

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Warrnambool — 30 July 2015

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Ms Deidre Bidmade, Vice-President,

Mr Damian Goss, Board Member, and

Ms Tam Vistarini, Hospice Manager, Warrnambool and District Community Hospice.

The CHAIR — I would like to welcome the Warrnambool and District Community Hospice, in particular Ms Tam Vistarini, Ms Deidre Bidmade and Mr Damian Goss. Thank you very much to the three of you for being here today. Before we start I will just caution you that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege.

Today's evidence is being recorded. You will be provided with proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed 45 minutes for our session today, so I would invite you to make some opening remarks, and the committee will have questions thereafter. Thank you again for joining us.

Ms BIDMADE — Good morning members of the committee and fellow guests. Thank you for this opportunity to speak at a very important inquiry about end-of-life choices. My name is Deidre Bidmade. I am currently the vice-president of the Warrnambool and District Community Hospice. Tam Vistarini is our hospice manager, and Damian Goss is on our board of management.

I would like to put in an apology for Dr Eric Fairbank, who cannot join us today. For those of you who do not know Eric, he has dedicated his whole life to the care of the dying. He has worked as a GP and then as a director palliative care in the region. In 2013 he was recognised and received the Medal of the Order of Australia for outstanding achievement and service, followed by the Victorian public healthcare award for lifetime achievement. Eric continues to shape care delivery for people facing end of life, speaking both locally and internationally, and he is now retired, although I question the word 'retired'. His passion for end-of-life care continues today with the Warrnambool and District Community Hospice, and we consider ourselves blessed to have his lifetime of wisdom, knowledge and guidance as he continues in his role today as our patron and our current president. He has reiterated that he would be happy if you were wanting to contact him and that he would make himself available, just so you are aware of that.

The CHAIR — Thank you for that.

Ms BIDMADE — The Warrnambool and District Community Hospice was established as a not-for-profit community organisation, incorporated in 2010 with tax-deductible gift recipient status. The vision of Hospice in the Home is to provide people who are dying with an option of compassionate care to stay in their own home setting, meeting the living needs of those dying as well as the needs of their families and their carers. Our values are around compassionate care, delivered with respect and sensitivity and focused on individual needs to maintain dignity. Our excellence in care is high quality, meeting the best current practice standards; it involves sustainability, also meeting the ongoing demands, both professionally and financially; and it also involves community care, where we are working in collaboration with existing services. As you commented earlier, Chair, 76 per cent of people would like to die at home, but unfortunately in Australia 14 per cent get to do that. This happens, we believe, because people are not prepared well for death because dying is seen as a medical event. People do not want the burden put on themselves, and caregivers become exhausted in that process.

We acknowledge advance care planning processes as a very important part of this solution. This framework under the authority of the Medical Treatment Act 1988 encourages people to think ahead and to make their wishes known about how they want to be cared for and where they want to be cared for. Important decisions then can be made when it is not a crisis situation, but unfortunately at this point a minority of people make use of that legislation. But as we have seen with South West Healthcare's presentation, there is work going on to bring that further to the fore.

More support for home care is another important part of this solution, we believe, because you cannot expect family to cope on their own with dying relatives. Some other solutions that we see is bringing the public, the private and the volunteer providers in the community altogether to work as one, and the provision of a dedicated end-of-life phone line to help families and carers and to help with the continued growth of hospice in home, supporting families, particularly overnight and on the weekends. Hospice in home will work in collaboration with existing services, in particular South West Healthcare, which you have just heard from, and community palliative care and local GPs.

We have specifically trained volunteers, who are trained through the Palliative Care Victoria program. They have gone through the same process to assist family and friends to care for people that are dying in their homes.

Our biggest point is being able to offer that overnight, weekend and extended day care, depending on of course the circumstances and our resources. Our service will be provided at no charge to the patient or the family. Initially the service will be confined to adults living in the Warrnambool area who are in their final stages of illness and whose symptoms are able to be managed at home. Referrals we will receive from community palliative care oncologists, other health service providers as well as families themselves. The eligibility will be available regardless of people's beliefs, origins, finance or diagnosis.

Tammy is going to intervene here and talk to you about her role and where we are since we opened on the 13th of this month.

Ms VISTARINI — Thanks, Deirdre. I am the newly appointed hospice manager — dragged in from retirement, a creaking geriatric. I started work there on 13 May, and we opened our doors for referrals on 13 July. So in the interim time we have trained 17 volunteers. They did the palliative care course, which is an accredited course, but they also did additional practical hands-on skills: no-lift policy, able to move patients in their beds, and to help the patients, if they are up to it, out of bed to go to the toilet, and things like that.

We have also spent a considerable amount of time in those last two months getting all our policies and procedures in place. That has been quite a challenging task. Palliative Care Victoria has a suite of policies, but they did not cover everything so we have had to write new policies. We have also been helped in that by South West Healthcare. Andrea Janes has given us some help too with that. We are very pleased actually to have all of those behind us because it provides a safety net. People have to know what our policies are, what they can do and what they cannot do. We are training the volunteers. A third of them, I think, are currently practising nurses who obviously see a need and want to be able to help people further. A third are ex-nurses. Some have worked in aged care. Some are cleaners. They are just wonder women. We only have one male, unfortunately, and we are going to be trying to recruit some more males.

I read the news and I get really discouraged about what is happening in the world, and then I think of the people who volunteer to work in hospice and I just think there are good angels in the world too; they are just wonderful. We have not had to advertise. The initial group all came to us offering their services, and we have another group of 21 ready to start training on 23 September.

The CHAIR — That is great.

Ms VISTARINI — Yes, it is fantastic. Then we will be better set up to cope with more patients. At the moment I do not know how we will go, because people as volunteers are not available 24/7 — 30 days, 31 days of the month. It is a case of us learning as we go.

My job is to help with the recruitment — although, as I said, that is very easy — all of the administration of the role, and receiving referrals. Most of our referrals we expect to come from the palliative care team. I was talking to a patient at the hospital yesterday as a referral from them, but unfortunately he has to have another round of oncology so he will have to stay in hospital for a bit longer, but I expect we will meet him down the track. I have met with the family and made the initial contact there. I will do the rosters and assign volunteers to families. I will monitor what goes on each day, how things are going, and then after that, if our volunteers require support, there will be follow-up and debriefing and counselling provided if they need it.

As Deirdre was saying, we will be able to offer overnight, extended, daytime and weekend care and at no charge to the patient. Unfortunately it is limited to the Warrnambool area at the moment, but we have had calls from Shepparton.

Ms BIDMADE — Tasmania.

Ms VISTARINI — Tasmania.

Ms BIDMADE — Macarthur.

Ms VISTARINI — Macarthur.

Ms BIDMADE — We have got a lot of people enquiring into Hospice in the Home.

Ms VISTARINI — I was just saying to Deirdre a moment ago that I think one of our roles will need to be in the future going to satellite areas and saying, ‘This is how you do it. Here are all your policies and procedures. You train up your own volunteers and you run it, but we will provide support whenever you need it’. I think that is the way it is going to have to go if we are going to get out of the main centres.

The volunteers, although many of them are nurses and ex-nurses, have it drummed into them: ‘You are there as volunteers; you are not there as medical people’. They are now spouting that back to me, so they are very well aware of that. We do have some patient eligibility. It is only available for adults because, as you heard, paediatrics is handled by the paediatric ward at Warrnambool Base Hospital. There has to be a primary carer there. We cannot go in and provide 24/7 care on our own. They have to have symptoms that can be managed at home, and we have to have volunteers available, and the environment has to be a safe one for volunteers to go in.

