TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Mornington — 29 October 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

Witnesses

Ms Rosemarie Draper, deputy chair, Peninsula Care Planning Group; and
Ms Michelle Clancy, team leader, palliative care, Royal District Nursing Service.

The CHAIR — I would now like to welcome Ms Michelle Clancy, team leader, palliative care, from the Royal District Nursing Service, and Ms Rosemarie Draper, the deputy chair of Peninsula Care Planning Group. Thank you very much, both of you, for being here today. Before I invite you to make some opening remarks 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 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 the proof versions of the transcript in the next week, and transcripts will ultimately be made public and posted on the committee's website. We have allowed approximately 45 minutes for our session today. Again, I thank you both for being here today and invite you to make some opening remarks, and thereafter the committee will have questions.

Ms DRAPER — I am here, as you said, to represent the Peninsula Care Planning Group. I did not bring along with me the terms of reference of the group, but I have them electronically and I am happy to provide them to the inquiry. Basically the Peninsula Care Planning Group are the aged and disability services in the municipalities of Frankston City and the Mornington Peninsula Shire. They are a range of a whole lot of public services, not-for-profits and private organisations that meet monthly to discuss issues that we have in common and look at ways that we can advocate for improvement in services, particularly for people who are older or have a disability.

Unfortunately I was only really made aware of this inquiry earlier this week because the chairperson was unable to attend. It did not give me very much time to contact all the other organisations. What I did was send out an email asking for some feedback, but I have only had very limited feedback, so I asked if I could bring Michelle along. I am actually the Royal District Nursing Service representative on the Peninsula Care Planning Group. I am employed by RDNS part-time as a social worker for the Mornington Peninsula area and also part-time in a role that is called a diversity coordinator. My focus is to ensure that everyone has equitable access to our services and health services more generally. Michelle is our palliative care team leader, and the situation down in this part of the world, Mornington Peninsula, is that we have a service that is called Peninsula Home Hospice, which provides most of the palliative care services on the Mornington Peninsula, and they use Royal District Nursing Service nurses to provide the home nursing for palliative care patients who are in the community. That gives a bit of context.

I would also like to mention that up until two years ago I was only a social worker at RDNS part-time, and I also worked for a local organisation called the New Hope Foundation, which is a migrant and refugee service. In that capacity I did a lot of work with older people from non-English-speaking backgrounds, particularly up to 20 different senior citizens clubs, some of which were multicultural, some ethnospecific, in this area. We did work depending on what people brought up. There were a number of different issues that they raised, and I just wanted to highlight that, because I think that that has given me a real insight into how a lot of the local community respond to issues surrounding death and end-of-life choices as well. My diversity role with RDNS is broader, so now I am linked in and work a lot with Aboriginal communities locally, the local LGBTI community advisory group with Peninsula Health and a whole range of different consumer groups that I engage with to try to ensure that they actually understand how the whole service system works in some ways to try to assist them in making decisions which are informed.

The CHAIR — Ms Clancy, do you want to add anything?

Ms CLANCY — No, my position really in this particular area is palliative care. I am working alongside a generalist role with Peninsula Home Hospice, as I have done for many years. It is interesting to read the information you have given and get some consistency. I think that is the main thing that I would like to see in the position, because there is a lot of inconsistency with information, education and general knowledge in the public with advance directive or advance care planning. This has been a bit of a bugbear for me for, I would say, the last 15 years, so to get here today and get a voice is very good.

I find that there are so many ideas out there but not put into one area. I think from a general public point of view, there is a lack of education and knowledge in this area. These words are thrown around like lollies, basically, and people think, 'Well, what do we do? How do we go about it?'. I would like to see something out there by one body, basically: how it is done, whether it is with a particular service. I am putting it out there a little bit, but since you said it is just evidence, that is okay, and you are not going to take it any further — —

The CHAIR — It is being recorded, obviously.

Ms CLANCY — Palliative care is not the only position to put this out into the public. Working with an agency for many years, it is generalised. We deal with maybe 90 per cent of elderly clients, and that is where it needs to be focused on as well as not just on a cancer diagnosis but chronic illnesses. So that is where I am coming from — from both sides of the fence — because I think palliative care, because they have got a terminal condition, it seems automatic that we set them on this process. But even like the gentleman said with dementia, dementia is a terminal condition. When, how and where is another question. We see that as a palliative measure, but it is not introduced as a palliative phase because the prognosis is unknown. I see that as setting it forth when that person can make that choice. That is where I come from.

