

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Geelong — 29 July 2015

Members

Mr Edward O'Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Mrs Inga Peulich

Mr Cesar Melhem

Ms Jaclyn Symes

Participating Members

Mr Gordon Rich-Phillips

Staff

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

Witnesses

Dr Peter Martin, Regional Director, Palliative Care,

Mr Paul Cohen, Acting Chief Executive Officer,

Dr Alastair Mah, Chief Medical Officer, and Chair, Barwon Health End of Life Care Steering Committee, and

Ms Robyn Hayles, Chief Operating Officer, Community Health, Rehabilitation, Palliative and Aged Care, and
Mental Health, Barwon Health.

**Necessary corrections to be notified to
executive officer of committee**

The CHAIR — I declare open the Legislative Council’s legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome those from Barwon Health and start by thanking Barwon Health for their hospitality in hosting us this morning. It is no small logistical feat and we are very appreciative of your hospitality and courtesy this morning. I would like to welcome Dr Peter Martin, the regional director for palliative care; Dr Alastair Mah, the chief medical officer, and chair of Barwon Health End of Life Care Steering Committee; Ms Robyn Hayles, the chief operating officer of community health, rehabilitation, palliative and aged care; and Mr Paul Cohen, the acting chief executive officer. We have allowed an hour for this morning’s session. I would like to invite you to make an opening statement, and thereafter the committee will have questions.

Visual presentation.

Dr MARTIN — Is it alright if I use slides?

The CHAIR — Please.

Dr MARTIN — It is just so that I can remember what I am going to say. I have been giving this quite a bit of thought for a long time, because I think it is a great opportunity to think about end of life and choices. I think the themes for me that are relevant right across health and in the various places that I have worked are that the important conversations about end of life are not happening often enough, and I think there is a wide variety of reasons for that which you may wish to ask about so that I can go into more detail. That will be my first point. I think there is still a culture of late referral to specialists in palliative care. I recognise this is about end of life much more than palliative care, but it is still a crucial part of it.

Again, I think there are multiple reasons why late referrals happen. The face of general practice is changing in ways that are challenging our systems and the supports we can provide to our community. I think we need to factor that into the way ahead. Palliative care probably needs to think about how we run and we need to be much more interlinked and bridged with all our key stakeholders. I was talking to some of these earlier, and particularly a more ambulatory kind of pattern; whereas traditionally the way that services have been set up, they have been set up in places rather than ambulatory, and that is something we need to reflect on. I think there are real capacity issues which have impacts on people’s end-of-life choices. That has lots of impacts on other parts of the health organisation as well, right from the emergency departments to the oncology services. But they are each independent, and that has some real stresses and difficulties for patients and their families.

Residential aged care has a huge variation between the services that are very well set up and others, but in general they need more help to essentially deliver more and more end-of-life care as frailer people with more complex illness end up there, often sooner than they used to. Respite is a massive issue that we have heard about during the consultation processes at Barwon Health for our own end-of-life strategy — and that is respite in-home and respite out-of-home — both for the patients’ sake but particularly for their carers. The funding models have probably not moved along with what I would say the core standard of care should be. I think sometimes we are working around them rather than working with them. That is all I was going to say as an opening statement. I am not sure whether any of my colleagues wish to add anything.

Dr MAH — I am sure we will explore more during question time.

The CHAIR — I apologise because I made an error with the time earlier. We have half an hour for your session, and one of your colleagues is joining us after that. I thought I would ask Dr Martin the first question. We have been lucky enough to look around this morning and speak to you about the services you provide. You have articulated to us some of the benefits of the model that you have here. Could you recount for the benefit of the committee and the benefit of the transcript how you see the model you have here in Barwon Health, why that works well and how it is different, perhaps, to some of the alternative service delivery models?