The process is that we receive a referral, and we meet with the family to discuss their needs and whether they want to go ahead with Hospice in the Home. I will go in and do an in-home risk and needs assessment, so we make sure there are no vicious dogs, that they are not going to be smoking when the volunteers are there and if there are stairs in the place. It is a four-page risk assessment. The patient or carer must sign a consent form agreeing that they can change their mind at any time — I can show you the consent form, if you would like to have a look at it — but also saying that there must not be any people in the home suffering from the risk of alcohol or drugs or smoking, just to keep our volunteers safe. Then we allocate volunteers to a roster. The family can refuse a particular volunteer or a volunteer can reject a placement with no reason given. There might be all sorts of things; we do not want to know about it. The volunteers have been trained in what to do when a death occurs. Then afterwards, as I said before, we provide debriefing and counselling support.

I would just like to pay tribute to Dr Eric Fairbank AM. Eric is the reason I am in this job because I have enormous admiration for him. You are looking at three palliative care volunteers, Damian, myself and we have got another one in the audience, who are committed to looking after people like this. We are there because we hope people who prefer to die at home will have a better chance to do that, that families and friends will be supported through very tough times and that there will be fewer inappropriate and inexpensive admissions to hospital. We hope there will be improved community resilience in the face of dying. It is a very much a taboo topic, but it is receiving quite a bit of publicity at the moment, so that is changing. I would like to hand over to Damian, who is going to talk about his experience as a palliative care volunteer.

Mr GOSS — I am an amateur in this business, so bear with me. I have worked in local government for nearly 38 years, and I got into being a volunteer because a friend of mine who I worked with for 28 years got cancer and needed to be looked after. His marriage had broken up, his children were spread around, and he had no-one to look after him. I ran messages, took him to the doctor and did different things, and when he passed away I was approached by palliative care and asked to become a volunteer. I was rather shocked because I am the sort of person who needed to have a general anaesthetic to go to hospital as a visitor. I did not think this was for me.

However, I was talked into it, and it will be the last thing that I give up, I can tell you. I went off to boarding school at age seven. I was the youngest in the school. I had 10 years there, and death was something that came along every now and then because either one of the kids at school had died or one of the brothers had died and his coffin would be sitting in the school chapel. Death is something that I have had to try to come to grips with. Since I have been involved with palliative care as a volunteer, I have had some absolutely wonderful experiences. Having been the third of nine children — six of us were born at home — I intend on dying at home. It has been underwritten by my experiences.

I have spoken to a few of the families, and they have given me the okay to mention some of the experiences I have had. During my time as a volunteer I get a patient who may be weeks or a few months away from going to the next life. When you go into their homes, you notice at times that probably there has not been a lot of talk about someone dying. Everyone is exhausted. They have gone through all the different processes and hospitals and the like, but I have found that the experience of going in as a volunteer is really fantastic. You are giving relief to families and the carers, and you have some wonderful experiences.

I will give you some examples. I had a young man who worked internationally with children. When his time came up, I had to introduce myself to him, and I found that he did not want to be confined to the house either. He wanted to go for walks. Often we would go for walks around here and have a cup of coffee and do a whole

lot of things. When he passed away his brother rang me and said, 'Thank you. You did a wonderful job. He really loved what you did'. I was a bit surprised, so I said to him, 'When's the funeral?'. He said, 'There isn't one. He's sprinkled at Thunder Point already'. I thought, 'Oh well, that's the way people do it'. Since then I have had some really wonderful experiences looking after people.

We had a situation where there was a man who had a number of different careers. One of them was as a butcher, and one was as a nurse. He too did not want to be confined to bed. When I turned up to give his carer a bit of relief, he was happy to go for a walk, get in the car, go out and do some shopping. It was really wonderful for him because everywhere we went he knew everybody. We had a wonderful time. It just helped him get on. One day we came down here and had a cup of coffee. As we came out of the Pavilion he looked over and he said, 'They're filleting fish over there. Have we got time?'. So we went over there. There was a fellow trying to fillet a gummy shark, and he was really struggling. My man went over and said, 'Excuse me, I used to be a butcher', and he grabbed a knife and filleted it. It made his day. Families say to you, 'The things that you have done have been fantastic'. It takes the weight off their shoulders, and it really makes living life worthwhile. That is it: they are living life. They are not waiting for death to come; they are living through to the end.

