

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Bendigo — 12 August 2015

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Dr Ewa Piejko, Medical Adviser, General Practitioner, Murray Primary Health Network.

The CHAIR — I would like to welcome Dr Ewa Piejko, medical adviser and general practitioner from Murray Primary Health Network. Thank you very much for joining us this afternoon. Before we start I caution you 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 and you will be provided with proof versions of the transcript in the next week or so. Transcripts will ultimately be made public and posted on the committee's website. We have about half an hour for our session this afternoon, so I advise you to make some opening comments, and thereafter the committee will have questions.

Dr PIEJKO — My name is Dr Ewa Piejko, I am a medical adviser for the new Murray Primary Health Network. Previous to that I was a medical adviser for the Loddon Mallee Murray Medicare Local, so around this region. That is a relatively new role, I have been there for about two years. I have been a general practitioner for about 28 years — I do not like to say that out loud! I am also a medical educator and acting director of education for Beyond Medical Education. I have been involved with training GP registrars for about 20 years and I recently took up an appointment at Monash as an adjunct professor for medical students. I am one of those GPs who probably does not get to the nursing home enough — although Melissa said it was not me she was talking about.

I guess I am coming at this from a whole lot of different perspectives because I wear a lot of different hats. There are lots of different ways of looking at some of the issues around end-of-life care. I think I would like to start off by looking at some of the organisational issues that come up. First of all are some of the legal issues that are around end-of-life care. There is a lot of confusion and there are lots of different titles, lots of different authorities and lots of different forms. From my perspective as a GP, it is very confusing as to what holds standing and what does not. As both Marlene and Melissa mentioned, you can make these plans and you can do it, then you get in there and a bunch of family members can suddenly override everything that the patient has wished for. It is a bit of a difficulty from our point of view, because it is so confusing as to what our role is. For example, I did a care plan today with somebody, and he said, 'But I want you to be my medical power of attorney', and I said, 'Well, I can't be'. I do not actually know if that is true — I assume I cannot be, but I do not actually know that. I thought that it was something for him to discuss with his family, but that is the reality, I do not actually know that I cannot be. 'I am happy for you to come and talk to me', but you know. It is all that terminology and all that confusion.

I think one of the recommendations is to try to simplify the process and try to standardise it in some way so it becomes clearer what the hierarchy of legality is, where it comes in and whose role it is for different things to happen. I think that would be one way of addressing those issues. We also have a very mobile workforce of health practitioners, whether they be doctors, nurses, or paramedics. Standardising that across the different states is also very important because it is different wherever you go. I think some standardisation, some guidelines and a bit of clarity — the legal profession likes to make things a bit messy, we doctors are quite simple, really.

The other thing that becomes quite difficult is the lack of access to that documentation and where it sits. That has been raised already. I will not go on about it because I am sure you have had other witnesses come forward and discuss that. You have a document that might sit in our medical records. We deal with a lot of different health services, and we deal with a lot of different healthcare providers. I had a patient who had been sitting in a nursing home for four weeks, and I did not even know she was there. I do not know where her documentation is. Things like that can happen.

Around that, there need to be better processes about where that document sits so that it can be accessible. If a patient has collapsed at home, and the ambulance officer — the paramedic — comes along, they are not going to sit there and read a piece of paper. They are going to sit there and try to instil some action. The same goes for emergency departments. We are looking at different groups. We have the end-of-life stuff where the elderly patient is chronically ill, but it can also happen to any one of us tomorrow. How is that information found out? How do we make that documentation and those wishes readily available? Hopefully the discussion is with the family and the family is aware and involved, but they might not be available. They might not be contactable. I do not know the answer. I would love to have an answer to that. I suppose getting electronic health records up and running properly and being able to use them — there is a lot of potential there. Being able to use them better might be one way of managing it.

The other thing is about the organisational side of it and the practicalities for us as GPs seeing patients. These sorts of conversations come up. We do have the odd person who comes in and says, 'I want to do my advance care plan. I want to talk about it'. But they are difficult conversations. They are very complex. It needs to happen over the course of many consultations, and it needs to happen with somebody you can trust and have that discussion with. That is difficult because people are usually coming in for something else. They are coming in for some other problem. There have been suggestions that the advance life care planning should come in under chronic disease management, but then that person is turning up, and we are trying to look after their diabetes and their heart disease. They cannot breathe, they cannot walk, their legs are sore and ulcers are not healing. Those medical issues are often much more pressing and need to be dealt with, so the harder conversations, for the patient and for the health professional, tend to be left behind.

I think there needs to be a system or structure for incentives to try to encourage medical practitioners to bring that up. I agree with what has been said before: the consultation and the conversation around this should not be happening when someone is acutely unwell. It should not be happening when they are coming into a nursing home. It should not be happening in the emergency department or in the hospital when someone is unwell, because there are a whole lot of other factors that come into play. Perhaps there should be either a specific item number or an incentive, like a service incentive payment, to try to encourage that activity to be taken up, just as we do with diabetes cycles of care and we do with mental health plans and asthma plans. There should be something like that where there is incentive to try to increase that uptake within the practice and to raise that conversation.

The other difficulty around that is that some people do not want to talk about it. They do not want to know about it. They do not want to plan. They want to leave it to whatever is going on. That makes it a bit difficult as well in that organisational — so it will take quite a bit of time for that to happen. I think: explore funding opportunities and some sort of incentive payment to try to increase that uptake.

Still on the practical side of things is assessing competency, because that is one of the things we have to sign at the bottom: 'Yes, this person is competent'. I have even had to speak to my own medical defence organisation about this — it was a different situation; it was a legal financial thing, not an end-of-life plan — and there are no clear guidelines. There are no clear criteria. You can do a dementia screen, but I can have patients who are a little bit demented and who I still think are competent to be able to make this decision and know what they want. That is another grey area and concern, particularly if you are going to then have family who are going to challenge you on some of this documentation and things that are happening.

Ideally you want the family in the room. Really, that is what you would like. You would like the patient to come along with their family, but that is not the reality of what often happens. Families are busy, they have got things going on and they do not want to take time off work. I run an hour late. That is not what they want to be sitting around doing, or people do not want to ask their family along. I think those conversations have to happen with family at home. I think another difficult area for practitioners is assessing competency and needing some guidance or some guidelines as to what would be deemed acceptable by the medical profession and the legal profession as to what we can measure as competency. It is a judgement issue, I think.

Communication is — and I guess you have heard this before too — the crux of a lot of things. There is a lack of communication between family members and between doctors and family members. That is certainly something that was brought up today earlier regarding case conferencing. There is also a lack of communication between health professionals and different institutions. Someone might have clearly articulated their plans and what they want, but that is not readily available, or we have misunderstandings around it. The natural tendency would be, as I said, to treat at all costs and for people to want to go ahead and treat at all costs. If you do not know what to do, you can treat at all costs, but once you get onto that treatment treadmill, it is very difficult to stop. But I want to bring that up a bit further in my medical side of things. I am still trying to do organisational.

I was speaking to a group of doctors and GP registrars last night. I was doing a tutorial. I said to them, 'What are some of your issues? You guys are still out there. You have just come out of the hospital system. What are some of your issues?'. They are saying that often it is that lack of communication. Patients might have a clearly articulated plan, but particularly from the hospital specialist point of view, they will go ahead with their treatment anyway and continue, and that information is not being communicated to them, particularly coming in as junior GPs. The group I was speaking to last night are in remote, small rural hospitals. We were doing a webinar-type thing. They are saying that their views and their understanding are often overlooked because they

are seen as junior and as not really knowing what the patient wants, and that treatment continues. Sometimes there is some poor decision-making there.

I do not know what the answer — how to improve communication for everyone — but I think there certainly needs to be more of a systemic change to the way we do things to try to improve that communication. I have never ever had a hospital ring me to say, ‘There’s this patient in hospital who’s sick. Do you know what their end-of-life care plan is? Do you know anything about them? Do you know what treatment they would want?’. I assume they are possibly talking to family, but as you have heard, what do you do when you have four family members who are disagreeing? It is often the family member who has the least to do with the person who wants the treatment to continue. I think that would probably often be the case. I have never been contacted by a health service. As I said, maybe they are talking to family, but again that comes into that hierarchy of whose opinion you get and whose information you get.

The other thing, I guess — and this sort of sits between treatment and organisational — is true informed consent. We make decisions and have knowledge — and that is after we have been through six years of medical school, lots of examinations, lots of experience and ongoing professional education — and sometimes I do not really understand stuff. Sometimes I do not understand the implications of different treatments. I think it is very difficult for patients to really understand that too. What does it mean? You might sit there and think, ‘Yeah, I can live with that’, but when it comes to it, maybe not. I think it is incredibly difficult for patients and for families to really know what informed consent means and what the implications are. That is why the dialogue has to start and has to start early, and it has to continue. It is something that needs to be built in in some way to society as an ongoing educational issue.

On talking to a few of my colleagues to find out about some of their issues, the feeling is that sometimes, particularly amongst the medical specialties, they do not give true informed consent about the consequences of treatment. They might say, ‘Hey, the treatment can do this, and this could be a side effect’, but they are not really informing patients very well. One example I have is that I had a patient, not here in Bendigo but previously, who had one kidney. She was a lady in her late 80s. She had one kidney, and her daughter-in-law worked for a kidney specialist. He had a look at it, and he thought she had a tumour on her kidney. She came in and told me, ‘I’ve got a tumour on my kidney’. I said, ‘Oh, if you say so. We will have a look and see’. Sure enough, there was a tumour sitting on her kidney. We did not know what the tumour was. We did not know whether it was benign or whether it was an aggressive cancer. The specialist said to her, ‘We need to take that kidney out. That’s the only way to find out. We need to take it out’. They were all ready, and then it took the registrar from the hospital to ring her and say, ‘You do know this now means you’ll be on dialysis, because you only have one kidney. We’re going to take it out, and you will be on dialysis’. She said, ‘Oh, no, I don’t want that. I’m in my 80s. Someone is going to have to take me. I don’t want that treatment. I don’t want to rely on people. I don’t want it’. