

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Traralgon — 9 September 2015

Members

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Witnesses

Ms Vicki Doherty, Manager, and

Ms Irene Murphy, Regional Nurse Practitioner Mentor, Gippsland Region Palliative Care Consortium.

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. It is great to be here in Gippsland. I would like to welcome Ms Vicki Doherty, the Manager, and Ms Irene Murphy, the regional nurse practitioner mentor, from the Gippsland Region Palliative Care Consortium. Thank you very much for joining us today.

Before I invite you to provide some comments, I will just 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 proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee’s website. We have allowed 45 minutes for our session today. I invite you to make some opening remarks, and thereafter the committee will have questions.

Ms DOHERTY — Thanks very much. My name is Vicki Doherty. I am the manager of the Gippsland Region Palliative Care Consortium. Firstly, I would like to declare I am actually not a clinician. My background is in health policy, but I have been working for the consortium for four years now. I am very pleased that the committee is looking at this very important issue, and also that the Department of Health and Human Services is currently reviewing an end-of-life care framework. I have put together essentially some demographic data, just to give you an idea about the health issues that we face in Gippsland and how we might be different to other regions across the state.

Visual presentation.

Ms DOHERTY — Firstly, we are one of the largest, second only to Loddon Mallee, in the state geographically. The distance from Mallacoota up in the east to Melbourne CBD is over 500 kilometres, so the remoteness causes a lot of issues for people in Gippsland accessing health care. This is just some selected indicators for Gippsland in comparison to the Victorian population. You can see that we only have a relatively small population, around 5 per cent of Victorians, but we have a very large population compared to Victoria in the over-65. We have a higher than average Indigenous population, and we also are more likely to have low socio-economic groups as well.

This is the death data over the last four years. You can see that Latrobe City Council has the largest population, so that is what we would expect, that we would have the most deaths in that LGA. However, when we look at East Gippsland, which is actually a relatively small population, they have a high amount of retirees, and Bass Coast as well. In Bass Coast we are looking at about 30 per cent of people are aged over 60. In the coming years we are going to be expecting to see quite an increase in deaths in those areas. Bass Coast and Baw Baw are one of the highest growing LGAs in Victoria as well. There are a lot of younger families and retirees moving to those areas.

Health outcomes in Gippsland: we have some pretty poor outcomes unfortunately. We have the highest smoking rate in the state and the lowest male expectancy, very high levels of psychological distress, high rates of disability and the highest rate in the state of drug and alcohol clients. As far as accessing health care, we have the highest rate of inpatient separations, which proxy indicator for admissions to hospital, and we have the lowest private hospital utilisation. We only have one private hospital in Gippsland, and that is based here in Traralgon — or Morwell, I think. Also attendance to GPs is below average, and we also have very high emergency presentations as well.

This is the palliative care services across Gippsland and where they are situated. We have eight community palliative care providers across Gippsland: in Gippsland Lakes, Central Gippsland, Bairnsdale Regional Health, Latrobe Community Health Service, Gippsland Southern Health, Yarram and District Health, Bass Coast Health and West Gippsland Healthcare Group. We also have other generalist providers that will take palliative care clients, who are then managed by the specialist palliative care providers. When you have got areas sort of up in the back of Dargo and Gelantipy, it is just not reasonable to expect a specialist palliative care nurse to be travelling every day out there. A lot of the health services, the bush nurses, work in collaboration with the palliative care services there to try and get the best outcomes for their clients.

We do not have a hospice in Gippsland. I think we are the only region that does not have one. Instead we have 11 palliative care beds across the region. There is no one particular bed that is dedicated to palliative care. You

would understand in health services with multiple programs going on they cannot keep a bed alone for a palliative care client. We have the largest amount of beds at the regional hospital, which is four, and then we have two in Bairnsdale, two in Warragul, one in Wonthaggi and two in Central Gippsland. When we are looking at that, I guess it is also very hard for services to be able to afford to have specialist palliative care staff if they are only looking after one patient. There are a lot of challenges that the health services face in providing specialist palliative care.

