But also the community service you are referring to is the clinical nursing care for patients in the community who wish to die at home. That is that service.

Mrs BROWN: And I think they now have a social worker for patients in the community, who is 0.4 FTE.

The CHAIR: Could you say a little more about the role of GPs in the provision of that community palliative care?

Mrs BROWN: There is a very small number of GPs now that still admit patients to the Busselton Health Campus. If their patient becomes an inpatient, they kind of hand over the care to the doctors that are on duty in the ward. A few have retained their visiting role and can come and see their patients in the hospice unit, but many relinquish that. They get their patient back, I suppose, when they are discharged from the unit if they have just been admitted for some kind of management of their pain relief or something like that.

Mrs MONSON: I think that is another issue or problem area, because some of the GPs do not even know that their patient has been admitted into the hospice unit. You see, this is where there is this fragmentation of services. We used to have a situation where the GP was the main medical person, worked with our team, but now we have got this more fragmented approach.

The CHAIR: Do you see this changing now that we have got the recruitment by WACHS of district-based multidisciplinary teams? This is following the funding announcement from last year. Do you see that improving or changing?

Mrs MONSON: Do you think the doctors' situation will change?

Mrs BROWN: Personally, I probably do not, but I am not sure that I am qualified to answer that question. There certainly is a presence now at Busselton one day a week of a palliative care physician, and I think she is able to provide a bit more direction and leadership for the doctors that are on the ward, but like most things, some are more interested in this area of medicine than others, so there is always going to be that level of interest and engagement by the medical profession based on a professional interest in end-of-life care.

Hon NICK GOIRAN: Is that the specialist based in Bunbury?

Mrs BROWN: Yes, so Sarah Dunlop is now assisting Dr Masarei.

Hon NICK GOIRAN: They are doing it as a team?

Mrs BROWN: Yes. Sarah comes down, I think it is a half day or it might even be one day a fortnight, a half day each week to see any of the patients that are in the hospice unit.

Hon NICK GOIRAN: But they are both specialists?

Mrs BROWN: Palliative care specialists.

Hon NICK GOIRAN: But both are based in Bunbury?

The Witnesses: Yes.

Hon NICK GOIRAN: And one of them is coming down approximately half a day a week?

Mrs BROWN: Correct.

Mrs MONSON: I think they do video conferencing too.

Mrs BROWN: As well, yes.

The CHAIR: Just to focus on the development of the community outreach program that you mentioned in your submission, you have got trained volunteers; they are available to support families caring for loved ones at home at the end of their life, including provision for the carer education package that is in there. Will the volunteers' role in this program be similar to the assistance provided within the hospice setting?

Mrs BROWN: Yes, correct. They will not be providing personal care. The nurse and hopefully the social worker will assist those patients who need assistance with activities of daily living through the HACC and various other programs and services and packages that can be put in place, hopefully swiftly in some cases. So, in terms of domestic support and assistance with housework, assistance with showering and those sorts of things, there will be other services that can be called upon to provide that kind of assistance. Our volunteers will provide respite for the carer and companionship for the person at end of life.

The CHAIR: Has WACHS had any involvement in the development of the program?

Mrs BROWN: Other than to say "go for it", because it will really help the nursing staff.

Mrs MONSON: They are very keen for us to—in fact, we actually had a donation from one of the doctors in the hospital to help us get it going.

Mrs BROWN: A personal donation.

Mr Z.R.F. KIRKUP: Shame we could not get more support from the state government, then.

Mrs MONSON: Yes.

The CHAIR: Is the carer education package available online to people outside the Busselton area?

Mrs BROWN: Absolutely. There are two things that we implemented around COVID-19. We accelerated the development of that carer education program and moved it to a webinar format so that would be available statewide. In fact, on our first program we had someone from Albany and someone from Northam as participants on that program. The feedback has been astonishing, and I think I have tabled some feedback that we have received about our services from families who took on the task of looking after their husband/dad who had oesophageal cancer, and they were determined to do it, but had no previous experience with health at all. Certainly, this series of three webinars does not make them mini-nurses; all it does is give them a bag of tricks to try to manage those typical challenging symptoms that people experience at end of life and give them some guidance around how to talk with healthcare professionals, how to manage the medications and gave them templates for recording what people were taking and when they were taking it and how it was working. It gave them some skills around pain management and how to measure the success of the medications, but also a range of non-medical strategies to try. So, they felt equipped to do what they needed to do, rather than terrified that they might be doing the wrong thing. Just that little bit of confidence and capacity meant that they could embrace it rather than do it with trepidation. It completely changed the complexion of the experience, not only for their loved one, who did not want to burden them with the task of caring for them who could see that they were coping really well, but for them to feel like they did everything they could. In this particular case,

dad was able to die at home the way he wanted to with the family, and they said it was the most amazing experience. The bereavement experience for the family when it happens like that is quite amazing and very different from the people who have had a bad experience of their loved one's death. They just get stuck.

The CHAIR: Your submission mentions that the carer education package was successfully provided online as a result of COVID-19, in fact. Are there other lessons that can be learnt from the COVID-19 experience in terms of the use of technology and provision of palliative care?

