TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

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Members

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Witnesses

Ms Tracey Mander, Manager, Palliative Care, and
Ms Deborah Fewster, Head of Policy, Advocacy and Government Relations, Melbourne City Mission.
The CHAIR — I would now like to welcome Ms Tracey Mander, the manager of palliative care for the Melbourne City Mission; and Ms Deborah Fewster, the head of policy, advocacy and government relations, also from the Melbourne City Mission. Thank you both, ladies, for being with us this afternoon. Before we start I caution 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 a proof version of the transcript in the next week. Transcripts will ultimately be made public and placed on the committee’s website. We have allowed 45 minutes for our session this afternoon. Again, thank you both for joining us. We look forward to your presentation, and thereafter the committee will have questions. Thank you very much.

Ms FEWSTER — Thank you. I might make a couple of introductory comments and then throw to Tracey, who has got a short presentation to take you through. Thank you once again for the opportunity to appear before you today. We were really excited to get the phone call last week, so thank you for your interest. I know a few of you have engaged with Melbourne City Mission in the past and seen some of our services in action, but for those who have not I might provide a bit of a background sketch around what Melbourne City Mission is.

We are one of Victoria’s largest and oldest community services organisations. We just marked our 161st anniversary in August. Our service platform is very large and diverse — for example, we do everything from providing parenting support and early childhood services in areas such as Braybrook, where we are working to break the cycle of disadvantage with families. We deliver education programs to young people who have disengaged from mainstream school. We are a statewide disability services provider. We are the largest provider of youth homelessness services in the state. We also, importantly, deliver palliative care in municipalities such as Hume, Darebin, Moreland and Yarra.

Melbourne City Mission’s palliative care program was established in 1981, and it was the first program of its type in Victoria, offering a community home-based alternative to hospital-based care. Consistent with Melbourne City Mission’s broader social purpose, our palliative care program is known for its care of people who have multiple and complex needs in addition to their diagnosis of a life-limiting condition. For example, we are providing palliative care to people who have drug and alcohol issues and people who are experiencing homelessness and we do work with community-based asylum seekers, so that is something a little bit different about Melbourne City Mission’s work in this space.

Tracey will, as I said, talk a bit more about the nature of this work shortly but I thought it was important — I know that we did state this in our short written submission — to highlight to you and restate that we appear before you in the context of our role as a community service organisation providing home-based palliative care. We emphasise strongly that we think palliative care needs to be well resourced to ensure availability and access, and thereby choice, and to ensure an effective level of care in the context of the broader community conversation that you are leading around dying and the choices available to die well. We actually do not have an organisational position on voluntary euthanasia or assisted suicide. Tracey in her presentation and during the conversation will be able to talk to you about how we respond in the current legislative environment where patients might actually initiate a conversation around euthanasia, but we actually do not have an organisational position on current laws or legislative reform going forward. It is really important to restate that to you. I will throw to Tracey.

Visual presentation.

Ms MANDER — I will provide a short presentation, which is really around the nature of the work we do, and some patient numbers and data around what we do, just to give you the context of the environment in which we work. Deb has gone through this pretty well. I would say that the area we service is quite large. We are based in North Fitzroy, with just over half a million people in an area of 628 square kilometres, so we do a lot of travel in the day. These are the special populations that we service: culturally and linguistically diverse; clients with drug and alcohol issues; homelessness clients who have a terminal illness; we are seeing some community-based asylum seekers who may not have access to the level of medical care that someone who lives here does; and we are seeing a slight increase in our children and adolescent referrals over the last little while as well, and we work closely with the children’s hospital around that population.
Just briefly around our model of care, we have a seven-day service with a reduced service on the weekends, and we have a 24-hour telephone service, so if there is a client we are not visiting, for example, they have the opportunity to call us if they are running into problems or are not sure about anything. We have a specialist medical palliative care consultant for three sessions a week, and they also have responsibility for teaching a registrar who is part of the federal specialist training program. We have counselling and spiritual care. We prepare carers of clients for bereavement. We use a screen for risk of complex bereavement and we follow them up. We also have a large volunteer contingent who provide companionship and errands to carers living at home.

