

# **TRANSCRIPT**

## **PANDEMIC DECLARATION ACCOUNTABILITY AND OVERSIGHT COMMITTEE**

### **Review of Hospitals and Care Facilities Pandemic Order**

Melbourne—Tuesday, 1 March 2022

#### **MEMBERS**

Ms Suzanna Sheed (Chair)

Mr Jeff Bourman (Deputy Chair)

Mr Josh Bull

Ms Georgie Crozier

Mr Enver Erdogan

Ms Emma Kealy

Ms Harriet Shing

Ms Vicki Ward

Mr Kim Wells

**WITNESSES** (*via videoconference*)

Adjunct Associate Professor Kelly Rogerson, Board Chair, and

Adjunct Associate Professor Violet Platt, Chief Executive Officer, Palliative Care Victoria.

**The CHAIR:** Thank you very much for attending this afternoon to speak to our committee. We are very pleased to have you. I will just introduce you to our committee members. We can see you. I have got Harriet Shing, Josh Bull, Georgie Crozier, Emma Kealy and Kim Wells, and we have Enver Erdogan on Zoom. Thank you. And I am Suzanna Sheed, the Chair.

All evidence taken by this committee is protected by parliamentary privilege. Comments repeated outside this hearing, including on social media, may not be protected by this privilege.

All evidence given today is being recorded by Hansard. You will be provided with a proof version of the transcript to check. Verified transcripts, presentations and handouts will be placed on the committee's website as soon as possible.

I welcome our witnesses and invite one of you to make an opening 5-minute statement, and that will be then followed by questions from the committee. Thank you.

**Adjunct Assoc. Prof. PLATT:** Okay. Thank you and lovely to meet you all. Thank you for inviting Palliative Care Victoria to appear at the hearing. I am Violet Platt, and I am the CEO of Palliative Care Victoria. Kelly Rogerson is Board Chair. We are both registered nurses by trade—from a very long time ago, I think it is okay to say. We are the peak body for palliative care and end-of-life care in Victoria. We are an incorporated association supported by the Victorian government, individuals and organisational members, and our vision is for all Victorians and their families—to support them so that they can live, die and grieve well with a life-limiting condition. End-of-life care is aiming to support the person at the end of palliative care to make sure that they can die in their place of choice—so in the right place, with the right people and with the right level of symptom control and support available.

As usual business, Palliative Care takes calls from members of the community and from health professionals seeking information, advice or connection to services, other people and resources. In our written submission on 1 October 2020 to the Public Accounts and Estimates Committee on the Victorian government's management of the COVID 19 pandemic we highlight the key challenges for those receiving palliative care and their families, palliative care services, health professionals and grief and bereavement and impacts on volunteer services, and we are able to present to the hearing today an overview of the challenges that the visiting restrictions cause everyday Victorians who have got loved ones who are dying during the pandemic.

We received many calls from family members who were told that either they could not visit, they could visit for a short period of time or only two members of the family could visit, and the types of questions that we would get asked were, 'Can we advocate for longer and unrestricted visiting times?', 'If we bring our loved one home, what care is available in the community to support us?', 'Is 24-hour care available?', 'We've been told there will be less community palliative care nursing time due to COVID. Are there any other extra supports out there?' and, 'The hospital rules for visiting where my loved one is are stricter than the government rules. What can I do to advocate?'.

An example would be a gentleman who was dying from lung cancer who had six children. They were told that he was going to die any day now, and with the introduction of a five-day lockdown in Victoria the hospital had decided that there were going to be no visitors at all. We received a very distressing phone call as they were urgently trying to get Dad home that day with community palliative care support or they would have to leave the hospital at 8 o'clock that night, when visiting ended.

Transferring across borders and boundaries added an extra level of complexity. As you know, we have got many families in Victoria where part of the family lives in the metro and part lives regionally, and the inability to cross that boundary to help care for families was of considerable concern and caused a lot of challenges for many, as did bringing Victorians home from other states to die. We had a lady whose son was 31 and dying in Adelaide, and she was actually in Adelaide with him and had gone there to bring him home. Trying to navigate

the complexity of crossing that border was just insurmountable—even transfers between hospital and aged care facilities for metro hospitals and regional hospitals.

We were contacted by hospital staff who were unclear about the government's directions regarding restrictions, because there would be the government direction but then there would be the hospital direction, and families would come in with an expectation of the government direction and often the staff were having to enact the organisation's direction, which caused a great deal of moral distress for the clinicians who were trying to provide the best support for the families at the time.

Families did advocate really strongly for their loved ones. They noticed deteriorations during those limited visiting times. One family talked about how much their nanna declined in aged care because they could only visit every other day. They actively fed and gave Nanna drinks when they were there, and they really noticed the deterioration when they were not able to do that every day. And mental health was obviously greatly impacted for people who were isolated from their family when they were dying, and we had quite a bit of advocacy just to try and reduce that isolation for the dying person in the facility.

Our experience is shared not just by the cancer council but by the breast cancer network, by Canteen, who did a lot of work with young people who had dying parents, and also by the Victorian palliative care advice line, who found that 30 per cent of their contacts were because they could not visit someone who was terminal, and of those 30 per cent, 62 per cent were in hospital and 25 per cent were in aged care facilities. Latterly the contacts are more about the inability to access community palliative care services due to the long waitlists, reduction in face-to-face visits and staffing shortages. That is just a very quick snapshot across the impact to the community. We are happy to answer any questions.

**The CHAIR:** Thank you very much, Professor. That was most informative. You have certainly outlined the issues of people who have come to you faced with a range of issues. As an organisation can you talk about the challenges that you and I suppose staff who work in hospice and palliative care have faced, perhaps on a more coalface level?