Mrs BROWN: Definitely. I am wondering if we will go to a face-to-face format to be honest, because a lot of the people said it was so much easier to go online than to leave their loved one and have to come to a venue. They did not seem to be wanting, necessarily, that link with other people in the same boat; they just wanted the information so they could get on with it. It will always be an option to run a face-to-face program, but it seems that the webinar style really worked.

The other thing that we implemented is a community-connect phone line. People will often just want to talk to someone about how they are feeling about looking after someone who is dying or talk about their bereavement, and because our volunteers do that on a face-to-face basis, we thought, "Well, we'll get a mobile phone and make that phone line available to anyone who is struggling with that." That is also something that can be available throughout the state. It is really interesting that many people just need to be able to talk it through a couple of times. We know that healthy bereavement and the transition to life without somebody who is ever so close to you in life when they were with you takes about three to five years. So, public expectation that "it's been three months, aren't you over it yet?" prevails. So people stop talking and they stop asking, and if they can ring a number where they know they will speak to a volunteer that they have gotten to know over a period of time, that listens without judgement, that can hear them say "I'm glad they're gone" without going "Oh! That's a terrible thing to say", because they understand it is because they are not suffering any more—they get it. That is hugely liberating and people can get back to normal life and be productive members of community instead of turning up for more antidepressants or sinking into depression and despair.

[12.50 pm]

The CHAIR: A number of submissions have mentioned to the inquiry that there is difficulty around the provision of respite care for carers, that that is an ongoing challenge. How do you think it is going in the Busselton area?

Mrs BROWN: I think since COVID it has been terrible because most carers, I think, who have had in-home assistance that just disappeared overnight. Being able to talk to one of our volunteers or have an ongoing relationship with one of our volunteers over the phone has held them and that has been a great thing. I think that a lot of carers and people at end of life who enjoyed coming for our complementary therapies have missed that too, because that was one treatment that did not hurt; it was one treatment that was restorative and relaxing and gentle and they could say nothing or they could say lots to, again, a group of people who understood where they were at at that given time. We are looking forward to starting that up again next week.

Mrs MONSON: I think one of the outcomes of the community outreach volunteer program will be to assist with that carer fatigue. One of the pervading reasons for admission to hospital towards the end of life is carer fatigue and people needing respite. People are often admitted to hospital for respite for the carer, then they go home again. We anticipate that by giving some support in the home and carers being able to have mini-breaks, if you like, and getting some support and assistance and confidence, that will alleviate some of that need for respite.

The CHAIR: Do you think this issue is impacted by the additional support provided by volunteers? The volunteers are helping filling the gaps more and more.

Mrs BROWN: Definitely. If a carer can go and get a haircut without fretting that the person they are leaving might have some kind of incident or need them, so they know that they are in the hands of a volunteer who is capable and comfortable in being present for them, that suddenly gives the carer that time out that enables them to still be who they are. Through their continued connection and social existence in their community they bring that back to the person at home and that keeps the person at home connected. It preserves that social identity of the person who is dying so that they do not die a social death before they die a physical death. Our social identity is everything. Our connection to the people that we have come to know in our community is so important and it is severed when people are admitted to hospital. Both the presence of their community members in those spaces says, “We still care about you, we can still connect with you; you’re not just someone with cancer, you’re still Joe Smith who used to be the president of the bowls club and who used to”—that is maintained and preserved.

The CHAIR: Are volunteer services provided in aged-care facilities?

Mrs MONSON: Sometimes.

Mrs BROWN: Yes, there are a few examples of that in Busselton. They tend mostly to be companions; they do not tend to do the end-of-life vigil-ing or anything like that, though. We did ask and have been asked by some of the residential care facilities to provide some training for their volunteers, but I think they find it difficult to identify the volunteers that they have in their existing cohort who want to do that kind of work.

The CHAIR: You would be aware of the end-of-life choices report that came out and the recommendations in that. Is the Department of Health doing a good job of communicating how well those recommendations are being implemented? Are you hearing about those?

Mrs MONSON: I do not think so.

The CHAIR: We have seen a number of submissions say perhaps there could be a more effective communication.

Mrs MONSON: Yes, I think there could be. I think people have got unrealistic expectations of this new legislation. I do not think it will turn out to be what people think they might get from it. It would be good to have more communication, which kind of comes back to the importance of having good palliative care when it comes down to it.

The CHAIR: We have received a number of comments around the need for palliative care navigators to help people navigate through the system, similar to a role that is being proposed for navigating through voluntary assisted dying as well. Do you have any comments on how that could look, that navigator role?

Mrs BROWN: I know that is certainly part of the “compassionate communities” movement. I think they call them “connectors”, people who understand the landscape and help people to find out how they go about organising whatever it is that they would like for end of life. We do a bit of that—actually, we do quite a bit of that. Just on Monday I had a call from a young man whose aunt is an inpatient at Charlie Gairdner’s and has been given a terminal diagnosis and advised she probably will not go home. She is a resident of Perth, but used to be a resident of Busselton and the family is still in Busselton. He was asking me how he organises for her transfer from Charlies to the Busselton Health Campus hospice unit. I was able to give him a little bit of advice about how he tries to organise that.