At the moment I have a person who is a very interesting character. He has had a variety of experiences throughout his life. At age 70 he got a pilots licence. He is now in his late 80s. When I turn up, he jumps out of the chair and grabs his walking stick. I help him down to the car, and I say 'Where do we go to?'. He says, 'Out to the airport'. He wants to see planes taking off and landing. He wants to see what work is being done there. We go off and have a coffee. Every time I take him home he says, 'Gee, I love it when you come. This is great. It gives my wife a break. She can go and catch up with friends, she can go and do some shopping or she can just relax'. These are the sorts of experiences I have had. Because of these experiences I believe there is a great opportunity to help people spend the rest of their life at home instead of in a hospital ward.

The work that the staff do in the hospital is just fantastic. The medical staff, the nursing staff and the volunteers — they are just brilliant. I also do massage, and it is interesting that when you go in and you do the massage people start to open up. Sometimes if their families are there with them, they open up as well. I get the impression that most of them, frankly, would prefer to be at home, not there. They would prefer to be in familiar surrounds where the carer can do some of the things they normally do instead of just sitting in the hospital trying to make conversation. I suspect in a lot of cases the conversation is not about the end of life. I think the experience now that I have had, and being part of this committee and trying to get it off the ground, I see a wonderful experience coming ahead for everybody — not only for the person who is nearing the end of their life but also for family and friends. It is something we all need to come to grips with. I think that probably too few people know how to talk about end of life, and probably the people who say that they would prefer to die as an inpatient somewhere say so because they have not talked about the end of life.

I think through the experience that the volunteers have, many of them would tell you that when they go into hospital or a home, they would prefer to be there. That is my experience, When this hit the newspapers, the number of people who came to me and said, 'How do I get involved in this?' was tremendous. I think it is something that is really worthwhile. The work that Eric has done over the years has certainly opened it up here. Our experience with meeting groups like the Anam Cara people at Colac is fantastic. I hope now that Tam's group is getting the referrals it will certainly make a big difference.

Ms BIDMADE — So as you can see, guys, we are pretty passionate about giving people the choice of staying at home. My background is as a palliative care nurse at St John of God. I have a graduate diploma in palliative, so I also see firsthand where somebody comes into hospital. A recent situation I can decant is where the patient did not want to be in hospital, but his wife was struggling with the ability to care for him at home because he was having difficulty walking around. Her comment was, 'If I had somebody beside me, we could do this'. Every day it is brought up: if you have that support for the people who want it, it can happen. It is the fear of not having that support — that carer burnout and that lack of social support — when things fall over and you end up back in hospital, and you are opening that blind thinking, 'Is today the day?' instead of being home surrounded by your loved ones and, as Damian pointed out, living well until you die.

We believe with Hospice in the Home we will be able to have a better chance of giving people that choice. We can support family and friends through that difficult time, and I believe in that process that we will improve community resilience in the face of death. So instead of death being in the cupboard, it will be out and about

and people will be talking about it. As the last presenter said, we come into the world with whistles and balloons, and there is nothing wrong with doing that on the other end.

I just wanted to make another point: as well as improving the quality of living and dying, there is also a strong economic argument for Hospice in the Home. According to the Grattan Institute *Dying Well* in 2014, the number of Australians who are going to die the next 25 years is going to double. We have hospital admissions for dying patients into beds that are already in short supply. If you look at the fact there are six at South West Healthcare and two at St John of God, where does that put us in the future? I think under an immense amount of pressure. We have calculated that it will cost about \$125 for Hospice in the Home to care for somebody in their home environment.

Ms PATTEN — Did you say \$125?

Ms BIDMADE — Yes.

Ms PATTEN — Over what period of time?

Ms BIDMADE — Per day. It is \$800 a day in a hospital bed, as opposed to what we believe to be \$125 in home with the support of volunteers. Hospice in the Home has been very fortunate. While it has been a few years in its making, we have had amazing community support. Deakin University, which you guys would have passed on your way into Warrnambool, kindly have given us a house out there at peppercorn rent. We are using that as our headquarters and also our training facility for our volunteers. We are hoping down the track to actually get more involved with Deakin, where the nursing staff can be exposed to death and dying too, because it is amazing how the younger nurses coming into the system do not get a big window into palliative care. So it would be nice if we could work along a pathway of creating conversation with younger nurses as well and trying to really turn that culture around.