Just listening to the previous speaker on dealing with pain, pain does not seem to be a problem with me in palliative care. It does not seem to be in aged care either, in what I do. My main thing is anxiety, the fear of dying and the distress that that dying brings. Pain — we have mastered pain. It is up to the professional who is involved how to handle that pain and to do it proficiently. But given the fear, the anxiety about dying and the distress that is amongst family, I would say sedation versus euthanasia. There is a lot of controversy between terminal sedation and what euthanasia means. There is a clouding amongst that. We do practice terminal sedation, and there have been various papers written on it. In some cases we are practising terminal sedation. Again if I go back 25 years or 30 years, people did die in pain because we were not as knowledgeable about the medication that was out there, whereas now we try not to have people dying in pain because of our knowledge of the drugs that are out there and the experience amongst people, GPs as well as professionals. It is the other things that go alongside it. That is my stance, really, on this.

Ms DRAPER — If I pick up on this, just to talk in terms of the context down on the Mornington Peninsula, I did get some feedback from the head social worker with Peninsula Health, who has responsibility over the advance care planning team and program that they have. In my opinion we are at a really early stage. I totally agree with Michelle that it is very ad hoc in terms of what information people receive and understand about advance care plans, enduring powers of attorney or whatever. Certainly in my social work role I regularly see people in the community and explain to them about powers of attorney, but that is only if they happen to mention something to a nurse who then thinks, ‘Maybe this person needs a referral to our social worker’.

The social worker at Peninsula Health said to me that there are issues not only amongst the community, where there is a lot of confusion about living wills, but there is also the terminology. When I actually try to explore with individuals what their understanding of, say, a living will is — it is not necessarily an advance care plan — they just have very different ideas, and there is confusion. That confusion also sometimes extends to medical and hospital staff and GPs. There is not a clear understanding necessarily, simply because someone works in a professional capacity. Peninsula Health has developed just recently an online resource so that people can fill out themselves an advance care plan. But part of what they are having to target — this was the feedback I received — is making sure that staff in the hospitals actually read the document and comply with the wishes. That is a gap at the moment in terms of education that needs to be developed, and also the staffing is only two nurses who make up the advance care planning team who go out in the community. Therefore, with that limited resource, one of the things they encourage people to do is actually talk to their local GP about these issues. But they have seen a real need for education for the GPs so that they actually feel comfortable discussing end-of-life choices and ACPs. There is that real range of different understandings of what it even means.

The previous speaker talked a lot about how it would be really good to have a more simplified document. I completely agree. Health literacy is something I am very passionate about. I think documents need to be something that people understand. I was actually involved when Peninsula Health and Medicare Local were looking into the advance care planning. I went along, and I spoke to them about how I have done internet searches and I have seen that there are lots of organisations across Australia who have information in other languages as a guideline, but no-one has looked at having advance care plans that can be completed and translated into other languages. I just see that as a really important thing for us to consider because it is such an emotive, difficult thing for people to do.

I think, however, it is no good just translating something from English into another language. Part of health literacy very much emphasises the need to consult with the consumers to get consumer participation in the development of translated documents. I think that is really going to be important — that for every language that is translated an actual process is gone through. Certainly at RDNS one of my roles is to develop translated information for different language groups. Just for example, one resource we have is what is called a talking book, because we are also considering the fact that not only do a lot of the population have very low levels of health literacy, but there are also low levels of general literacy amongst a lot of the community.

This year we have launched talking books in Vietnamese just on subjects to do with dementia and diabetes. That process involved me going out and working with the Australian Vietnamese Women's Association, the largest organisation that delivers aged care in Victoria to the Vietnamese community. So we had a collaboration with them and then also went along to community groups of Vietnamese people from different parts of Vietnam as well, because the language is different in different parts, and we worked with them to ensure that we actually also tested it with people who had absolutely no education in Vietnam, let alone in Australia. They were not literate in their own language in terms of reading. With the talking book, which is an online resource, they can listen to the information that is being provided. Then we tested the information with the community, and we tweaked it to make it more understandable to them for different cultural reasons, health beliefs and those sorts of things.

I think something as emotive as an advance care plan really needs that sort of level of work in terms of developing translated resources. But then we really also need to begin that conversation. You can only get the message out properly with a lot of the communities if you actually go to places where they feel safe. It might be seniors clubs or a whole range of other forums. You actually go along with an interpreter, begin a conversation and get them to give you the feedback and tell you what the barriers are, and then you work out together how we can try to overcome them.

That is one of my, I suppose, little passions. I think we really do need to think broadly about everyone out there, and something like a talking book resource does also help for people who are vision and/or hearing impaired. It overcomes a lot of the barriers that exist in terms of people getting information that they can actually understand and then making an informed decision to act upon.