**Adjunct Assoc. Prof. PLATT:** Yes. I think the biggest challenge has been about communication, understanding the rules and their implications and how we can work with them to get the best outcome for the person that is dying and their family. Every family situation is unique, and trying to apply that uniqueness against very rigid restrictions brings a daily challenge.

**The CHAIR:** So I imagine there would have been a lot of restrictions on being able to provide the services that you would normally provide in homes, for instance?

**Adjunct Assoc. Prof. PLATT:** Yes. Palliative Care Victoria as a peak body do not deliver direct care but our members do, and we had a great deal of engagement with our members during that time. Perhaps Kelly, as the leader of a service delivery organisation, would like to jump in here.

**Adjunct Assoc. Prof. ROGERSON:** Thanks, Violet. I might take an answer to that question. I obviously have the role of chair at Palliative Care Victoria, which is fairly new for me, but I am the CEO of a community palliative care organisation that covers 1800 square kilometres of Victoria. We saw a significant increase in the amount of people accessing or requesting access to community palliative care services because the community members chose not to have their loved ones in either aged care facilities or in-patient settings, such as acute hospitals, or in-patient palliative care services. What that meant for us at a real level was that we had to limit access to people who were stable or doing okay who would normally have regular visits and we had to really focus our efforts onto those with the greatest need—so those who were either in the terminal phase, of the last weeks of their life, or deteriorating or very unstable at any given time.

We also needed to reduce the number of visits that they would receive, so the ability to visit someone at their end of life a couple of times a day was completely out of the question. So we would do telehealth and other appointments and phone and video support rather than people physically being able to visit some people. And for others there were delays in getting to them because there was an urgent need for people—the length of stay in hospitals was reduced quite dramatically and so people were urgently—needing care out in the community, which was a real challenge for not just my organisation but all the palliative care services across the state.

You may not be aware that the state runs community palliative care to provide these services in home, and they are free and accessible to individuals out in the community, so to large numbers of the population, obviously—a 63 per cent increase in admissions for our organisation over the last two years, so a significant increase. But we are not part of the acute care sector, so we did not receive additional funding to support that workload or care. We did do a lot of modifications of what we could do, and I still believe that we did our best to be able to provide services to individuals as best we could, but we certainly saw a reduction in the quality and level of capability just to meet the high levels of demand.

**The CHAIR:** And just finally from me, I am just wondering about the level of consultation and interaction between you and the Department of Health in relation to the challenges that you were facing and also perhaps to inform the making of the orders that were made and how they might have affected you—were you asked?

**Adjunct Assoc. Prof. ROGERSON:** No.

**Adjunct Assoc. Prof. PLATT:** No, we were not asked.

**Adjunct Assoc. Prof. ROGERSON:** We do have links into the department. The staff member that we have in the department has been involved in palliative care and she is very informed about palliative care, and we do work very collaboratively with the department. We certainly did inform the department of our increased need and have continued to do so, but it is very challenging to get a seat at the table.

**The CHAIR:** So do you feel that you did not have the opportunity to share those incredible stresses and increased workload in the way you would have liked to?

**Adjunct Assoc. Prof. ROGERSON:** I think we shared them; I just do not think we have been responded to.

**The CHAIR:** Yes, okay. Okay, thank you very much. Look, I will move on, on that basis, to Ms Shing.

**Ms SHING:** Thank you very much, Associate Professor Platt and Associate Professor Rogerson. It is a qualified room this afternoon. Firstly, thank you to you and the teams and to all staff and volunteers who work in this exceptionally important part of care and dignity. It has arguably never been a greater focus than at times where limitations have been in place for visitation and the things that people hold most dear when they are at the end of their lives.

I would like to take you to a number of the things that have been raised in your presentation, Ms Platt, in particular, around changes to visitation and the impact that that had on people. We had anecdotal information from you around longer visiting times and what could be done there, alongside the—I think you have referred to it as an insurmountable challenge on cross-border relocations—young man I think from Adelaide. I would like to understand a little more how the exemption process and consideration of a discretion operated within the bounds of the orders as they were implemented over time and as they changed over time and the extent to which flexibility was able to be incorporated and, if not, what were the discussions to communicate effectively not just with patients and clients of care but also with their families and loved ones. So there is a bit in that. I would invite both of you to provide comment with the time that we have available. Thank you.

**Adjunct Assoc. Prof. PLATT:** Do you want me to start, Kelly?

**Adjunct Assoc. Prof. ROGERSON:** Yes, more than happy, Violet.

**Ms SHING:** There is a lot in that.

**Adjunct Assoc. Prof. PLATT:** Look, I think the flexibility and the recognition of the compassionate grounds and needs of Victorians has definitely changed and improved as we have gone through the pandemic. And certainly at the very beginning we had some very challenging conversations and some very hard ones, which really took the choice away from the individuals and their families in terms of navigating care and options, because for some people it was actually, 'Right. We'll just take the person home and we'll manage to do what we can at home for them', but then they faced the reality of having that person at home without proper pain management and with no nursing skills and the distress that was caused with that and then, when that got really difficult and they thought of taking that person back into hospital right towards the end of life, they were faced with that really hard challenge of, 'Well, they'll have to be COVID swabbed. They'll have to be isolated. We won't be able to see them probably for the first two days, if we're lucky, and they could well die in

that process'. So what we do know is that putting families through making those decisions, we have got a lot of extended grief and bereavement and issues that people have to work through because of the choices that they were first forced to make and also, for the individual, not wanting to be a burden on their family and trying to cope and pretend that the pain is not as bad as it is and all of those implications. So there were some really hard, horrible choices and decisions that had to be made.