We have been really fortunate that local trusts and foundations, our community in general and our fundraising team have done a remarkable job to see us have enough finance in the bank to see that this project is able to be sustained for a few years. We have investigated far and wide and believe to the best of our knowledge that the Hospice in the Home program is a first for the state, if not for Australia, in providing this type of care. We have a dedicated website now. We have been very fortunate to have our media outlets support us in this endeavour. Our local radio station dedicated a whole month to hospice and death and dying. That was amazing in itself. From that we have received, as Tam alluded to, a phone call from Tasmania, and some of the committee are going over there to be part of a presentation. We have had calls from the Blue Mountains in New South Wales, from Macarthur — lots of people ringing up saying, ‘How do we do this? Can we get on board?’.

Given the fact that we are weeks into our opening, we are very aware that we need to gather data plus, plus, plus, and do this well. I believe we are well and truly on the way with our policies and procedures, and the expertise of Eric, who has given his whole life to death and dying. We know the problems. We are not saying there are not going to be teething problems. I am sure there are with any new venture. But as a very dedicated team, we are happy to deal with that as it comes along.

Again, we believe families cannot do death at home on their own, unsupported. However, with a funded government strategy for end of life it is essential for hospice to be made widely available and be sustainable into the future.

Mr GOSS — I would just make the point too that sustainability is going to be a real issue. It is all very well having the local philanthropic societies, sporting clubs, Rotary and all of those giving us money, but the reality is you cannot go back to them every year and drain them, because they do not the capacity to just deal with one organisation all the time, and they have a lot of other organisations they would like to help. Sustainability is going to be a real issue for us. Whilst we might have the funding for the first couple of years, because of the generosity of a lot of groups and organisations, we really need input from government.

Ms BIDMADE — As pointed out by our colleagues South West Healthcare, rural is just so badly in need of support. We have at this point in time made it specific to Warrnambool only, but we really want to take this out to everybody. We want to do this absolutely right and get all the players involved. We have approached all the GPs here locally, the oncologists; they have been more than supportive. They can see the gaps in the system,

and they too really want to be able to give people that choice to say, 'Okay, here is something that is going to help you go home'. We are pretty passionate about filling that gap.

The CHAIR — Thank you to the three of you for your presentation this morning. It gives us a real insight into, first of all, what a great community obviously it is here to have yourselves and so many volunteers donating your time and energies to such a worthy cause, but also to hear how you can help people stay at home and continue to live life, as you said, Mr Goss. It has been really informative for us.

If I could just pick up, Ms Bidmade, the point you made about Deakin University, because I think that is really interesting. In previous hearings we have had in Melbourne the point was made to us a number of times that many medical practitioners do not have experience with palliative care and perhaps do not encourage those conversations that many people have said need to occur. I am really interested to learn more about what you are planning to do with Deakin and with the nurses there, and perhaps that could be something that could be picked up in other parts of Victoria as well. I invite you to make further comment about that.

Ms BIDMADE — In my role as a palliative care nurse, I have observed that new graduate nurses receive brief exposure to acute medical and rehab wards but very little exposure to palliative care.

I remember when Eric was wanting to retire, just to get somebody to replace him was incredibly difficult, so we are all on the page of saying, 'Okay, palliative is worthwhile. Let's have conversations'. You see the younger nurses will walk into a room where somebody is dying, and the awkwardness of that is very evident, because they are just not sure. They think, 'If I say the wrong thing, am I going to make things worse?'. While we have not firmed up how we are going to go about it, we believe because we are on premises and they are so very supportive of us, that we are going to devise a plan that will see an opportunity to have new nurses and doctors come in and see Hospice in the Home and be comfortable with somebody who is dying. We are very keen to just get the news out there and have people comfortable.