Dr MARTIN — The model we have here is an integrated model where one provider offers a whole range of services. Just to recap: that would be services to support, in the hospital, bedded palliative care services, community services and subregional support. The advantage for patients and carers is that these transitions are quite different from services that are run by different organisations. We have the ability to look at an integrated program. Health professionals can follow patients and carers to make those transitions more seamless. That creates some efficiencies as well. What we have really tried to articulate more recently is a range of services that are customised for the needs of the patients and carers. Whether that is that they need to be in the hospital

because they might need some specialist pain interventions and they are still getting chemotherapy, whether that is they need to come to a subacute environment place where we can link with our aged-care and rehabilitation colleagues, whether they go home with a package of care or whether they go to a residential aged-care facility that Barwon Health run that we can have a much bigger input with, as well as a range of these kinds of outpatient services. That has been set up, as well as supporting our subregional colleagues in the likes of Colac and Bellarine. Whilst there are some challenges in some of the resource issues and some of the transitions, I think we are able to provide that kind of linkage and continuity of care that is harder to do in other parts of the health system.

Ms PATTEN — Thank you for the tour. I am very interested in advance care planning and I suppose particularly with an organisation like yours, which does have this integrated system. Would you support us moving to almost a more mandatory advance care planning that was used as people went into an aged-care facility, for example, or went into hospital with acute conditions? Secondly, would advance care planning somewhat simplify the complications that you mentioned about where to place a patient if you have no idea about how that patient wants to go in the future?

Dr MAH — My comment on that is that at Barwon Health for the last year or so we have started having a goals-of-care discussion for all our patients who come into the health service. This is something probably that a few health services around Victoria and nationally have gone towards as well. It gives the treating team an opportunity to discuss, as a starting point, about where you want your care to be and whether there should be any limitations, and it has evolved over the years from what was previously, ‘not for resuscitation’. Now we are asking the patient, the consumer, ‘What is it exactly that you want?’ And then, ‘How can we partner with you to achieve those goals?’.

So we are starting to see that in some residential aged-care facilities, where you talked about advance care planning and advance care directives, they are part of the conversation on admission. Do we do it well? I think there is still room for improvement, and certainly within Barwon Health ourselves, I think we can have the goals-of-care conversations a little bit more, and they can be a little bit more targeted. That is what we have been working on, and I think you will be able to ask Neil this this afternoon as well.

Mr COHEN — I am not sure about mandatory care planning, but anything that encourages and facilitates GPs and other primary carers to start these conversations early and get care plans and care pathways understood across the family and by the individuals before they come into hospitals — it is all very well us asking when they are in, but often people are too late in the system by the time they get through there.

Ms PATTEN — That is right. I think the paper that you wrote, Peter, was saying that most people end up in hospital because the doctor sends them there rather than anyone saying, ‘Do you want to go?’.

Mr COHEN — Yes. So we have done a lot of work with our GP community around how they are introducing their patients to advance care plans. We find it is practice nurses, early on, who work in practices, who can ask patients as they come in or who target patients as they come in. I am not sure about mandatory, though.

Ms HAYLES — I think there is maybe somewhere in between mandatory and actually measuring what we are doing now, knowing that some of the panel’s interest is about how you can monitor and measure that those conversations are happening. I think at the moment there is probably some room to think about what that measuring framework across the state looks like, and how it can be made transparent. So one of the challenges for the health system is, while the end-of-life discussion might be happening, where is that documented? Who looks at it and therefore is it enacted? So the IT systems and the interfaces around that are challenging across Australia, let alone across Victoria, so while we have a national record, some of the thoughts about how you might mandate where that has to be seen, and how, I think are worth giving some consideration to because it is a challenge.

Ms PATTEN — Yes, good point.

Ms HAYLES — Certainly from an aged-care perspective, and having as much preplanning in this area — diseases are different and people are different and so the process and timing of these conversations is variable but, as you say, some type of legislation that triggers the process is important, if not actually mandating that you have to have the discussion.

Mr MELHEM — This is for anyone on the panel, really. What are the choices available at the end of life for those who are terminally ill? Dr Mah talked on the way here about how cancer is one of the major triggers but there are other diseases as well. In your experience, what are the choices available to people now in relation to their end of life?