The border crossing at the very beginning was just absolutely impossible. You would either hit a brick wall in the other state or you would hit a brick wall in our state. We advocate through the health department, through local ministers, through the local community. We chatted up everyone that we thought we could get there, and for a couple of people right at the beginning we just did not manage to get that border crossing happening, so the result for one family in particular was that they left Victoria, went to the state where the person was dying and the death occurred there—

**Ms SHING:** How has that changed between early in the pandemic and now? You have said that there has been a change around compassionate grounds over the course of the pandemic. What does the cross-border issue look like now?

**Adjunct Assoc. Prof. PLATT:** Now you can drive between the states even if you are COVID positive and go to your home or a place. You can do RATs, you can be tested, you can isolate, you can actually cross the boundary. You obviously cannot get on a plane, but there are ways to travel between the states. As I say, we have not tested that with Western Australia, but we have certainly tested it—

**Ms SHING:** Yes. But there is room for ongoing improvement I think is what you are saying.

**Adjunct Assoc. Prof. PLATT:** Yes, absolutely.

**Ms SHING:** Yes. I would like to have an understanding if I can, save for anything you wanted to add to that, Ms Rogerson, around the way in which you are managing a recovery for the people who work within the palliative care and end-of-life organisations that you work with as we return to—I do not want to be trite—a business-as-usual model for the work that you are doing in light of the changes as they sit within pandemic orders now, and also how that sits with managing proportionality and a precautionary model on the one hand to prolong life in a way that is comfortable and dignified wherever possible, to accord with people's wishes on the other hand and then also to work alongside family members and loved ones. The two prongs of that: how are we recovering and what is your experience of this, and how are you managing the competing, I suppose, tensions between human rights incursions, on the one hand, because of restrictions and the primacy of the objective on preservation wherever possible of life and quality of life?

**Adjunct Assoc. Prof. ROGERSON:** I think our focus has always been very client-centric or person-centric or patient-centric—it depends on whichever language. Individual-centric really—so what is important for the individual? Our goal throughout the whole pandemic has always been that: what is the primary concern for the individual? Where is their priority, and how can we increase or improve their quality of life? That adapted very strongly throughout everything that we did. We have a very strong and interdisciplinary workforce that works very collaboratively together. We adapted very much to online platforms and things for allied health staff, for example, to ensure that those services were still able to meet the needs in people's homes, but some of our services need to be on site and obviously include physical assessments. We are really specialist palliative care services, so the generalist services have always been a bit of a gap for us. What we have seen most predominantly is that people have learned that being in the community and out of an acute sector hospital is something that they now desire and can see is achievable. They feel safe in their own homes, they want to be in their own homes and they want to be surrounded by that.

Early in 2020 and at the start of 2021 we saw that real challenge around access to community support such as our volunteers, and also your own family not being able to visit was a real challenge. That has improved, I would have to say, which has been great, so you can still get some more people in your home and get that support if you are caring for someone. As a team our focus is really about what can we do within the confines of our staffing levels and our capabilities at any given time. We have adapted every single process that we have had to increase and streamline every system and service to be able to do things within the available resources that we have. But we have never come back to normal. So more people have sought our services and sought our services in the community, and that has not bottomed out or levelled. It has just sort of hit a plateau and then

risen again and risen again, and I think that is one of the challenges that we now face in the recovery: there is a greater demand on community services because I think generally the population wish to be out in their homes and feel safe in their homes, and how will we meet that into the future?

So they are the discussions that we are having at both a strategic level at Palliative Care Victoria but also at an operational level in each of the services across the state. The inpatient units, for example, who are our colleagues, are finding that people are coming to an inpatient palliative care service for a much shorter length of stay, which is creating challenges for them. So someone only comes in in the last few days of their life, when they are terminally ill and do not have the symptoms managed quite as easily as if they have got longer term care. So we work very collaboratively with the acute sector, and we are much more adaptive. We have a crisis response process, so we have got an extra nurse available to us or we are allocated a nurse specifically to be able to look after people who are coming out of hospital earlier without adequate assessments. Our occupational therapist and allied health assistants are able to get equipment out because the redirection of staff in the acute sector has meant that a lot of our patients are not coming home with the appropriate resources that they would need to be safe at home. So we are adapting as best we can, but I do not think that is sustainable given that we were provisioned with some COVID surge funding, which was really valuable, but that runs out really at the end of this month. But the actual client numbers have not reduced at all.

**The CHAIR:** Thank you very much. We need to now move to the next member of the committee, Emma Kealy.

**Ms KEALY:** Thank you very much. Can I just thank both of you and also the organisations and members and volunteers that you represent for the amazing work that you do, not just during a pandemic but all the time. And taking on that additional burden—I find it actually quite emotional because I have an electorate which is on a border. I absolutely understand the challenges of trying to get somebody home for their last days of life or to get someone back here or a visit in place. So thank you so much for all that you have done in that sector. I would like to just go back to a comment, I think it was Professor Rogerson who shared the data about an increase of 63 per cent in admissions to community palliative care. Can you quantify that? How many people does that represent?

**Adjunct Assoc. Prof. ROGERSON:** Emma, to put that into context, we are now caring for about 450 people in the community at any given time. That is enough people to fill the Royal Children's Hospital. If that was patients in a hospital, it would be the size of the Royal Children's Hospital, to put that into context. Of that, at any given time, 30 per cent of those would be in the last month of their lives but about 50 per cent would be in the last 12 months of their life. So we are managing them—managing their symptoms and giving them really quality of life by multiple different strategies and approaches.

If you think about that, we cover 1800 square kilometres of the state, from the south-eastern suburbs of Melbourne through to just on the border of Warragul. Sort of from Dingley to Warragul is where I generally put it, or just before—Bunyip Creek. But that is just one services catchment. Eastern Palliative Care, for example, are larger than us, as are Melbourne City Mission. Each of these services covers large geographical areas, and one of the challenges we find with an increased number of clientele on the books is that you have got to travel between those. If you can only do four or five visits per nurse a day, it is a large volume of people over a large geographical area, trying to service them.

**Ms KEALY:** Yes, absolutely. Can I just clarify: it is 450 you have now—just for this catchment, I think.

**Adjunct Assoc. Prof. ROGERSON:** For this catchment, yes.

**Ms KEALY:** And it was around 200. Is that the 63 per cent increase?

**Adjunct Assoc. Prof. ROGERSON:** Yes.

**Ms KEALY:** Excellent. Okay. Thanks for that clarification. I would like to explore further any impacts on staff, because obviously there are clinical impacts in terms you have mentioned that people are in later stages when they go into hospital. They are avoiding that admission because it restricts them from visits from family and friends. How has that impacted on the palliative care nurses? Have you found, I guess, impacts on their mental health, but also has it impacted on the number of staff that you have, attracting people to work in palliative care, or perhaps has it worked to attract more people to work in the sector?

**Adjunct Assoc. Prof. ROGERSON:** I think it creates a complexity in the visits, Emma. Your client mix on a day or your patient mix on a day—you would normally go and see two or three clients who are relatively stable, who you are sort of tuning up a little bit and giving some support to, whether it be psychosocial support or physical support or some minor symptom management, and keeping them well, and then going out to see one or two terminally ill clients or very unstable clients that have complex needs. Through this process it has meant that, of your visits today if you are a nurse in our service—and I have certainly been on the books and out on the road almost during this time when we have been short-staffed—you are really visiting people with intensive needs at any given time. The complexity of doing that over an 8-hour period is tough—you know, day after day. There is no moderation; it is like working in intensive care for 8 hours—and that is my background, so I have got a good thing to compare it to. It is very intense, the work that is happening, I think, and so we have put a lot of strategies in place to support their wellbeing. But there is no time for education, for knowledge development, for learning or even for debriefing about those cases, because the work is so intensive at all times, and it has been for quite a period of time. Many of the services are experiencing significant shortages at the minute and people leaving the workforce.

Our nurses are three-year registered nursing trained individuals who then do a postgraduate certificate in palliative care, so my workforce is 80 per cent pall care trained, which means they have done five years of training and education to become a registered nurse with a palliative care qualification. A nurse practitioner has a masters degree, and I have two nurse practitioners in the team—and clinical nurse consultants. These are senior nurses because it is specialist pall care. We do not have a generalist workforce, which is something I think we do need to meet the needs of general hygiene, dressings and other complementary needs. We are really doing intensive management of individuals.

**Ms KEALY:** Absolutely. And just one final question: we have heard in other hearings about the situation of dying with COVID as opposed to dying of COVID. What palliative care services have been provided to people who may have other comorbidities which are bringing them to their end of life but they also have COVID? Has there been access to palliative care during that period for that cohort of people, and how has that been delivered or restricted? Has it been negatively impacted just through the other impacts of COVID orders and restrictions?

**Adjunct Assoc. Prof. ROGERSON:** Our staff have been wearing full personal protective equipment since mid last year, and so that care has all been provided in-home with full services available to them. I think the biggest challenge that individuals have experienced is if a transfer to hospital has been required. They have needed to go through a COVID ward to get screened for COVID and may have died before they hit a palliative care ward or could get treated for their palliative care symptoms, which is what they are getting admitted for, which is probably the biggest impact. But from a community palliative care service profile, we are still providing full services as a service. Aged care created some challenges for us, and we were not always able to access aged care facilities. Because it is a residence for an individual, our service treats individuals who are in aged care the same as if they were living in a home somewhere else, but we have not been able to access aged care facilities as often or provide a full range of services. Their registered working nurse workforce in the non-state-run services is very limited, so it is a bit of a challenge, and I do not believe the care has been at an appropriate level there.

**Ms KEALY:** Thank you.

**The CHAIR:** Okay. Thank you. Moving on now to Mr Bull.

**Mr J BULL:** Thank you very much, Chair. Thank you, Kelly and Violet, for your time this afternoon, for presenting to the committee and for your advocacy on behalf of members. Can I also join the Chair and Ms Shing and Ms Kealy in acknowledging all of the work that has been done. I did just want to ask off the top: the representation for the 155 members—included within that, I think, is around 80 organisation members—can you just explain the difference in how the membership works and how the advocacy on behalf of those members comes in to you?

**Adjunct Assoc. Prof. PLATT:** Yes. We have got 87 organisation members at the moment, and 61 are specialist palliative care services, three aged care services and eight palliative care consortiums then the remainder are a mixture of other peak bodies and smaller organisations. On any given day we can get a call from any of our members about an issue that is arising. So one of the community members last week made contact with me because COVID is having an impact now on the My Aged Care assessments and how long palliative care clients are waiting for

those assessments. So as challenges start to arise for organisations and they feel that they want to check out with other organisations, ‘Is that happening or can we do some advocacy?’, then they will bring it to us and we will raise it across our membership, do some background exploration, talk with Palliative Care Australia in the other states and then formulate things into a representation, which is what happened with the document we submitted in 2020 about the impact of COVID in palliative care.