After reading the terms of reference I have just put some points together as well. The first one is about what is end-of-life care. I think a common perception in the community is that palliative care is terminal care, end-of-life care, but of course palliative care is much broader than that. As well, not all of end-of-life care requires specialist palliative care. There is only a very small amount of clients who need that specialist input, so a palliative approach is actually much more appropriate. End-of-life care in the palliative care context frequently does mean terminal care, because there are lots of other types of care going on, but in the broader health care context, end-of-life care, we need to start looking at preparing for that at least one to two years before death — at least.

Palliative care is a multidisciplinary, holistic approach. With the terms of reference, I suppose what we fall under is medicine, but we see palliative care as much broader than the medical model. I think we need to be particularly careful around that, because basing it on the medical model, it is costly to start off with, and it is also not providing that holistic approach. We run the risk of really over-medicalising death as well.

I think one of the major issues in planning for end-of-life care is the capacity for clinicians to actually have difficult conversations. There is lots of documentation around about how to complete an advance care plan, but it is actually starting that conversation with the clients and carers about what it is that they want. We know not all clinicians have good communication skills, but they can be taught and they can be learnt. That is something that we have been trying to do across our region. There was a recent publication in the *BMJ* that found I think about a third of GPs have never raised the issue of death with any of their clients. In the UK it is actually mandatory — they have annual communication skills training for their doctors over there. However, that is a different system. It is much easier to mandate doctor training in the UK, of course.

Dying at home — that is what the evidence points to as what most people want to do. This requires adequately funded community palliative care services. That is where we need the resources directed to ensure that people are able to stay at home. We need educated clinicians, and that is a lot to do with the primary care sector and the generalist care sector knowing when to refer to palliative care. We need an educated community as well so that people know what services are available, what their rights are and what their options are for end-of-life care.

We also need adequate access to respite. In Gippsland we have mapped respite services, and there are a few different options. There is the National Respite for Carers Program, which really only provides emergency respite. In palliative care we need access to planned respite so that carers know when they are going to be able to get that relief. There is the unassigned bed fund, which is part of the community palliative care funding, but that is used for lots of different things, not just respite. Then there is access to aged-care beds, but you need an aged-care assessment to have that done, and then of course that is only available to people aged over 65, so you are missing another group of the population.

Lastly I just wanted to mention data and outcomes. There has been a very big focus on whether people are dying in their site of choice. That is very easy to collect, but also it does not give us a really good indication of whether people are being cared for in the site they want to. Often people can see it as a failure — that their loved ones have died, maybe in hospital, even though they have provided all that care for them right up until towards the end. With data and outcomes we just need to be mindful that if people die in their place of choice, it does not always mean that they had a good death. It is also about collecting process outcomes around that. That is about all I have to say. I might hand over to Irene, because she probably has a few more things to add.

Ms MURPHY — I will make a few statements. Thank you again for the opportunity. In terms of people nominating their choice for a site of death, it is true that there is extensive data about what the enablers are in terms of assisting people to die at home, particularly the data that is there already and emerging from Western Australia. Professor Kristjanson, Professor Aoun, Professor Hudson here in Victoria and Professor Rumbold. These academics have written extensively about the major predictors to help people to die at home in terms of practical support and good psychosocial and physical symptom management.

It is true that dying at home is not the cornerstone of good palliative care practice or evidence-based palliative care practice, and in many situations we do not know why that person has spent the last 24 hours their life in a hospital bed, having spent all that time being cared for by their caregivers and their families. Also, research shows that with targeted respite, when the terminal phase is identified, perhaps two weeks prior to death, we can provide some good practical support for people either in-house or out-of-home, it has been shown that the caregivers and families' confidence and ability to care is actually strengthened.

Those are the things that we need to look at, there is extensive polemic and debate about why people are not dying in their site of choice. But actually the data exists as to why they are not. It is about the processes and appropriate funding — 'Don't mention the war', they say about the funding! — about how we can really enable and procure this. Again the respite in Gippsland is very scarce, as Vicki said.