Dr MARTIN — I think the first point you made was how much of this end-of-life care is cancer. Traditionally, that has been maybe a strength that we focused on with clear links and bridges. I think non-cancer diagnosis or non-malignant palliative care has been a huge growth. I think I mentioned that about 35 per cent of our hospital team's activity is spent looking after people without cancer. Increasingly, that is people in general medical wards, often who are frail, elderly and have multiple comorbidities. So that is the first point of clarification, and that would be reflected probably in the community in a fairly similar way. In our inpatient unit, there is probably still a slight under-representation for some of the reasons that I was talking about, of some of the other needs that they may have or they may encompass.

There are some challenges about where that end-of-life choice is for those people who still may need to see the dialysis team and the oncology team et cetera, and that is one of the challenges about, for instance, our beds being placed here in a subacute campus. In terms of their general end-of-life choices, sometimes they want to rapidly go home after a fairly catastrophic event to have their end of life at home, including residential aged-care facilities, and there are some real limitations and tensions about what we can deploy in that time. While we have set up systems and processes, I think the way the current model works does not always facilitate the ability to rapidly head home to be cared for at home to die.

Then at home I think the two major tensions around end-of-life choices are what supports we can provide both to the patient and the carer in terms of respite, which I mentioned earlier. Lastly, particularly in those last days where their physical care needs are very heavy, what flex have we got? So we, for instance, have partnered up with some not-for-profits here, used some of the local charities or philanthropic bodies to kind of enhance support, but that is not available everywhere. If I head 50 or 60 kilometres west, they may not have that flexibility to put in a kind of customised package of hands-on care in those very physically demanding last days of life.

Mr MELHEM — As a follow-up, there is the medical assistance to make life decisions possible, but what would you change from the current situation, going forward, to make it easier for people at the end of life? I would even go as far as the patient saying, 'Look, I want to go now, I am not going to wait two weeks or two months'. That is the first part. The second part, which is not available at this stage, at least not in the legal sense, and I know it is a long question — —

Dr MARTIN — That is all right, I will try my best to answer it, and I one of my colleagues might chip in. So the first part I think is moving to a much more flexible model of what each individual might need, because it varies enormously — a kind of more bundled type of care rather than silos of care that are each trying to do their best. I think that has been a real challenge. Some of the kinds of things we have created around the system have achieved that to a degree. I think it is certainly having more availability to put things into the home, and whilst the medicine and the nursing, do it to a degree, it is sometimes just that physical pair of hands 24 hours a day to support a frail, elderly carer who wants their elderly loved one to die at home. That is predominantly it. I think some of that flex about how we integrate and how we have bundles that can kind of follow patients and achieve the goals that they wish is not currently really available in the models we have got. That would be the first point, and I hope I have addressed your question.

Mr MELHEM — Yes.

Dr MARTIN — In the second point, I think you are alluding to their choices of what would be intervened in terms of active things and euthanasia. I think the first thing is that it is interesting how many times they do not realise how their choices can actually reflect their wishes. If you get a pneumonia tomorrow, do you actually want that treated? Because a lot of the time that almost negates the issue of euthanasia, which I know offers a variety of views. That is, I think, about those conversations and having the skills and the processes around the system. I think the skills have maybe been a bit underdone. You can set up good processing systems but if people are not skilled to have the conversations, then I think that goes back to education and professional development. I think we know that with a lot of it, for instance the junior doctors really struggle with those conversations and default back to a safer, more interventionist approach.

Mr COHEN — And that is the program we are running at the moment. You are seeing Neil Orford this afternoon, after us. We have been to Cambridge, which is the world centre for junior doctor communication with patients, and I forget the name of the program — —

Dr MARTIN — Calgary Cambridge.

Mr COHEN — But we are trying to bring that in in our university hospital, so that is a hugely important point.

Dr MARTIN — The link-up between undergraduate education and graduate education and the training days right across and right up to, obviously, specialty.

Mr COHEN — Explaining what pneumonia means.

Dr MARTIN — Yes, and saying what their choices are, and maybe having them understand that if they get pneumonia, unfortunately their illness will likely cause another one a week later, and is that what they want? Some will and some will not. I think that is the first point. Do we see people who ask about euthanasia in our practice? Of course, almost daily in clinical practice. When you unpack that, I think it is about them having heard their choices. For some people if it was available, just knowing it is available would be the issue, not actually doing it, and that is my experience from overseas as well. There is a small cohort, in my experience, that have a clear and consistent wish that that would be available to them, but I think there are the other issues where it is explaining what choices are already available and respecting their wishes to fit with their own values and systems.

Dr MAH — I think access is one of the things that we should consider, especially in regional Victoria. In regional and rural Victoria you might not have the specialist skills that a place like Barwon Health or Melbourne would have, and there are often communities who do not have that level of support that they need. When the patient deteriorates, the only way to go is to drive an hour or get an ambulance to go to the nearest emergency department for half an hour, wait 6 hours and then go home. Access is an issue in regional Victoria. Access also goes the other way from a patient's perspective: whether they want to access palliative care services or whether they are ready to have the conversation that needs into issues like health literacy. In a culturally diverse population in Victoria that can sometimes be a bit of a challenge.

Ms FITZHERBERT — Dr Martin, I was interested in what you said before about late referrals for palliative care. I just wanted to get a better understanding of how you define a late referral and what the consequences of that are, because I am conscious, particularly from earlier testimonies that we have had, that doctors can only predict what is going to happen. People can change and circumstances change. Could you just take us through what you meant by that and what are the consequences?

Dr MARTIN — Sure. You are right; it is a hard thing to define what is late and from whose perspective. In general we would find that there are a lot of people views, or a community perspective, that they are fearful of palliative care, and they associate it very much with that very end of life or meaning days or weeks. Therefore they are concerned that it has prognostic implications for them and their families. We need to move it to a much more needs-based approach, where they recognise that we are there. Some countries have changed the name to supportive care or symptom control or other things that reflect the breadth of what we do. Yes, end-of-life care is a core part of what we do, but also in terms of symptom support, planning and helping them. Part of the bridging has helped that.

I think there is a community perspective, and then what is a little bit more challenging are those issues where the health professionals may guide them one way or another and of what are the influences of guiding from an earlier referral to later. Some of the international literature now is suggesting that people have better outcomes. There was a fear that palliative care would change their outcomes, and now there is a growing body of literature to suggest that seeing us earlier would have a range of outcomes around terms of quality of life, survival and symptom burden. There is an emerging body of literature around that.

Some of it is about the reticence to have the tough conversation that their illness is progressing. I do not think it is out of gatekeeping or malice. I just think there is sometimes a reticence and a reluctance to have what is a difficult conversation around where their illness is heading and what choices there are. Sometimes I think there are some assumptions made about what choices they wish, which may not be truly reflective.

I am not sure I have been able to give you the answer. I think if I could give you a unique answer about the referrals, I would be in a very envious position. It is something that is a challenge right across the international landscape. There have been some good initiatives elsewhere about changing that. We are working it out ourselves about how we bridge with our key stakeholders.

The CHAIR — I would like to ask a follow-up question to that. Mr Cohen, you referred to the nurse practitioners that have received some training at GP clinics to have those discussions. We received evidence last week that the GPs could be a good central point in the system to drive those sorts of discussions. Would any of you like to comment on that in addition to what Dr Martin just said to Ms Fitzherbert about how you in practice drive those discussions and whether GPs are indeed the appropriate point to focus on?

Mr COHEN — They are a hugely important member of the care team. They are the people that know the patients and their families the best often. They are in a very strong position to really identify people who are ripe for those conversations. And family issues — they have a much deeper understanding than an emergency department will when someone turns up in an ED. Absolutely well placed.

The other part of it is that there is a whole society issue here around how sophisticated we are as a society. I personally shy away from using other words, because we are trying to move away from this point where we are all going to die eventually. We pretend we are not, so we moderate the language, whereas we need to be stepping forward probably and being much more honest, open and sophisticated about these conversations, and probably GPs are in a very good position to do that.