This is the make-up of our team. In allied care we have a range of disciplines under that heading: specialist palliative care nurses and an educator. We use RDNS after hours for visits and calls, and we would not be able to function without our administration services, so it is quite a mixed team, all very reliant on each other.

This slide is a high-level profile of how a client comes to us and what we do when we receive a referral. We triage them for complexity and urgency, and we do an environmental risk screen as much as we can before we go out to the home and make sure there are no barking dogs and that there is access, light and all those sorts of things. Then we arrange a visit. It might be just a nurse, or it might be a nurse and one of the allied care staff, depending on what we profile when they come in. We go out to their home. We will spend probably about 2 hours with them on the first visit and see what their set-up is, see what their carer situation is and what supports we need to put in and then how often we need to visit, which also includes contacting their GP and letting them know of the admission as well.

Once the client dies, then we have a bereavement program for up to 13 months. Obviously it is not for everyone; we could not see everyone. Most people do not need it; it is the people who are at risk of complex bereavement that we screen. That 13 months will start not necessarily at the time that the client dies — it will start when the person needs the follow-up. Often in the first six months things are very busy, things are settling down, and then the issues start to come through probably from about the six-month mark.

In this slide I wanted to give you an idea of the complexity of the environment that we work in, and this does not include the Melbourne City Mission hierarchy. This would be consistent with all community and probably a lot of acute palliative care services as well. We are in the middle. We are part of a consortium in the north and west region, so we collaborate with our colleagues in the region. But we have a whole lot of reporting, representational, consultative arrangements with the rest of the sector. They have been nicely divided into the funders, the people we seek advice from. On the right-hand side at the bottom are the academic organisations we may or may not be collaborating with. We have a national benchmarking organisation that we have to provide data to. We work with funders to provide data around how our patients are going in terms of outcomes. On the bottom left we have our peak bodies, both state and national, and also our accreditation bodies. At the top left are all the people that we coordinate with in terms of providing palliative care, and the patients at that top left-hand side move in and out. That black arrow is really the crux of it.

Ms PATTEN — Sorry, I cannot see that. Could you list those referrals?

Ms MANDER — Sure. We receive referrals from mostly hospitals — and I will show you some data about that in a tick — mainly oncology, haematology and palliative care units and the children’s hospital. We also may refer in for respite if we can. Aged-care facilities we receive referrals from and general practice. Everyone’s eyes always bug out a bit when they see that slide!

Our top five referrers, and this is consistent year on, are the five major tertiary hospitals. As a result of that, our clients are complex and may have many social problems. A lot of care coordination is needed about them, and their disease processes can be quite complex as well. We have just a little bit about our client data. This is really consistent with what happens in palliative care in Victoria and Australia. At any one time we have got around 200 active patients that we are seeing on a regular basis. We see between 80 and 85 new referrals a month. We do not necessarily admit all of those, but we still have to process them. About 25 per cent of our clients die at home, and again that is consistent with what is happening elsewhere. The rest of them are either in a hospital, palliative care unit or aged care. The length of stay varies, from between 2 days and, as you can see, 742 days. But as our referrals go up, we need to do some work around what our parameters for admission and discharge are so that we can accommodate the really specialist complex needs.
On our client age range — again this is consistent with elsewhere in palliative care — most of our clients are around 75 to 84. We expect to see a rise in the 65-84 age group with the baby boomers getting older. The gender split is about what I would expect for the state and the country.

Our trends in referrals have been going up over the last few years, so again that impacts on the resources, our funding. We did have a bit of growth funding this year, but it has not gone up in terms of what we need, and that impacts on how we can resource our clients as well.

I go to the top 10 diagnoses. Most of our patients have lung cancer. It is not the most common cancer, but it is the one with the highest mortality, so that is what we see the most of, followed by gastrointestinal, colorectal, breast, haematological and pancreatic cancers, and then some non-malignant ones sneaking in at the end there.

Our ratio of malignant diagnoses to non-malignant is about 80 to 20. That has probably gone up about 5 per cent over the last 10 years or so, I would say, in palliative care. We are seeing more referrals coming from non-malignant areas.

We see a lot of CALD clients, and this is an audit of our patients last year. Most were born in Australia, but 34 per cent were born outside, and 43 per cent of those prefer not to speak English at home. So we do utilise a very high number of interpreters. This is just the year to date. The orange one is number of CALD patients admitted and the number of interpreters we have used per month. We cannot get by without them, obviously. We really need them to be able to interpret in the right way and to provide culturally appropriate care.

This is just a bit about our after hours. Most people will call because they have got an issue with uncontrolled pain, and that probably bears out across the state, I would say — or other uncontrolled symptoms, or there may be a problem with a piece of equipment that we have got in the home that is delivering some medication.

I just want to highlight a case study which is just around the complexity of care that we do. This was a gentleman who was homeless who was referred to us, I think via the mental health service at St Vincent’s, and they had referred him to palliative care. He was a 49-year-old of Macedonian background. He had no contact with his family, and he had an extensive history of alcohol use since he was a child. He did become aggressive when drinking, expressed a lot of isolation and loneliness, which was worse when he was drinking. He had had some legal issues in the past and obviously financial issues with that background as well, and also with a mental health disorder. When we met him he had chronic suicidal ideation. He was living in a boarding house. He was non-compliant with his medication; therefore his symptoms were uncontrolled, and he had difficulty complying with institutional conditions.

So we got together with all the people who had been involved with his care to date and worked out a plan for him, really. We had a small team of nurses and allied care looking after him so that we could develop some trust with him and so he felt confident to call if he needed any advice. We developed a plan of care with his input, so he felt he had some control over what was going to be happening for the next little while. He expressed that we allowed him to be heard and respected. We had joint visits because of his mental health disorder and his drinking, so we did not let one person go in the house — or the place where he was living. We managed his pain in collaboration with his GP and a registrar. We had daily visits, and we actually maintained good pain control. Because we were able to see that he was being compliant, then his pain control got better. We were able to admit him to De Paul House for some detoxification and rehabilitation, which were successful.

Because of that relationship and work we had done, he had chosen to die at St Vincent’s in Fitzroy, and we were able to achieve that aim for him, with well-controlled symptoms. But as you can imagine, that took a lot of resources, but work on his behalf as well, to gain a lot of trust.

Ms PATTEN — How long were you working with him?

Ms MANDER — Two to two and a half months, I think, so not a long time in the scheme of things, but we really had to work as quickly as we could to get him to a good place.

These are our challenges, which you may have heard of before, I am sure: access to respite for carers particularly; hospital admissions for end-of-life care because we are not able to resource at home — I will speak to these a little more in depth — and still a little bit about general practitioners and the confidence of them being able to prescribe the medications in the way that we need them prescribed.
In our region there are limited resources for respite. Planned respite can often go awry because if it is for an inpatient unit, then a patient who has got more pressing needs will take precedence, so they will get bumped. We have some limited funds provided by CarerLinks North, but we have to be really careful about how we plan for that, and what we like to use that for is for end-of-life care so that someone can stay at home. There is a huge impact on the client and the carer if they want to stay at home and we cannot provide that respite.

I had a look at our hospital admissions for our patients, and all of them experienced between 1 and 10 inpatient admissions. Many of those were appropriate, and they came out again; but 20 of those died within two days of admission, so I am wondering, if we had had some resources at that time, could they have been supported to die at home?

I go to the topical issue at the moment. As a service we do not receive a lot of sustained requests for assisted suicide, and we invite those conversations if they happen. They are not the typical reaction of someone with a terminal illness, and it often indicates there is some unaddressed burden or need around that; it might be about being a burden to others, depression or uncontrolled symptoms. So what we try to do is explore that, control their symptoms, see what their existential issues are, put things in place to try to make them easier and then see where we are after that. I see it — and we would see it — as a trigger for assessing whether there is a potential crisis or a crisis happening. That is the end of my presentation.

The CHAIR — Thank you both very much for your presentation. I am particularly interested in the case study you gave and perhaps any further information you could give, particularly given the range of services that you provide, about the specific challenges and the numbers in relation to people who are homeless. That is something we have not really heard about previously from others who provide palliative care services, so I am particularly interested in what else you may wish to add to that.