I am just trying to think about what else Sally mentioned to me to provide feedback from, but I see that you have got someone from Peninsula Health coming in anyway. The main message that she had was that we are at an early stage. If an online resource like that is available, that is great if you happen to be computer literate or have someone who will walk through it with you, but you then need to have the linguistic ability as well to understand the information that is being provided.

The CHAIR — Thank you both very much for those really insightful comments about possible areas of reform and some of the challenges. Ms Draper, if I could just take you to the partnership between the RDNS and the Peninsula Home Hospice — and I know that Peninsula Home Hospice has a fantastic group of volunteers that do a lot of fundraising and a lot of remarkable work locally — we have heard evidence from around Victoria, and we heard evidence earlier today, about some of the challenges about providing care in the home, particularly palliative care and advanced care in the home. Do you want to just talk to some of the challenges perhaps both from a funding perspective but also with the geography of the peninsula in providing — —

Ms DRAPER — I might handball that to Michelle, if you do not mind.

The CHAIR — Sure.

Ms CLANCY — Challenges in the home, of looking after somebody: there is a lot of funding to assist with the financial burden on families, especially equipment and medications. For instance, some of the medications that we use can be expensive, and they are not on the PBS. I know there is what we are calling the unassigned bed fund that was created maybe 10 or 15 years ago, which did give funding for people to be at home and have equipment. I would say over the last maybe six or seven years that has increased because our workload is increasing, and we are always going over budget by providing hospital beds within the home. That seems to be more of a target for occupational health and safety issues for families and staff.

So the bed fund has really not increased, and that affects the family keeping them at home. Respite in the home is obviously great, by the volunteers, and that is good, but to actually get night respite and night services, I think they have compromised a little bit, because funding is not readily available. RDNS do the after-hours calls, but again there is limited funding, because they have got to cater for the generalist side of the nursing as well as the palliative care contracts.

The challenges really for relatives are having carers to actually keep them at home, the equipment, the financial burden, and again it is the continence. Even though the government has given the patients $500 per year to provide incontinence pads, it is not enough, because it is not just the pads — is the bedding, it is everything else. These are the burdens on families. Especially if somebody is on a pension, they have rent to pay and they have got medication and medical bills, they are compromised. Obviously RDNS do waive some of the funds, because it is only a limited fund, and help them not pay for visits, so that helps in financial crisis. But the challenge generally is equipment and funding for these people. When you think that they would be in a hospital bed, it would cost them something like $400 a day, and these people are having to fund it themselves. That is the difference.

What do they do when they cannot cope? They go into the palliative care unit. The beauty of having the contractual arrangement with Peninsula Home Hospice and RDNS is the fact that, for people with Alzheimer's or circulatory problems — I had one the other day — or chronic respiratory conditions, the transition from that general type of nursing need to a palliative need is quite smooth because of our relationship and the experienced staff that we have there. That is a bonus with the type of model we have, which I understand is very fragmented up near the city areas. The relationship with Peninsula Health and the palliative care unit and working with the physicians has been quite a fruitful relationship and makes it a seamless system to admit them — home, hospital, home, hospital.

The CHAIR — Thank you for that answer. I just wanted to ask one other question. Michelle, I was interested in your comment that we have mastered pain. I think we have heard varying evidence about that around Victoria from different witnesses, but I am particularly interested in your comment that anxiety and fear of dying are the principle issues. How can we address that? How can we reduce that anxiety?

Ms CLANCY — First of all, by involving palliative care services. Where palliative care services work is, again, that all models are so different within Victoria. You have got some that — and again this here is a specialist palliative care nurse — might not do hands-on, but they will do a consultancy and they may use a general side of, say, RDNS to do that part. I think how we can make that different is to always involve a palliative care service in whatever phase. It is always money, money, money and staff, staff, staff, but I think it is training and education. It is the same with these advance care directives. Have education to the GP level, staff level, public awareness level. I find the biggest thing is they have not received the education — even from the doctors, from their training in the early days. If you want to go ahead with this and follow it through, start with the education at the unis.

I understand from the previous one about the dementia client that it was his wife he was talking about, and the issue of doctors and the fear of prescribing. I had one the other day, a young doctor who — this was not cancer but a circulatory, gangrenous leg basically — was fearful of: 'Are we anaesthetising this patient?', 'Are they ready for dying?', 'What's she dying of?'. And I am thinking, 'Oh, my God, this is still happening today in a young medical doctor'. I had to be very assertive to put my opposition across as a palliative care nurse consultant to say, 'Palliative care is about symptom management', no matter what it is — end of life or during that phase of illness. I would not, and their theory is not to, harm the patient. It is to give them comfort, so I have to have a level of medication to do that within the boundaries of palliative care.