Ms SPRINGLE — If you could indulge me a little around the logistics of exactly what happens when one of your volunteers goes into a home, perhaps overnight — or, it says, 'overnight, weekend and extended daytime care'. I am assuming that that is around respite for carers? Is it just respite? Can you give me a little bit more practical information about that?

Ms VISTARINI — It can be just respite. It can be going in and just staying with the patient while the carer goes, has a haircut, does some shopping, whatever. But it could be a whole range of things: it could be talking to the families; it could be hanging out the washing; it could be washing their hair; it could be cooking a cake; or it could be assisting them in bed, to turn the patient over. It could be staying there. We have a shift from 10 o'clock at night until 7 o'clock the next morning, so the carers can just go to bed and get a sleep and not have to worry that the patient is going to have a fall or wake up in pain. They can ring the 24-hour palliative care number if there is an emergency and they can support the family. They can be there at the time of death — they need to use their own discretion there — but they have been trained to make the body straight, stay with the family as long as it feels right, and not to overstay their welcome but not to just say, 'Okay, I am out now'. So it is a whole range of things.

Some people are happy to go in and do housework. I have got two volunteers who desperately want to go and clean people's houses. That is fine. I will ask the families what they want and try to match the specific volunteers with those needs. We have to be careful, too, that there is some consistency. You do not want a different person coming in every time — three different people in a day — so we have to try and work out the quite complex issue of sorting out the rosters. Does that answer your question?

Ms SPRINGLE — Yes, thank you.

Ms BIDMADE — If somebody is close to death, just being able to position the person on your own is incredibly difficult. If you have got somebody right there beside you who can roll somebody to do a pad change or something like that is very important. It is just to be supported in that. Everything little is just insurmountable in this situation so by just putting, as Tam so eloquently refers to, the angel in the house, it just makes such a difference. If somebody is not bedridden at that point but they are in a wheelchair and the wife cannot get the husband into the wheelchair, here is the person who can do that. They have been trained in no-lift techniques, and while we have to refine that a little because it is not a hospital environment per se, they have been trained on just ordinary double beds at home as to how best manoeuvre people in the bed.

It is about that caregiver, who has been three days without sleep, and being able to say, 'Okay, I am here. I will just sit here and you go to bed'. So they actually sleep and the next day they can cope with what is in front of them, but without that it is just insurmountable. Hence that admission into hospital comes, in a lot of cases, for that very reason; they are just burnt out and they have not got the supports. So that then drains the system by putting a person into a bed when somebody medically needs to be in that bed. We feel the benefits from a hospital perspective as well, with freeing up hospital beds for people who are dying, and who do have medical needs, so we feel it is a win-win all around.

Ms SPRINGLE — And you are the only staff member?

Ms VISTARINI — I am, yes. Not even full time.

Ms PATTEN — It is fantastic and a first in this state, which is well done.

Ms BIDMADE — It is exciting.

Ms PATTEN — It is exciting, and I hope we will see this replicated in lots of other areas. I have two questions. One is that yesterday we were speaking to Max, from the multicultural home care support, and they are starting to be trained in palliative care. Again, it was around providing that crucial respite for the carers or assistants. The area that they noted as being a problem was in those overnight stays when they were not allowed to use medication. They were saying, 'We are staying here overnight, but we have to wake up the family member every time the medication needs to be provided, which might be every few hours or as needed'. They talked about being able to possibly train those carers into being able to medically assist or medically supply medication. Is that something that you have considered?

Ms BIDMADE — Not at this point in time. We are quite the contrary in that this is not a medical model. As you point out, you might have to wake that carer up, but the point I make there is that at least they are asleep. If they did not have somebody beside them, they would not be asleep and the escalation would be continuing. That is not something at this point in time that we are considering going, as far as medication goes. The GPs have been very supportive in their ability to help us and they will be very much part of that process. We are not going in to take over. We are going in as part of the team, so we will have community palliative care, we will have the oncologists, we will have the GP, but we are all working for that one goal.