**Mr J BULL:** I am sure the phone would be very busy in that sense, given that level of representation. Thank you for that. In terms of the 264 beds across the 31 state-funded health services you mentioned in evidence that you provided to Ms Kealy’s question, for the 39 community palliative care services across, I think you said, 1800 square kilometres, can you just run us through some of those challenges and how you think the current state of play is and how that might look over the next 12 months?

**Adjunct Assoc. Prof. ROGERSON:** Just to clarify, just my service covers 1800 square kilometres—so Palliative Care South East covers 1800 square kilometres—but the whole state is covered by a service, yes. Violet, did you want to take this, or are you happy for me to go?

**Adjunct Assoc. Prof. PLATT:** No, you go.

**Adjunct Assoc. Prof. ROGERSON:** I think certainly community palliative care is a very collaborative network. So the community palliative care services do work really collaboratively together because we do not compete for funds. We are predominantly non-government organisations who are funded as charitable organisations—block funded through the Department of Health—to provide services over postcodes, and so we are not competing for anything really, but we collaborate and get consistency as much as we can.

I think regionally they are experiencing very large challenges in accessing specialist workforces. I sort of mentioned the time it takes to train and educate a palliative care nurse. First you have to have people interested in it—not everyone is interested in providing end-of-life care—and so attracting and promoting the profession is something that we do very well, I think. I think workforce is going to be a real challenge for us over the next 12 months and maintaining that workforce—like any health workforce—because we are seeing a depletion everywhere. People are leaving nursing, as I am sure you have heard. It is a challenging role to take on, but it can be one of the most fulfilling and wonderful professions at the same time. How do we support the workforce to stay engaged and also to feel like they are not working at this level and that there are some other opportunities? I think we are going to have to really address operationally how we support or pull back on what we are able to do, which unfortunately has an impact on individual community members, which creates that moral distress for individuals.

So we have to really balance what our strategy is, what we can deliver, what it is realistic to deliver with the current funding and then how we keep pace with the acute sector around pay rises and things when we are not funded that way. So we are working very closely with the department on looking at where the opportunities are. The funding for different services has not obviously kept abreast with—the funding models were developed in the early 2000s, not really looking at population growth or any of those kinds of things. In areas such as Banksia our service certainly is really impacted by that population growth, as some areas within the state are.

**Mr J BULL:** I am glad you mentioned funding, and I have just been given the green light from the Chair for one more question. The \$2.8 million in funding provided in November 2021 and the \$170 million of funding across 2021–22 for the delivery of hospital, home-based and regional and rural specialist services, can you run me through how that will assist in the work that you are doing or the member organisations are doing, and just connect that to your previous point around the shortfall?

**Adjunct Assoc. Prof. ROGERSON:** That was provisioned as COVID surge funding—

**Mr J BULL:** Correct.

**Adjunct Assoc. Prof. ROGERSON:** and so it was short term and it was non-recurrent, it was time limited and it was matched to outcomes, which we have not been measured against yet, but subject to recall. If there are any services we have not used—I know it has certainly been utilised well in ours. I talked about the crisis response nurse as a model, and also increased medical staff for us was really well supported. It was fantastic. It was valuable. It was late. It was really challenging but really wonderful to receive.



**Mr J BULL:** Thank you.

**The CHAIR:** Thank you. We will go now to Ms Crozier.

**Ms CROZIER:** Thank you very much, Chair, and thank you, both Ms Platt and Ms Rogerson, for being before the committee—really invaluable information that you have provided to the committee. I want to go to some of those issues that you have raised. Certainly for the last two years my office has dealt with some extremely heartbreaking stories, as you have alluded to. Whether that was not being able to visit loved ones or not being able to get across the border, it was just story after story after story. I am not talking about one or two; there were dozens of these Victorians who were stranded, who could not get back, and I think the Ombudsman highlighted that in her report about the human rights that were breached through this process.

I am really concerned about the visitation rights as well, and I would like to understand—certainly I have heard from people who have said, ‘We don’t want to put our loved ones in hospitals because we can’t visit them. And we want them to be at home. We want to be with them at home’. Can you give the committee a bit more of an understanding of that? Is that the experience from the services that you represent as well? And those numbers that you spoke of—I think you said that at the palliative care advice line there was an increase in that. What does that look like? What are those numbers as well?

**Adjunct Assoc. Prof. PLATT:** Yes. I think the culture of palliative care—we have always had this research number as we trained as a junior palliative care nurses. There was always this research number that was sort of the magical number of 80 per cent of patients who wanted to die at home that we all worked towards and tried to achieve. But the practice was that we actually never got anywhere near the 80 per cent number most of the time. Some of that was because the reality for people, when they were at home and getting close to the end, was that they actually did want to not be at home for various reasons. From the calls that have come into Palliative Care Victoria over the last two years I have seen a real change in community culture, which has gone from wanting the access to visit their loved one in the hospital and be alongside them—or the aged care facility—and assist with their diet and nutrition needs or emotional stimulation or whatever to much more now the calls are about ‘How can we get mum or dad home? How can we keep them home and provide care for them?’. It is much less about accessing the support and care that they can have in the hospital settings, and that is across many populations and cultures.

**Ms CROZIER:** Is that because they know that they cannot visit and be with their loved ones at this time?

**Adjunct Assoc. Prof. PLATT:** I think the trust element is gone of, ‘When’s that next lockdown going to come?’ or ‘When’s that next rule going to happen, then we’re trapped with our loved one in the hospital and we can’t get them home’—so that safety.

**Ms CROZIER:** So that fear of lockdown—knowing what the lockdowns have meant. It has shut people out of seeing their loved ones, and as you say, a change in the community culture is there now. To go to Ms Rogerson’s point about the demand in the community: if it is 450 in Ms Rogerson’s area, what is the demand across the state? What are the numbers?