I would also like to say that I am a nurse practitioner in palliative care. I was one of the first endorsed in Victoria. I have been in clinical practice for many years — and I do not care to tell you how many. I have worked in many fields in nursing. I worked in oncology first. Then I decided that palliative care was an important area for me to go and practice, mainly because many years ago people were dying in a very old room in a hospital where everyone was whispering. Nobody was saying anything. Caregivers and family were kept at bay in terms of what was happening. In a way this prevented them from experiencing one of the most profound changes that we experience in our lives when we care for someone or witness a loved one's good death. I guess this can be how we individuals ascribe meaning to what constitutes a good death.

I would also like to say, with respect, that I have a degree of concern that end-of-life care discussions are linked to euthanasia discussions. I think they are both very different entities, and by virtue of doing that both aspects of this important health professionals and the community in general's discussion could be trivialised.

As Vicki said, end-of-life care is the business of all of us, but in the health landscape or in the health professional business and the multidisciplinary team it is a collective responsibility where we can raise our awareness as individuals and professionals and move away from prejudice and judgement in terms of helping people to arrive at what they believe, because of their life experience, is the most important decision in their life.

With the advent of very good treatment — we are in the 21st century, and there is very modern targeted treatment — there is much more bargaining now in terms of offering people more years to live and in terms of people awareness and understanding of their prognosis. They are mostly aware that their disease is not curable, but there is constant bargaining. 'Yes, I can live a bit longer. I can see the birth of my granddaughter'. People find it very difficult to arrive at what they believe is a good decision. In the majority of cases this decision is not made in isolation.

We are defined by our relationships. We are defined by our own family culture, our own set of beliefs and philosophies. I have to say personally, because I have a different background — although I certainly feel that Australia is my home — that I have witnessed quite a bit of dislocation sometimes in families about what constitutes good decision-making. But at the same time, with good facilitation from clinicians, the capacity to grow in what Vicki described as good communication can still be obtained with good training, debriefing and supervision, so that we can help people to arrive at good decision-making. In palliative care we do not often achieve the best outcome, the optimal outcomes in what is acceptable to people. I think sometimes it is a case of the aspiration versus the reality. Sometimes I think the reality of what is achieved and acceptable could be good enough for a many people.

I believe that in terms of funding, inasmuch as the hospital bed being very important, there is a perception among clinicians who spend considerable clinical time in the community that there is an "obsession" with the hospital bed, especially when we find that people could have done a lot better with more resources. The definition of end-of-life care needs to really be looked at in a way that we can arrive at a meaningful definition for all of us, because some good deaths also happen in intensive care and cardiothoracic care. Palliative care does not have a monopoly on best communication of a good death. It does happen if clinicians are well equipped and supported to do this.

I think we have yet to arrive at a good definition of what constitutes end-of-life care, as Vicki said. End-of-life care sometimes could be the last two weeks of someone's life. Sometimes it could be the last 12 months. People 60 years and over, in the face of terminal illness, spend 90 per cent of their time in their homes with infrequent trips to hospital for treatment sometimes and sometimes for short-term admissions for symptom management or

psychosocial support. Caregivers and families sometimes just put their white flag up and say, 'Look, I can't do this for some time'. Also with some of that support I have seen so many people who, at the beginning of their episode of care, say, 'I don't think I can do that. I know my husband wants to die at home, but actually I don't think I can do that'. Then as care progresses, there is good support and good access to expertise or specialised care even after symptoms become refractory, difficult to manage. These are the caregivers like us, ordinary people who become extraordinary at what they do.

It also often happens that if people are able to procure good care for their loved ones in their home, it has some good implications for bereavement. We are talking about the health of populations here that extrapolate into good societies. If you have a difficult death, where you are left with a sense of what it could have been and was not, with regrets not only about the care but about how they conducted themselves, that not only impacts on their loss and grief but also on the family. If we are talking about the health of a population, that has got great implications for 5, 10 or 20 years. As you know, mental illness and depression is a high priority for Victoria.

I think we need to have greater availability and resources for equity of access and quality outcomes, and quality is how clients and caregivers see it. I think again for those people who nominate home as their choice of site of death, only 14 to 25 per cent make it. I would like to know why those who have said that they want to do it do not make it. I think it is most important that we do that.