Ms MANDER — It is hard for me to give numbers of people who might have terminal illness whom we do not see because they are either in another area or they just do not get to us before they are diagnosed. I have been with the service for a year and a half. I have probably seen about two or three people in that time. We have another patient at the moment who is from Pakistan, who was homeless. He is now seeking asylum so that we can provide the medical treatment or so that he can get access to medical care, but he also had a mental health disorder. He is 25 and was diagnosed with metastatic melanoma. He was being supported by the Muslim community in a boarding house and had no access to anything and no access to any medical care at all. He is currently being looked after by another Melbourne City Mission service while he is well enough, but we have to put a lot of resources into getting his medications paid for. He does not qualify for PBS so he has to pay full price for his medication. At the moment we are using donations and various other sources to pay for that. He did not have many clothes, so we have been providing them, and because of his schizoid affective disorder he was quite isolated in the community and in his own community of Muslims as well, so he is actually quite delighted to be where he is. He has a room with a window — —

Ms FEWSTER — Sorry, I have not come prepared with my homelessness hat on, but we can forward some more information to you via Lilian after this. In terms of the bigger picture context, we know that, generally speaking, homelessness is very much correlated with complex health conditions. So the impact of sleeping rough or living in insecure housing has tangible impacts not just on mental health but on your physical health and wellbeing.

We also know that the rate of homelessness is continuing to grow. It has been very topical over the last decade or so and there has been a lot of federal and state government investment in homelessness, but we still have not got it quite right in terms of our responses to homelessness. We know that in Melbourne rough sleeping is becoming more visible than ever, so there are growing rates of homelessness, both in terms of youth homelessness and adult homelessness as well. We are seeing the impact of family breakdown on women and women’s vulnerability to being in precarious housing or losing their housing altogether, with financial insecurity associated with long-term relationship breakdown. In terms of the data or picture around homelessness, it is a growing kind of issue and we know there will be growing impacts on health and that that will translate down the track into some kind of complex and chronic health conditions that might end up requiring palliative care response.

Ms MANDER — That would be right, yes.
Ms SPRINGLE — I have a couple of questions. What are the criteria for referral into the service, because it appears that you are actually servicing some of the more vulnerable communities. Are there criteria that they need to meet to get entry into the service, and do you have the capacity for the need?

Ms MANDER — The criteria are they have to have a terminal condition of some sort, requiring specialist palliative care needs, which would be needs that perhaps a general practitioner or a more general service would not be able to provide. So they might have issues with pain or complex pain, or other symptoms — nausea or vomiting. Depending on what their disease process is, they might have symptoms of their disease, or all of the above. But they do have to have a terminal condition to be referred to us first and foremost, and that can include something like dementia but with uncontrolled symptoms.

Ms SPRINGLE — Would those clients also be eligible for other more broad-based palliative care services?

Ms MANDER — Yes, they would.

Ms SPRINGLE — There is no difference, really?

Ms MANDER — What do you mean by broad-based palliative care services?

Ms SPRINGLE — From your submission it appears that you are servicing a certain demographic of people, so it is more community-based. It says people with multiple and complex needs, including the CALD communities, the homeless and what have you. Would those clients also have access potentially to more mainstream palliative care services? I suppose that is my question.

Ms MANDER — They would be referred to specialist palliative care for those needs. If they had less complex needs, then we could work with, say, a more generalist service, like an aged-care facility, for example, which could provide the care, because not everyone — I do not know how to say this — has complex dying. So we would support people who could look after their symptoms, give them advice, and they would be more than capable of doing that. If you are talking about someone with medical needs who is not in the health system being looked after, then that would be a different thing.

Ms SPRINGLE — I suppose I am referring to some of the other palliative care services that we have heard from, and they have not identified their intake as necessarily being people with complex needs. They have been people with a general illness or someone who is sick and needs care. I am just looking at that point of differentiation in terms of your presentation and trying to get a handle on what the difference is between what you are offering and what they are offering.

Ms MANDER — I think we are all offering the same thing. It is just the demographics of the area that we serve; that is the demographics of the area.