There, education is to the fore of everywhere, and I think that is the biggest thing in this if you start it, whether you have one site from your position, from a government position, and it includes education and being out there in the community, and having designated staff in the community and in the hospital who go out there and talk to these people about advance care planning directives, because everybody has got a certain level — and again a cultural level — of what expectations are. It is almost that you come into that hospital and, if you have got a chronic illness of some kind, 'Here is the package, let us talk about it' — basically from wherever you are. But you have to have specialist staff to do it, because it is a very tentative subject. It comes with a lot of, again, fear — 'What you are going to do', 'I don't want this' — and acceptance. It has to be done gently with an experienced person to do that. Not just anybody can do it; I think it is people who are trained in the area.

Ms PATTEN — Thanks very much. It is great to hear about the different types of work and so on and the models that you are getting so you can have that smooth flow for people moving from in-home care into palliative care. I was just struck by a point you made very early on about terminal sedation versus euthanasia.

Ms CLANCY — Oh, oh!

Ms PATTEN — Yes. I was wondering, because in some countries they do not see any difference, so in the Netherlands terminal sedation is a form of euthanasia. They record it as such, and it is counted as such. What would be, in your opinion, the difference between a terminal sedation and euthanasia? You were quite clear that you saw them as quite different.

Ms CLANCY — Yes, I do think it is separate. I have actually had three cases in the last two weeks — the same thing. What it is is when a person — how can I say it? — is deteriorating quickly, the symptoms are there, you have got evidence of mild pain episodes, but the fear and the anxiety of that dying phase and when it is going to happen, how it is going to happen, is tremendous. But it is also the acknowledgement of the dying, and they do not want to know about that too. To me euthanasia is: you give an injection, and they die within an hour or two.

With terminal sedation that does not happen. We use the common drug, which is midazolam. Midazolam is an anaesthetic drug, and it is given in low doses to obviously take away a little bit of that fear and anxiety within a level that is not causing them to die. And you ask the patients, and the doctors ask the patients, ‘Are you ready? Would you like to be not aware of this dying phase?’. I have asked them that, and they have said yes. But the doctor knows when he is ready, and the doctors do, and the nurses do to a certain extent, but it is the overall decision of the doctors. So you would go on that phase and give the midazolam.

I have had different people where it has gone differently. I have had people who have died within a day and a half. I have had another gentleman who took a week, and I have had some taking two weeks. So it is not causing them to die. Okay, they are not eating, they are not drinking and they are in a comatose state, but it is letting the body die of natural causes within the town without the patient suffering mentally or physically of that dying phase. That is how I would describe it.

Ms SPRINGLE — My question is for you, Ms Draper. Could you unpack a little bit around what you were talking about with CALD communities and people from different cultures and perhaps their barriers towards advance care planning and end-of-life choices and the differences in their belief systems around this issue — whether they are actually prepared to buy into this sort of model of planning for death?

Ms DRAPER — Obviously there is huge diversity among different individuals, let alone ethnic groups, but I will just give one example. I mentioned that I am on a Peninsula Health community advisory group looking at CALD issues. There is another person who is on that committee and she regularly talks very angrily about the fact that when her mother was in hospital the doctors were going to tell her mother that she was terminal. She was arguing that there is a Carer Recognition Act and they need to check it with carers first, because it was her belief that if her mother was given that information she would just decide it was time to die and she would not fight to continue to live. So there was this big taboo. She was very angry that the doctors were going to tell the mother. I just use that example because it is just one of those really ethical dilemmas. I can hear what this person is saying, and she is a consumer on the group. She is saying, ‘Doctors should not tell my mum’, but I am thinking, ‘But if mum has capacity and is alert, surely she has the right to have that information’. So it is really about sitting down and having the time to talk through that with different groups. That is just one example of an issue.

Certainly I find that a lot of different communities say to me, ‘Oh, we don’t talk about death’, and yet if you do it in a way that is not confronting, they actually do want to. They want to talk a lot about it, and they actually want to talk about how they want to go. But it is actually about being able to overcome that sort of mentality, I suppose, that it is a completely taboo subject. And there are a lot of — and I have come across different — ethnic communities that do not want their person who is dying to be aware of that. I have not got the answers, but I am just sort of saying what we need to do, especially if we are going to develop translated advance care plans. That would be all part of that conversation that we would be having with consumers in developing the document.