When I talk about funding, it is not only about resources for those people who have a terminal illness, but it is also about capacity building. Good communication does not just happen. Training, mentors, support, collaboration with GPs and the establishment of networks is required. The raising of awareness in the community needs some support behind it. I think that is all I have to say. I finish with the notion that quality care needs to continue to increase in line with population growth, ageing, the growing incidence of chronic illness and people living with a life-limiting illness. As you know, people with a chronic illness live with the burden of disease for 15 to 20 years. It is a very gradual decline, and those are the people who are and want to be at home. Thank you.

The CHAIR — Thank you both for your presentation, and particularly Ms Doherty for those statistics that give us some context for the Gippsland region. Noting the older demographic in East Gippsland and the Bass Coast in particular and perhaps often the isolation from family members if people have moved, from Melbourne or from elsewhere to retire or for lifestyle reasons, down to the Bass Coast and East Gippsland in particular, do you want to make any comment about some of the challenges that will emerge in those areas as we move forward as that population grows?

Ms DOHERTY — I think in Bass Coast we find that because it is on the edge of metropolitan Melbourne when client needs are not getting met in that catchment, a lot of people are going up to Melbourne for treatment. Ideally that is not great. We would like to be able to provide that care in our community as well, but I think there are going to be more and more challenges as more and more people are ageing in those areas.

We have a lot of people moving into aged-care facilities, and that is another issue in itself. Through the Department of Health and Human Services we have been trying to upskill staff in residential aged care to provide a palliative approach for their clients. I think Victoria is leading the way in the country as far as that is concerned. There have been a lot of resources and commitment by the government to building capacity in aged care. There is still a long way to go, though.

I think that, particularly in rural areas where you have a generalist workforce providing a specialist service, there can be some issues around who is best placed to provide that care. In East Gippsland I suppose that is a completely different story because of the remoteness of it. Even though we have a regional hospital in Bairnsdale, it is still a very long way from places where some people live. The community nurses and bush nurses who work in East Gippsland have to travel enormous distances to their clients. There is not as much opportunity for nurses in those really remote areas to get the actual support that they need to thrive in their roles in providing care to the community as well. I think there are going to be a lot of challenges in providing care in the future, just because of the demographics of those LGAs.

Ms SPRINGLE — Can you flesh out a little bit what you mentioned just now about efforts being put into a palliative approach in aged-care facilities? Can you just talk a bit more about that?

Ms DOHERTY — About what a palliative approach is?

Ms SPRINGLE — More logistically, what is actually being done and how successful that has been.

Ms DOHERTY — All the regional consortia were provided with funding under the last palliative care policy that finished in June. That was based on a couple of pilots that were run in the southern metropolitan region and Barwon training link nurses — so essentially appointing a nurse in the aged-care facilities to act as the portfolio manager of palliative care. They have been trained in using the palliative approach toolkit which has the three key processes around providing a palliative approach. Those nurses will then go on to engage and train other nurses in the facility as well. We have also expanded the training in that. We have done some community aged-care nurses as well — so ones that provide HACC services — and also specific subjects under the palliative care umbrella, such as a palliative approach to advanced dementia. That is another big issue with the ageing population, more people getting dementia and clinicians having the capacity to understand when someone is in pain when they cannot communicate and those sorts of things.

Ms MURPHY — I think the success of the activities has been enormous in many ways, but also there are some deficiencies because, as you know, human resources in aged-care facilities are very transient because of the burden that it is, with aspects like a lack of resources and being overworked. Again it is challenging because what we have offered has been very sound in terms of increasing knowledge and attributes to manage those residents who reach their end of life. I think that will continue to be a challenge because, again, of the nature of the transient population in residential aged-care facilities. There is a great diversity. Some seem to do it very well, in terms of recruitment and retention of staff, but others seem to be transient. I think we still have a long way to go, as you know, to reach a degree of stability. But I like to believe that some of the data is emerging that the activities of the consortium in capacity building are paying dividends.

Ms DOHERTY — We are seeing a greater uptake in facilities that provide advance care planning and end-of-life care pathways and have family meetings — all those processes that are required to ensure that people are able to make decisions before it is too late.