**Adjunct Assoc. Prof. PLATT:** Across the services that we represent in Palliative Care Victoria they definitely mirror what Kelly has talked about. If we can take that question on notice—we are actually just completing a survey with KPMG with all the membership, so we will have very up-to-date information available.

**Ms CROZIER:** That is great. We would be very appreciative of getting that data. Can I go back to the issue around the funding? This is a critical need—to provide the dignity and the care at the end of life. You are both nurses. I am a former nurse; I understand the work that you do in very, very testing and trying and emotional times, and it does take its toll, especially when your workers are also dealing with the pandemic and their personal situations. But why has there not been a recognition by government to provide additional funding? Why are you coming up against a brick wall? They are my words, not your words. The funding model was developed in the early 2000s. What is the problem here?

**Adjunct Assoc. Prof. ROGERSON:** Georgie, I think it is a difficult one to answer. I have been trying, as the CEO of an operational service, to influence on that for quite some time, for the last number of years. I think that during the pandemic the focus was very acute focused—acute hospital and public hospital focused. The

inpatient units obviously were capturing that. When there was an increase in community funding for services it was through hospital in the home or acute-based services; it was not out to NGOs or disability services or other complementary services that were necessarily supporting people out in the community. So we saw a restriction of other NGOs being able to provide support outside of palliative care, so disability or council-based services, for example, and they withdrew their services. So those of us that were available continued to provide support, but we have ended up providing meal packages and anything else that we could do to fill those gaps. I cannot answer you about the ‘Why not?’. I feel that there is a desire from both sides of politics to support palliative care, but it is not recognised enough as an essential service. It is a right for people; it is not a ‘nice to have’. Nobody wants to sign up to be a palliative care patient or to have a terminal illness.

**Ms CROZIER:** No, quite right. Yes, thank you, and I could not agree with you more. My point is that we are at this point where we have got this huge demand because of the population growth, as you have said, but on top of that, knowing the impacts of the lockdowns—we have had significantly more lockdowns than anywhere else across this country here in Victoria—surely that should have been foreseen by government to understand that the restrictions on the visitations and the harshness of those restrictions would have an impact for people who were going to continue to need palliative care services. So I am sort of trying to get to the point of: why are we struggling with this after so long, after two years of being in this situation?

**Adjunct Assoc. Prof. ROGERSON:** I think it might be an answer for the panel, not us, because we are strongly advocating.

**Ms CROZIER:** Okay. I will leave it there.

**Adjunct Assoc. Prof. ROGERSON:** I will leave it to the panel, I think, rather than comment.

**Ms CROZIER:** No, and I appreciate your advocating and the ongoing support and the tremendous work that you all do. Thank you very much.

**The CHAIR:** Thank you. And we will move now to Mr Erdogan, who is on Zoom.

**Mr ERDOGAN:** Thank you, Chair. And thank you to our guests, professors Rogerson and Platt. Going on from the issue of the impact of restrictions, there are some existing exceptions to entry requirements, including a person attending for the purpose of providing end-of-life support. How does your facility—or your stakeholders more so, as a peak body—handle those exceptions? Have you provided some guidance to them on how they should manage that situation?

**Adjunct Assoc. Prof. ROGERSON:** We were contacted by a large number of people, especially when the stricter lockdowns were occurring, and there was a lot of concern. We recorded individuals as primary carers on our electronic medical record and provided advice that if someone was, you know, questioned about their whereabouts or their mobility, for example, in the middle of the night we could be contacted directly, and our phone numbers were provided to be called after hours even, so we could look up someone’s medical record to ensure that they were safe. I think the missing point was that we talked a lot about terminal care, which is the last number of days of someone’s life, not in the last weeks and months of someone’s life when you can get some quality-of-life and quality interactions with your mum, your dad, your aunt, your sister—and it did not really extend to aunts and sisters. It really was Mum or Dad or your child that you could support. There was very limited acknowledgement that it might be your next-door neighbour or your friend that you have had since birth that you are not a direct relative for, so you could not visit—so many people did not visit. We had a lot of distressed calls into the service that I, myself, and the other clinical managers handled really to support people through a process of feeling safe that they were able to travel from Ballarat to Melbourne, for example, to visit their brother, sister, aunt and acknowledge that really the intent was not for them to get in trouble for that but this was okay, and to support them.

Our counselling supports were in great demand and have been since. Many of the social norms that we get to do as a society to grieve someone—our loss and bereavement support has been severely impacted through the pandemic in that we provide 13 months of bereavement support following the death of a loved one and many of the social norms have not been followed. You know, there have not been funerals—which is nobody’s fault; it has been an outcome of the pandemic—but it means that people have not felt that they have celebrated the lives of their loved ones and then they are having ongoing, complicated grief that has required counselling and psychological support and into mental health support rather than having grief as a normal, societal—

It is not a nice thing to go through, grief, but it is a natural passage in all of our lives. So one of the biggest impacts I think is around bereavement support and ongoing issues for individuals that are really struggling with what this means for them longer term and have they done the right thing by their loved one.

**Mr ERDOGAN:** I have to agree. I think bereavement and dealing with the grief is an important part of life in that regard. In terms of bereavement services, how are those services now with the new orders? Have all the restrictions been removed in relation to those bereavement services?