Mrs MONSON: I think you said he had to be a project manager.

Mrs BROWN: I did say he needed to be a project manager and put him in touch. It was a case of he would need to get her a GP in Busselton who could then work with the doctors in Charlies to get her transferred to his care via the health campus. I said “The staff won’t necessary know how to do that, so, you’ll probably have to keep asking to see if things are being done so that it happens in a timely manner”, because my sense was he did not have a lot of time to organise it.

The CHAIR: This is a role played by all the volunteers?

Mrs BROWN: The volunteers probably would ask one of the staff at Busselton hospice, so myself or one of the coordinators, what to do.

Mrs MONSON: They could be trained in that. We have talked about involving them in some of those advance care planning conversations. They could be trained to do that, yes.

Mrs BROWN: There is a program I think that we were looking at asking if there was a group of volunteers that might like to do that training to be able to raise awareness of what is involved with advance care planning and advance care directives. We have had a few workshops at our facility about that, educating the community on advance care planning.

Hon NICK GOIRAN: Just on this, I think that there is a real opportunity here to upskill some of the volunteers in this area, this gap at the moment with regard to navigation. Having said that, my personal view is if any state government is going to fund professional VAD navigators, then there should be funding for professional palliative care navigators. I guess my concern with regard to us trying to shift that on to the volunteers is that I would not want the roles to be conflated, because the roles currently placed by those volunteers, say for instance in compassionate communities to provide that fellowship, that support, you know, that wrapping around of the arms of the community around the person in need is quite a different and crucial role to the navigation. Yes, you could well have people who are capable of wearing double hats, but I do not want that to be lost in all of this.

[1.00 pm]

Mrs BROWN: No, I think you are right, and that is certainly a boundary that we have to manage really carefully for the volunteers that we have who used to be nurses or health professionals. They have to work even harder, I think, than those volunteers who have not had a professional background in health, to wrench that clinical hat off their head and know that when they are a volunteer, they are a volunteer. They are not being a nurse anymore. So definitely those sorts of boundaries and limits around responsibilities and the sorts of advice they should give and the sort of advice that is not in their remit to give is one of the reasons they need good ongoing management by a professional coordinator.

Mrs MONSON: We believe that the volunteers are not there to save money; they are there to add a great deal to the experience and to the service that people who are dying receive. We have had so many experiences of this. Just as an example, I remember one family where the mother wanted to die at home. Her daughter did not have the confidence, so the mother was admitted to our hospice unit. What happened in about a week of the family watching the volunteers—these are just ordinary people who had the confidence and the positivity to be around death—within a week, that family said, “I think we can take mum home.” Mum wanted to die at home, so mum went home and died, and it was really because of the confidence that they derived through just being in that atmosphere—a positive atmosphere around death. It was just that whole climate. The other thing is that volunteers provide inclusion in the community. Years ago, people who were dying used to be avoided. That was the history from which hospice came. So, they are very much there to

communicate the inclusion and the valuing of dying people, right to the end. They provide a lot of—it is that emotional support. When we say “spiritual support”, it is not about a particular faith; it is about that whole giving of love and respect and being there and accepting the person, with whatever is happening.

The CHAIR: We are just about out of time. This will be my final question, and other members might have a final one, too. Some submissions have talked about confusion in the community around what is palliative care and what is voluntary assisted dying. Is that something that you are seeing as well?

Mrs BROWN: I think that the community is confused about what palliative care is, and it all gets muddled up together. I think a lot of people think it is the last days of life. I think they believe that it is when you are relegated to God’s waiting room, you know, the scrap heap, we cannot do anything more for you, we have given up on you, so that is when you go into palliative care. I think that even the specialists—oncologists, radiologists, chemotherapists—do not tend to make palliative care referrals, even when they know there is nothing much more they can do for their patients. They leave it to the GP, and hopefully the GP makes a referral. But how much better would it have been, when it was evident that treatment was not going to be curative, if a referral could have been made at that point? We know people live longer and live better and their direct family and friends do better with an early and timely referral to palliative care, but it is not happening. I think it is because health professionals are not well versed in what it should be and what it is, so it is not surprising that the general public are not either.

The CHAIR: Thank you so much to both of you, Ms Monson and Ms Brown. It was a really valuable contribution. We can end the broadcast there, thank you. A transcript of this hearing will be forwarded to you for correction. If you believe that any corrections should be made because of typographical or transcription errors, please indicate these corrections on the transcript. Errors of fact or substance must be corrected in a formal letter to the committee. When you receive your transcript of evidence, the committee will also advise when you are to provide your answers to questions taken on notice, but I do not think we had any questions taken on notice, so that is all fine. If you want to provide additional information or elaborate on particular points, you may provide supplementary evidence for the committee’s consideration when you return your corrected transcript of evidence. Thank you again.

Mrs BROWN: Thank you very much for having us.

Mrs MONSON: Thank you for the opportunity.

Hearing concluded at 1.04 pm