Ms MURPHY — Advance care planning, as you know, is an important issue at the moment. Our consortium with the McCabe Centre for Law and Cancer are doing capacity-building activities with GPs. We bring the legal frameworks and we bring education in terms of what constitutes advance care planning, plus the Office of the Public Advocate, and they have proven to be very successful. What we do is go to the GPs. We do all the organisation and delivery, and I think that is really paying dividends because again, as Vicki said, it is difficult to engage for all the reasons that we know.

Mr MELHEM — Irene, you talked in your opening statement about the palliative care. You mentioned something about euthanasia and said that it is not something we ought to concentrate on. Can you expand on that a bit?

Ms MURPHY — I think, as I said, they are two separate issues, because end-of-life care is about how we want the last stages of our lives to be conducted, and I believe that the majority of time that is done in conjunction with our own beliefs and values in how we define ourselves in terms of our relationships and how we have conducted our relationships.

Lamentably, the issue of euthanasia is always hijacked and polarised. As a professional in palliative care, if you were to ask me, I am bound to say that euthanasia is illegal in Victoria, and Palliative Care Australia and Victoria require me as a health professional working in palliative care to say that I do not agree with the practice of euthanasia. However, there are some situations where by bringing about good symptom management, particularly in the last few days, in giving a particular type of medication, it is true that by virtue of doing beneficence you might bring about acceleration of death in a few days. For me that is not euthanasia; for me it is that ethical principle of bringing about beneficence.

In terms of linking these together, it is because with euthanasia it is a debate that we have to have but it is extremely polarised and it becomes black and white. People's lives are never black and white; people's lives and experiences are enveloped in shades of grey. I could say to you and often we are found saying, 'I would never want that happening to me', if we see that someone is being resuscitated or has had a major trauma, but as we grow we might have a chronic illness, we change our values and we start changing our position in life. That is what I mean.

Even respecting deeply people are saying, ‘If it gets to a point that I cannot even go to the toilet without being assisted, of course, life is not really meaningful to me’, I have no argument with whatever that person will do privately. But bringing that concept into end-of-life care for all of us, in terms of what constitutes that and how we are going to behave at the end of our lives, I think it is very presumptuous because of this polarisation, because of some very rigorous beliefs of some people where it is black and white, not the shades of grey that I often see in palliative care.

The last thing I am going to say is that I have been in palliative care for nearly 18 years now. People in their homes have ample opportunity, ample medication, to do away with their lives, to finish their lives. I have only seen that incident once, in 18 years of palliative care. Existential distress cannot be solved by pharmacological regimes only. Existential distress may arise is often a life perhaps not well lived, and perhaps some people have got every right to finish their lives, and with that I have no argument.

Mrs PEULICH — Irene, could I just say your submission today is probably the most profound, the most powerful, the most considered, the most thoughtful and the most lucid that I have ever heard, and I have been in Parliament for 19 years.

Ms MURPHY — Thank you, Inga.

Mrs PEULICH — You have really moved me with your understanding of these issues. I am interested in a lot of your statements, but I need to focus, given that they are apportioned and time is running out. I am particularly interested in your reference to cultural differences in attitudes to death and also the process of bargaining one’s position in relation to the approach of death and how that might change — even though someone may have entered into a end-of-life care plan — by milestones that may emerge during that period — the birth of a grandchild, their wedding, their engagement and so forth. Can someone enter into an end-of-life care plan and be held or bound to it, or does that professional discourse and education require a person to be nuanced and attuned to the changing position that occurred during this most vulnerable stage?

Ms MURPHY — Sometimes the burden of treatment can be so tricky that people might not necessarily be in the end stages of their life. Because of the fact that they are having extensive treatment (chemotherapy and radiotherapy) they feel so unwell that they say ‘Good Lord, I don’t think I can continue. This is really hard’. But as treatment progresses and they start getting a bit better, they start feeling a bit differently. The fact that they can make it to the letterbox and collect the mail, believe it or not — something we take for granted — huge milestone for people. The fact that they could go for a drive and have some lunch elsewhere rather than at home, can also be a huge milestone.