**Adjunct Assoc. Prof. ROGERSON:** Some of the challenges we have is bereavement support is often best in group therapy and coming together, so as things are lifting now I think we can see a return to having more socialised efforts in grief and bereavement support. For people often who have been socially isolated through the pandemic and had the death of the loved one occur, trying to then draw them out of their homes and into social settings has been a real challenge for us because we cannot bring them to a facility, because for us we are in a healthcare facility that does not like visitors at the moment unless you are coming in for an appointment specifically. But also we cannot run group sessions or things like at the moment. That is a real challenge for people and so they are becoming more and more socially isolated and then they become more unwell, and it becomes an issue and impacts on our mental health system rather than something that could have been handled at a local level. So we are certainly advocating very strongly to have facilities and support for people to be able to come together in group therapy sessions, art therapy, music therapy and other things that bring them out of their homes and into a social environment where they need to resocialise after having such a big impact on their lives.

**Mr ERDOGAN:** Operationally how are your facilities dealing with the current COVID settings in terms of visitors, in terms of vaccine mandates? What is in place at most of the facilities that you look after?

**Adjunct Assoc. Prof. ROGERSON:** Certainly we are community facing, so we go out into people's homes, and we have been very successful with the vaccine mandate. Not every service has; they have had quite a number of people that have not—not so much in nursing but potentially more in the allied health space, you know, counselling and social work and other allied health staff choosing not to vaccinate so therefore not continuing their service with the organisations. That has had certainly had a workforce impact for many of the services, and then the subsequent HR issues that come with that are very time consuming obviously and have been really challenging. We have been very fortunate here; we have a very supportive workforce who have gone out and vaccinated very quickly and easily. We have been very grateful for that, but I know the hospitals and the health services have had some real challenges around that.

**Adjunct Assoc. Prof. PLATT:** Yes, and I think to add to that, across Victoria there has been a real impact with the vaccinations on the volunteer community. Especially within the culturally and linguistically diverse communities there has been a large loss of volunteers who have chosen not to be vaccinated. We already had the gap in community support that we lost during the visiting limitations with volunteers, and now there is a lot less volunteers on the ground trained in palliative care who are able, so many volunteer services and culturally and linguistically diverse support services are almost having to start from the ground up and grow a new palliative care workforce.

**Mr ERDOGAN:** Thanks for sharing that, Professor Platt. I think it is an important point, because we heard in previous hearings we have had about the loss of volunteers in this space because of obviously all the health restrictions we have had in this period. How have you gone in re-engaging with volunteer groups and recruiting new people, especially now that the settings have somewhat come off?

**Adjunct Assoc. Prof. PLATT:** Within Palliative Care Victoria we have got a volunteer manager who supports more than 90 organisations of volunteers, and we have done a lot of shared learning, shared strategies, re-engagement and reinvigoration. We have actually got a palliative care volunteer conference happening in May. The tickets are flying off the shelf because volunteers and their managers are so passionate about wanting to come together. So we have had to take lots of shared learnings and shared strategies and try to put that reassurance back in the community—that it is safe to come and be a volunteer and how to make those informed choices.

**Mr ERDOGAN:** Thank you.

**Adjunct Assoc. Prof. ROGERSON:** Many of them are retired and in the highest risk category, which was a real challenge for us. We actually had lots of training and development to have them go online and still provide a lot of services, which was fantastic. We were sharing the story programs, different bereavement programs that we support that have gone online, so that has been a great opportunity to adapt and change.

**The CHAIR:** Thank you.

**Mr ERDOGAN:** Thank you for all the work that you are both doing and the organisation Palliative Care Victoria. Please keep it up. It is very important work. Over to you, Chair.

**The CHAIR:** Thank you. Mr Wells.

**Mr WELLS:** Thanks, Chair. Thanks for the work you do; it is certainly not a job for just anybody. I for one could not do it for the life of me. I could not do it. You spoke about the volunteers and the impact that the non-vaxxed volunteers are having on the organisation. Do you have an actual number or a percentage of volunteers that are not fronting up? I understand the reasons why. As you said, they are sometimes in an older age bracket. But do you have any numbers or percentages?

**Adjunct Assoc. Prof. PLATT:** I could certainly take that on notice and talk with our membership and come back to you.

**Adjunct Assoc. Prof. ROGERSON:** It was 10 per cent of my workforce, my volunteer workforce, so I lost at least 10 per cent, and two of those were really 25-year volunteers with the organisation, which was such a shame, that knowledge and skill being left. We use about 5.2 FTE volunteers at any given time, whether it be clerical support, engaged in a support with lots of different things, and lots of bereavement support, taking people to appointments, in-home respite. So we do equate and quantify our volunteer workforce. They are so highly valued, and we utilise their skills and need them. We have attracted some younger volunteers who have been very IT savvy and deliberately sort of attracted people who could help us problem-solve some of those challenges. Some of our more wise and skilled volunteers have been the most adaptable, I would say, which has been wonderful, and they are very engaged in this community and the work that we do.

**Mr WELLS:** So with the unvaxxed volunteers, were they able to have meetings or virtual visits with patients by Zoom or Teams?

**Adjunct Assoc. Prof. PLATT:** The unvaxxed volunteers, the cohorts that we know about, within Palliative Care Victoria were within specific culturally diverse groups and older populations where using technology was not first nature to them. So we have limited ability with that. With the Chinese community, for example, they had a whole cohort of younger volunteers who taught everyone how to use iPads, and they have had Zoom meetings and everything going, but for some of the other cultural groups that have been very dependent on older volunteers who are not tech savvy, that has not been an option. There has been some telephone support, particularly in language to people in aged care facilities who are isolated, but again we run into challenges with people's hearing and actually the nurse getting the phone to the person in the aged care facility to talk to them.