Ms PATTEN — Considering the whole toolbox that this inquiry is looking at — and I think that is one of the benefits of this inquiry, that we are looking at a whole bunch of areas and you are creating that very innovative space in there — with all of your experiences, I wanted to know whether, you would see physician-assisted dying or voluntary euthanasia as part of the toolbox in your experience as palliative nurses in the past. Obviously not with the hospice, but is it something that you think can be part of that toolbox?

Ms BIDMADE — From what I read on euthanasia people have concerns on being a burden to their loved ones, a fear of a loss of autonomy and ability to participate in life, and are frightened of dying because they feel unprepared or conversations haven't happened, and possible increasing pain also being of great concern. Would you like to make a further comment on that, Damian?

Mr GOSS — I just think from my experience, the fact that volunteers have been going into the home and giving family relief, people start to back away from that idea. I think when they get that level of support it is not something high on the list, and I would suspect that, particularly with this type of help, it would go further down the list. I think once people learn to talk about the process of end of life and they make those decisions — and it is really good to hear Dr Emma and her crew talk about when someone goes into hospital now and they fill out the forms and they are talking about resuscitation and things like that, I think that too will help people in many ways. I think it becomes less of a proposition.

Ms BIDMADE — In my short time in the last 10 years the biggest factor when somebody is dying is how I am going to die. Is my pain going to be out of control? These conversations before somebody is in their last phase of dying is so important, because if you allay those fears and reassess the fact that we have such wonderful drugs out there to ensure that people are not in pain and that we do have things like Niki syringe drivers, so that you can go home with that in situ and that can be titrated to the needs every day, if you can give people peace of mind that they are supported in the journey and that there is no need for acceleration of symptom, that in my experience has been most of the underlying issue.

It is the same for the caregivers. If they are unsure about taking their loved one home, and you can say, ‘But this person will be here with you’, the shared journey is so much more achievable. The stress levels are up here and by the time you have had those conversations and put things in place, it all seems achievable and it is on a supported playing field.

Mr GOSS — I also think if people have a better understanding in communicating with their medical people that pain control is pretty tops these days and once people understand that, there is a lot of relief. The other point I would make is that in my role as a palliative care volunteer, I really only get involved in the last months of their life, and I would say that everyone that I have dealt with in the last 15 years has had a good death.

Ms PATTEN — That is great.

Ms BIDMADE — There is no reason why we cannot have a good death.

Ms PATTEN — No. Thank you.

Ms BIDMADE — That is the whole point, and it is about these conversations. They are just so important. We cannot stress that enough. They are just so important to have.

Mr MULINO — I just wanted to say congratulations on what you have achieved, and I think what you are doing is very important. I can say from personal experience that the kind of work that you and your volunteers do does make a huge difference from the people that I have seen benefit from it.

The more I hear from people working in the space that you are in, it does seem as though — and I noted that one of the eligibility criteria is that there is a primary carer — it is a team in a lot of ways, the family and the person going through the experience. I suspect that as you develop your capabilities as an organisation and you have more and more volunteers, even though you do not want to be in the medical space, you will have a lot of scope to help that team in a sense with their skills, their competence and their confidence and their resilience and give them many more strategies to deal with all the different things that they will face. In addition to spending time with the person, I imagine that part of what you will be doing is also helping the carer with their confidence and their skills.

Ms BIDMADE — Absolutely.

Mr MULINO — Without wanting to get into medical expertise, there are a lot of strategies that you will be able to help them develop to work through what it is they are going to face.

Ms BIDMADE — That is right. Again, I just keep saying, ‘Support it’. It is the catalyst for everything. If you can support the caregiver and the immediate family, it is an easier journey; it really is.

The CHAIR — We had better leave it there. Mr Goss, Ms Bidmade and Ms Vistarini, thank you very much for your evidence today. To the three of you and all your volunteers — and I know we had some other volunteers in the gallery today — the committee would like to acknowledge the work you do for the community. It has been a real privilege for us to be able to hear what you do and learn more about what you plan to do in the future. We wish you every success.

Ms VISTARINI — Thank you for the opportunity.

Witnesses withdrew.