Ms HAYLES — Part of the reason that the model has worked here in Barwon has been the EFT that has been resourced within the GP facilities. Jason hopefully will talk a little bit about that later in the day, but one of the challenges obviously for GPs is the time that these conversations take and that exploration of understanding of what are a person's values and what is it that they value about their life and all of the things that they are predicting that might happen to them moving forward, and that takes time. Our model of GP practice is obviously a bit of a challenge to that.

What we have found has worked well is having skilled-up staff that have visited clinics in regular times so that the GP can commence discussion, evolve the discussion a bit and then, when people are ready, have a resource — an educated, trained, in our case nursing, staff, who have those conversations in more detail and take people into the legislative framework of advance care planning et cetera if and when that is appropriate.

Part of our focus in Geelong has been that we see this as needing to be nearly a movement of conversations, so that it is not all just about the very end days of life and what that looks like but it is about planning for our circumstances and ageing. We need to do that in a community rather than in the four walls of an acute hospital. Our end-of-life strategy has really been about trying to engage in those conversations and planning the whole way through, and we think GPs are really well placed for all those reasons that Paul said. But the framework of payment and time is challenging.

Ms PATTEN — Just following on from the question that Mr Melhem asked about people referring to voluntary euthanasia as part of what they see as an end-of-life choice for them, I agree with you that once you can unpack what is available that passion probably declines. You said a small cohort, and I am wondering if you can give me an idea. I am also wondering, Ms Hayles, if that is a regular conversation that your staff are having with these patients.

Dr MARTIN — Do you want me to start?

Ms HAYLES — Sure. They are a bit one and the same.

Dr MARTIN — We have not defined how large that cohort is. I think I said that with the right conversation it does become like having permission to have a frank conversation about what their choices are and I think often reframing it. For some people it kind of indicates the discussion in the first place but for others it does not. I am not able to quantify it because that is not something I feel I have good data to be transparent with to the committee, but I think it will be a much more common conversation and there would be people that appreciate that. And it is an important conversation because it really dictates determining their values and their wishes and frankly the critical medical decisions that are likely to be imminent in their care. That is probably the best I can respond without quantifying it in a way that I am not clear about.

Ms HAYLES — It would be the same in terms of numbers but based on a couple different sectors of the health service. In residential aged care, clearly the same conversation comes up. We have a nurse practitioner who works in residential aged care and residential in-reach, who would, I am sure, report that that conversation happens on a not too infrequent basis. But it is, as Peter said, about what is that about and why are people asking around that, and if we can have the conversations earlier and plan better, then we are in a much better position to provide the care that they need.

While Barwon Health in particular provides great care and as a health sector people receive really good care at various points, one of the things we do not recognise is what we are not doing. We need to acknowledge that we are in the six bottom of the OECD countries around the world in terms of where people get to choose to die, so there is a lot of work to do in this space. We know the numbers that come through the system, but we do not record them. We can give audit numbers of people who have been waiting for beds for respite or waiting for direct hospital admissions into palliative care beds at various points in time, but we do not know that on a routine and regular basis. I do not think the demand for that system is clear and does not even address minority groups within that. I think there is still quite a bit of system work to be done around that to be able to accommodate this. Knowing the drivers of things like your accident and emergency targets and how beds within a broader system are used and pressured means that protecting beds for emergency admissions, like respite and palliative care, becomes a challenge in the sector. I put it to the panel that that is something we are thinking about just having seen some of the remit that you are looking at.

The CHAIR — We are running short of time, but we have three more questions.

Ms SPRINGLE — Which is a nice segue into my question. In response to some of the things that you have talked about, I am trying to get a little bit of a perspective on the wider situation in Victoria. You may or may not be able to answer my question but, firstly, how common is the integrated approach? Is Barwon an anomaly, or is it happening all over? Secondly, in terms of that broader dialogue about end-of-life choices, obviously a very concerted effort is going on here, is that something that is widely being addressed across the health sector in other areas in a similar manner?