The barriers to developing translated, basic advance care plans that I have been told about include that you cannot do that because it is for the health professional to know, and they will not be able to understand the document; and I say, ‘No, not if you use good practice translation standards’ like the ones we use at RDNS. They are bilingual documents; there is English on one side and the language on the other side. I have also been told that it is pointless, since they will be using an interpreter and that is a far better way of eliciting information. I know the realities of interpreter usage down on the peninsula. We have had a couple of cases recently with a palliative patient. We have not been able to get an interpreter to travel down this far, or something has gone wrong, or whatever has happened. So there are assumptions made which you actually need to, as you say, unpack. That is why I think it is so important.

But in terms of giving you specific examples of the sorts of barriers, they are diverse, so it is really about working out where they feel safe enough to have that discussion, working out how to have that discussion safely, eliciting information, providing information and explaining how things work in Australia — that you do have choices that you might not have back in your country of origin — and saying, ‘How would you like to be able to participate in your own healthcare decision-making?’.

Ms CLANCY — It does not always have to be a cultural thing, as well. It is also about a family being protective. They feel she will give up if she knows what is happening, and things like that. We do get them occasionally, but eventually the clients usually tell us, ‘I’m dying’, and then we are at a dilemma. Do we say something, or do we do it in a roundabout way? There is always that. In saying we have mastered pain in palliative care, we have not mastered it totally, because there is always the individual who will have extreme complications from their condition, and there is a small percentage where, no, we do not master it, because we cannot. But I would say we try to at least 99 per cent of the time.

Mr MULINO — I just want to go back to that issue of pain management. I think a lot of people, healthcare professionals, have talked about the fact that there have been significant advances over the last few decades in that area. We have also heard of some instances, though, where it does not appear that all of the options have been on the table, whether that is because the patient’s or the family’s wishes were not acceded to or maybe doctors or nurses did not feel confident using the full array of options. Do you think that there would be benefits in the legal framework clarifying the current situation and providing more protection for health professionals so that where they are using pain relief options they are protected?

Ms CLANCY — Everybody works within a legal framework, and I think it is about knowledge more than legal, because we all have standards of practice. So for a doctor to say, ‘I am frightened of this’ — of giving a patient medication — because it may cause their demise, the theory is you are giving the medication for comfort and in palliative care you are not giving large doses to cause their demise. You are giving it purely for symptom management. The way our girls work and the doctors work is that it is the minimum and it is a skilled approach of what they had orally to what we give them subcutaneously through injections. That is our guidelines. We have guidelines for working on them. I do not know; I think it is all about knowledge and education. No matter how well set and people do it enough, there is always going to be somebody who is going to miss out because of their lack of knowledge. I think legally we all work within the guidelines anyway.

Mr MULINO — Just in terms of the training and the education that you are talking about, do you think it should be a combination of formal training at the degree level for nurses and doctors but also ongoing training in the health system?

Ms CLANCY — I think ongoing training. You have got people who are working presently. Doctors can have competencies they have to meet. This would be one of them too, the same as nurses; they should go through that, and I am sure they are doing that now in the training. But I think it is for the people who are working presently in these areas — how to deal with this, how to speak, how to discuss, how to approach and administer these documents and things. I think it is more out here now because I think people should be getting the training already in part of the courses.

The CHAIR — Thank you both for your evidence today and your practical experiences, which were most informative for the committee.

Ms CLANCY — Thank you very much for the opportunity.

The CHAIR — As I said at the start, a copy of the Hansard transcript will be sent to you in the next week or so.

Ms DRAPER — Can I just make one last comment? I have also had feedback from a number of people about real confusion about whether there is an actual difference between an advance care plan and an advance care directive. I have a colleague who is from Queensland and she says that, in her mind, the directive has a much greater legal status — it is something that has to be followed by hospital or medical staff — whereas a plan is more an indication of your wishes. If it continues that what we have are plans, I do not know that systems will respond to them as efficiently as we would ideally like.

Ms PATTEN — Do you think with directives you need more certainty in the present environment?

Ms DRAPER — That there is an obligation placed upon the professionals to carry out those wishes.

Ms CLANCY — For instance, if you are talking about the ‘not for resuscitation’, this is a little bit of a ‘shall we, shan’t we’ type of thing. Documents are out there that people get completed, but when they go to a hospital they might not abide by that. They do not carry it through. Again that is maybe something that if a person has it then that should be carried through. Ambulance people are asking for these documents now. We have had a few and they have said, ‘Have they got one?’. And this is where relatives have a dilemma because they know they do not want their relative resuscitated, but there is that dilemma between the ambulance staff asking, ‘Should we do it?’, but they are saying no but there is no evidence. We all are aware of it. A directive would be to follow that stance.

The CHAIR — Thank you both very much.

Witnesses withdrew.