**Mr WELLS:** So I guess the impact with the unvaxxed volunteers is primarily less visits?

**Adjunct Assoc. Prof. PLATT:** Yes.

**Mr WELLS:** And you mentioned some clerical work, I guess, not being done. That is a sad state of affairs, if there is a reduction in visits because of the volunteers not being vaxxed.

**Adjunct Assoc. Prof. PLATT:** Yes.

**Mr WELLS:** With the pandemic orders, is there anything that your organisation would want to change or amend or alter in any way? We have heard at previous hearings that the interpretation of the orders or the intent of the orders has not always been clear. Is your organisation impacted in any way by that?

**Adjunct Assoc. Prof. PLATT:** I moved to Victoria from another state at the start of the pandemic, so my whole life in Victoria has been living in the pandemic—this pandemic world. What I know is the lack of palliative care at the strategic and planning table. I feel that if palliative care had a voice and a seat at the table

when decisions were being made we may have the opportunity to influence a more supportive approach for our community.

**Mr WELLS:** Okay.

**Adjunct Assoc. Prof. ROGERSON:** I think for me, Kim, the visiting restrictions across the state have taken health care back 10 to 15 years. When the Australian Commission on Safety and Quality in Health Care included person-centred care as standard within healthcare quality and safety in 2012, I think health services finally had a really strong focus on individuals, their goals of care and their need, and palliative care is very, very good at this. We are very good at being very patient centred, individual centred—what is important to you, because you are dying and nothing really matters when you are dying except for what you want. Limiting who can be your person—who can go to your chemo appointments, who can go to your treatment options, who can go to your doctor's appointments, who can go and sit next to you while you are having symptom management in a healthcare facility—severely impacts an individual's choice and rights to choice.

I think if there is one thing that I would like to change, I would like to open up the doors a little bit to hospitals. If I can go to a football match with 50 000 people, then I should be able to take my husband or partner or loved one to a medical diagnostic appointment where I am going to have a test that is not a very nice test to have to tell me whether I have got a life-limiting illness or not or whether or not my treatment options have been successful this month or not. Us separating people from other people has been unacceptable. It was not an intended consequence but it has been an actual consequence of some of these orders, and I think it is something that has had significant impact on individuals throughout the state, no matter what their condition is—whether they were going to have their gallbladder removed or whether they were going to be told they had pancreatic cancer. It has still been a significant impact on individuals across this state, which I would like to see changed.

**Mr WELLS:** Okay. And part of the question was also about the intent of the pandemic orders. Has there been any confusion about the intent or the understanding of the pandemic orders that you have had to go back to seek clarification from the department on?

**Adjunct Assoc. Prof. ROGERSON:** I think the intent has been clear, but the hospitals have had the opportunity to be able to determine what was the best fit for them. Each health service was able to still determine a different set of rules, dependent on the ward or the unit or the area of the hospital. So I am not sure if it met with the overall intent.

**The CHAIR:** Go—one more question.

**Mr WELLS:** My last question, I guess. Have there been some misunderstandings between palliative care and a hospital in your understanding of the pandemic orders—you have interpreted it one particular way but the hospital that you have been dealing with interprets it a different way?

**Adjunct Assoc. Prof. PLATT:** Certainly early in the piece a lot of the phrasing was about 'end-of-life care'. If you googled 'end-of-life care' you would probably get 10 different descriptions of what that is classified as. Within the Victorian palliative care and end-of-life strategy, they talk of end-of-life care being the last 12 months. But when hospitals are applying end-of-life care, some people would talk the last few weeks and some people were talking the last few hours. So it really came down to interpretation and negotiation of those types of terminologies.

**Mr WELLS:** Yes. Okay. Thank you.

**The CHAIR:** Just to clarify one of the answers, Kelly: when you were talking about the importance of people being able to have people with them and take them to appointments and the like, do you draw a distinction between the period before vaccination was widely available and the period after?

**Adjunct Assoc. Prof. ROGERSON:** I am not sure it is any different.

**The CHAIR:** Yes.

**Adjunct Assoc. Prof. ROGERSON:** My understanding is the limitations on visitation are still quite strict at the moment.

**The CHAIR:** No, but you were giving your view on it—that you really should be able to take people in any of those circumstances broadly. I was wondering if you thought differently about those first 14 months before there was vaccination, when people were operating in a different environment to the environment we are in now?

**Adjunct Assoc. Prof. ROGERSON:** I think we certainly know more now, which is good. I think the risk needs to be managed based on the setting at the time, but it needs to be individual focused, not just hospital focused, to manage the risk and consider the impacts.

**The CHAIR:** And you mentioned that a lot of your work is done in the home, but you also visit aged care facilities but you have not been able to do that so much because of the restrictions on visiting. Are those restrictions placed on you and your staff and your organisation or on family members?

**Adjunct Assoc. Prof. ROGERSON:** Both. Many of the facilities will lock down if they have got a number of COVID-positive patients, like residents, in their facility, and so we are not able to visit. It will be deemed on a case-by-case basis. So if they have got enough registered nurses, we will liaise directly with the registered nurse in the facility to be able to support the symptom management and provide phone support, but some facilities will not let us visit individuals while they are in lockdown.

**The CHAIR:** Yes. Thank you for that. Thank you both very much, first of all, for all you do. It is an incredible service and one that is widely valued. But we also appreciate as a committee having the chance to talk with you and get your perspective on particularly these visiting orders as they have impacted over the last two years. You will receive a copy of the transcript of today's hearing for you to review, including a list of any of those questions where you may have been put on notice. Thank you again for your attendance today.

**Adjunct Assoc. Prof. ROGERSON:** Thank you so much for the opportunity.

**Adjunct Assoc. Prof. PLATT:** Thank you.

**Witnesses withdrew.**