Dr MARTIN — Regarding the other services, I am not aware of many other integrated services. It may have a couple of parts linked with no hospital part or a hospital team part but not the whole integrated package. There are some places that would aspire to more an area model where that is kind of a population model, but I think there are some areas that probably do some parts of it better, but to be honest it is rare. I think that is your first question. Was your second question regarding the — —

Ms SPRINGLE — It is around the dialogue at a community level but also at a one-on-one level about end-of-life choices. Several of your contributions have talked about needing a more open dialogue around end of life that needs to be more broadly spread culturally. I am trying to get a handle on whether this is something that is happening everywhere — that is, facilities are trying to address that issue everywhere — or whether that is unique to here?

Dr MAH — I suspect Barwon is quite unique in this sense. It leads to a larger question of how fragmented health is in general, and I do not think that is an easy answer. You have different funders, different people looking after different parts of a patient's care, and it is fragmented. As has been alluded to by Paul, we have great partnerships with our GPs and with our community sector, but in my experience that is not the norm.

Dr MARTIN — Because the end-of-life strategy is integrated, people look at it in a much more global integrated way. People might look at pockets of end-of-life choices but not as a global issue, so in my experience for an organisation to put that at the forefront of one of their significant strategic objectives is very unusual.

Ms FITZHERBERT — You said that funding models for palliative care need a major revision.

Dr MARTIN — Yes.

Ms FITZHERBERT — In the time allowed — I know that it is really short — what is wrong and how would you change it?

Dr MARTIN — I think in short they are based around those silos of care. Whilst you could critique the minor parts of that, it is about taking a much more global integrated look rather than what happens in an inpatient facility versus what happens in a community provider et cetera. That is at the core of it, and really being much more person centred, allowing that flex and bundled approach. That is the short answer, obviously because of the time constraints.

Ms FITZHERBERT — So rather than saying a person might be able to access funding buckets in these areas, are you saying, ‘This is what we allocate per person’ and then you work out what you need?

Dr MARTIN — Yes, I think having more flex at a regional population model to create a range of services where you are not trying to worry about shifting costs that accesses a bigger area that would go from inpatient to outpatient, to respite, to residential support; so yes, a much more integrated way. Obviously the detail would need some significant planning, but I have to say that at the minute we work around it rather than with it.

Ms HAYLES — Some of the thought process that we put behind what this might look like moving forward has been the ability for health services to be able to use — —

It does not matter in some ways what the numbers are. At the moment funding is bed based, but there is the ability to use some of that flexibly. You might nominate for your population two beds, one bed et cetera to be able to accommodate the flexible packages of community care and respite in a way that can move across the sector rather than be isolated to certain spots in the sector and not meeting the need of clients. Therefore it would enable us to address the gaps that we have at various points and provide more person-centred care. While still being sure that we are accountable and reporting for all of that activity, the department can still set activity targets et cetera, but it would enable a more flexible opportunity to provide some personalised care.

The CHAIR — Thank you very much for your answers. As a final question, Dr Martin, I am interested to know what sort of demand growth you are seeing and how you are responding to that. You have got the new infrastructure that is being built, and hopefully that will be operational in the near future. Can you perhaps talk to the demand growth you are seeing in the palliative care area?

Dr MARTIN — Sure. The demand is right across the board. Cancer is growing because of our ageing population, so year on year they have seen growth which has a direct flow on to us. As I mentioned before, the need for palliative care for those other chronic illnesses is growing, and therefore the demand on the home service is to rapidly respond to people who have been discharged, often with quite complex needs. The other part of the major demand is how we are able to respond to people who suddenly say, ‘I need to come in and be cared for’. That is probably the hardest one for our system. Having to send somebody to an emergency department close to the end of their life because we have no alternative is heartbreaking for all concerned, and that is a real challenge. That is probably the real area that we have been aware of for a decade, our need to address that kind of capacity. There are other things we could do at home to support, but I think there is still going to be a need where people need care, and at the minute that is not always available.

The CHAIR — Ms Hayles, Dr Martin, Mr Cohen and Dr Mah, thank you very much again for your hospitality in hosting us today — we sincerely appreciate it — and for your evidence to the committee this morning.

Dr MARTIN — Thank you very much.

Witnesses withdrew.