Ms FEWSTER — It is also Melbourne City Mission’s reputation as a broad-based community organisation that tends to work in areas of complexity. If you look at our work as, say, an early years provider, there are lots of general kindergarten and childcare provisions and we deliver the standard kind of curriculum and programs, but we are particularly known for going into areas where there is generational disadvantage. We are known for having the core expertise that any early childhood service would have, but we are then able to draw on the specialist expertise in terms of our ability to deal with complexity and creatively engage people who are often hard to reach and who are not particularly accessing mainstream services and supports. We are able to create a culturally safe environment where people do not feel judged, and I think that is across the board, including reflected in our palliative care program.

Ms SPRINGLE — My second question is on the graph that you showed around the CALD communities that you are servicing. I noted that the majority of them are probably more established CALD communities. I am just wondering about any work you are doing with new and emerging communities, so more the African diaspora and some of the Asian refugee communities.

Ms MANDER — We are finding that we are getting more of those; they are just not reflected here because they are not in the top 10. What a few of us from Melbourne City Mission did last year was take part in a project with Palliative Care Victoria, which was around engaging with CALD communities. I talked to a Muslim community about palliative care and got them to translate palliative care into their own language. Then they would go out to their communities and say, ‘Look, here are the services’. Often they have a picture of what
death and dying is like wherever they have come from, for whatever reason, and they are not aware of the palliative care services here. So there was a huge project done around that, engaging with different CALD communities and raising the profile of palliative care.

Ms SPRINGLE — Is there any way we could get more information on that? That would be wonderful.

Ms MANDER — Yes, there should be report on that.

Ms SPRINGLE — Terrific. Thank you.

Ms FITZHERBERT — I was wondering whether you are funded in a way that is different from other organisations that provide palliative care because of the complex needs or different nature of your clients, or whether it is on the same basis?

Ms MANDER — We are funded according to a formula called PCRAM. I have a Department of Health and Human Services colleague in the audience who might be able to tell me what that acronym stands for. Sorry, I spotted you there, Carol. PCRAM is ‘Palliative Care Resource Allocation Model’. I am just so used to that acronym I could not remember what it stood for. That takes into account the demographics of the area. Then we get block funded, but we get block funded according to the demographics of the area, and that would be for every community palliative care service.

Ms FITZHERBERT — That makes sense. In terms of the clients you have, what is their average period of involvement with you, and is that comparable to other organisations or is it different?

Ms MANDER — Without knowing what their data is intimately, I would say that it is probably about the same. The slide I put up there said between 2 days and 794 days and the median of that at the moment is 123 days. I could not tell you the average, but I could tell you the median because the average changes according to how many deaths, how many admissions — all of that.

Ms PATTEN — Respite care for the carers is something that has been raised many times. What number of the clients you are seeing actually have carers?

Ms MANDER — Most of them do have a carer of some sort. What we try not to do is put a value judgement on that carer. They are managing however they manage. What we try and do is let the client and the carer drive their care, and we will support around them. Most of them would have a carer of some sort, but quite a few of them do not as well. We will probably see more of that as older people are divorcing more and more and living alone and all of that, so that is probably going to change as well. People who do not have a carer have higher hospital admissions, and it is hard for us to keep them at home.

Ms PATTEN — On that, is it preferable to have respite at home or respite beds at a facility?

Ms MANDER — It depends on the nature of the respite needed. The patient just might need some hospital stay because managing at home is hard, but the carer might be okay. Often it is that the carer needs a break. There are a couple of ways we can do that. We can try to arrange an inpatient respite stay, and we often use Caritas Christi at Kew for that, and sometimes the Austin Hospital. They are probably the most common ones, or Broadmeadows. I have lost my train of thought.

Ms PATTEN — At home?

Ms MANDER — Yes. At home what we try to do is we might be able to get some volunteers in there for the short term, either someone to stay in while they go out or to do some shopping for them or something like that. We will do that, or we use the CarerLinks funding that we have got for 24 hours. We really do not have any other source of funding for that. Our donations do not really run into that sort of money. Probably for us, depending on what day of the week it is, it could be $1000 or over to have a nurse in for 8 hours of a night-time. We have to be really careful how we use that 24 hours of respite, and we do not really have the resources to provide any more than that at the moment.