I think that some of the challenges arise because again health professionals, although very well-intentioned, sometimes can be very misguided, and we can be very much permeated, as it is, by our own principles and values that inevitably or inadvertently we try to instil into other people and it is a very difficult thing. I have been in health for a long time, and it is a very difficult thing to depart from what you believe and to genuinely listen to the person and say, ‘What would this person really want? What really is important to you?’. I think that is why capacity building and education is paramount. I think all health professionals can all learn to communicate better.

The other thing is that the medical profession is very powerful, and it is. They do a magnificent job. As you said, we are trying for meaningful relationships and the patients and their families start ascribing a lot of meaning to their relationship with their medical oncologist and to their relationship with their GP, where they do not want to hurt and they do not want to upset the medical oncologist. The medical oncologist is not well-equipped to really facilitate that discussion. You know what, maybe we need to look elsewhere because the words that they use are, ‘There is nothing we can do for you anymore’. That should be removed from the medical lexicon. There is always something that can be done for people.

So people feel abandoned, and they do not want to feel abandoned. They may continue with their bargaining ‘I will continue with the treatment, as much as I am very burdened’. But I think also there are so many elements in terms of what really influences people’s minds and people’s decision-making at the end of their lives. Regardless of how distorted it is, for health professionals, it is our responsibility to ascertain where possible are coming from and speak to the family also. As you know, people feel incredibly burdensome to their families. They are not going to work now; they have stopped working. Financially they are very burdened. There is so much going on.

Answering your question, there is such a variety of situations there. Culturally, I think we can talk about culture or diversity. I would like to remove my statement however because every family has got their particular culture. Every family has got a way of managing their own lives and their own relationships, so it is about us health professionals, with respect, with the ability to listen, to try to find out from their perspective what really matters, because what matters now might not be the same thing that mattered six months ago. It is in many situations the birth of that grandson or that son or daughter getting married that seems to be the rubric for some people, and actually you almost see visibly that, 'You know what; I am ready to go'. For some, no. They continue to fight the good fight until the end, whatever that is for them.

Ms PATTEN — Thank you both. It has been fascinating. I want to pick up, Ms Doherty, on your point about how we are over-medicalising death. I wonder if you could expand on how you think we could solve that or at least start going in the other direction?

Ms DOHERTY — I think culturally we have gone from having death all around us, when only one out of five babies survived to five years of age. Now we have excelled in health care, so the idea of people dying is not as common. Also, as Irene was saying before, death is always done out the back. I recently bumped into an old colleague I used to work with at The Women's Hospital, who is an obstetrician and she is Irish. She said, 'Tell me, Vicki, where are all these dead people? They must be underground. In Ireland they are in hearses everywhere; we just never see it'.

Going back to medicalising death, it is a bit of a double-edged sword. Palliative medicine is a relatively new specialty in itself, and I think it has been very hard for the general workforce to acknowledge that and know when to refer. But then also, like Irene was saying, it is often about the acute focus of death as well, whereas in palliative care we take a multidisciplinary approach. Doctors cannot provide everything. They are very good at what they do and all that, but it is often the nurses and the allied health professionals who can really assist people at their end of life with their existential problems and with basic care and that sort of thing. It is a bit of a political argument, I think, as well as a funding one, and health care in itself — valuing the different expertise that different professions can bring to the care of people at the their end of life. I am sure Irene can probably add to that as well.

Ms MURPHY — I think I like when you said this is end of life and also the social aspect of end of life. I think that is very important. We are all social beings, and I think that as much as the medical fraternity plays a very significant role, largely when people are talking about end-of-life decision-making it is very much informed by their socialisation and how they view life. But at the same time many of them do believe that doctors know best. Doctors have impeccability about their activities, there is no doubt about that, but often I hear doctors - not long ago a medical oncologist — said to me, 'Irene, I can't talk about this. Sorry, I can't talk about end of life with my patients, particularly when witnessing their spiritual or existential distress'.

The CHAIR — We had better leave it there. Ms Doherty and Ms Murphy, thank you very much for your presentation today. It is much appreciated. As I said in the introduction, you will be given a draft copy of the transcript for any name changes or minor changes; otherwise your transcript will ultimately be made public. Thank you again for being part of today.

Ms MURPHY — And thank you to all of you. It has been a great opportunity.

Ms DOHERTY — Thank you.

Witnesses withdrew.