As to picking where it should be, if someone wants to stay at home, often we find that the longer someone has been on the program, their needs ramp up as they are dying, their symptoms increase and their care needs increase. The carer burden is extraordinary. If they have been doing it for 12 months, they often flag at that
point in time. Picking when that person might die can be really tricky, because that can lead to complex grief if they say, ‘Well, they wanted to die at home. If I’d known it was going to be another day or two, I would have just hung in there’. That has a whole lot of other flow-on effects.

Ms PATTEN — It must be more expensive to put someone into inpatient care.

Ms MANDER — Absolutely. We feel incredible guilt when we do that. The carer feels guilty and we feel like we are not providing the service that we would like to provide. We know it is an impost on the system if they do, particularly if they die in emergency. That is just awful. It is really awful.

Ms PATTEN — If a government looked at the balance sheet, it would fund respite care in the home?

Ms MANDER — Yes, and we can respond quite acutely if we need to, if we have got the padding in place to kind of divert and then replace where we need to. We do that now. If someone has got an urgent need, then will look at the other patients and say, ‘Well, okay, that person could probably wait for another day. We will go and do that’. It is destructive to them as well of course, but you have got to service what you need to service at the time.

Ms FITZHERBERT — What would you say is your unmet need? Are there people that you need to turn away who ideally you would look after?

Ms MANDER — Our unmet need is being able to respond to the number of referrals that we get. I will give an example of last year where we had an unprecedented number of referrals in winter over a couple of months. I liaised with my colleagues on the borders to see if they could take some of our patients while we serviced the ones that we needed to. That was something that I called the department about, just to say, ‘Look, we’ve got this situation here. Just want to let you know it’s high risk, and if there are any complaints, then I want you to be aware that this is what’s happening’. Our waiting list goes up and we have to just keep re-triaging and re-triaging, or we have to send people back into hospital.

Ms FITZHERBERT — How long is your waiting list at the moment?

Ms MANDER — The waiting list varies. We are just coming out of winter, so it is coming down. Probably the worst it has been is 50 people waiting, without a space to book them in. At the moment, as of today, we have got 28, with about 6 in hospital, so they are not ready for care yet, and they are all booked in for a visit over the next week or so. We triage them. If they need to be seen within 24 hours, then we will do that. But we have got them all booked in. It is kind of a bit of an art of juggling triage, the number of patients you have got, the urgency of the new ones.

Ms FITZHERBERT — The other thing is we have heard lots of evidence about people making end-of-life plans and so on. Do you have that sort of process within your way of working with people, and could you tell us how that works?

Ms MANDER — Do you mean an advance care plan or an end-of-life care plan, because I see them a little bit differently?

Ms FITZHERBERT — Both.

Ms MANDER — We do introduce advance care planning, which is particularly if someone is still having some palliative treatments or other treatment, and we will work with them to work out what it is, which is, ‘Have you thought about what you would want to happen if you can’t speak for yourself?’. We do work with them around that process. But often when they get to us that is not really appropriate because they are here for end-of-life care, so we will do an end-of-life care plan rather than an advance care plan. But with the patients who get referred to us early we have probably got some time to do that sort of work about, ‘Okay, here’s where you are now. Have you spoken to your next of kin about what you would want to happen if you couldn’t speak for yourself?’.

Depending what treatment they are having, we might go through some scenarios with their treating specialist about, ‘If this happens, what would you want to happen? Would you go back to hospital? Do you want to stay at home? What level of intervention do you want?’ We do both of those things, but I would say that most of the work we do is around end-of-life care planning, which is, ‘Where do you want to die? What do we need to put
in place for that to happen? What if X, Y, Z happens and things change, if you change your mind along the way?’. They might decide, ‘No, I can’t be at home anymore, I want to die in a hospital or palliative care unit’. We are constantly having those conversations with our patients around that as their condition changes. I hope that answers your question.

Ms FITZHERBERT — Yes, it does.

The CHAIR — Anything else you would like to add before we formally conclude?

Ms FEWSTER — No. We just thank you once again for the opportunity to be part of the conversation. We really appreciate it, and we really commend the work that you are doing. I know it is a very difficult topic to grapple with, so thank you.

The CHAIR — Thank you for your presentation and for the remarkable work you do and for giving your unique perspective.

Witnesses withdrew.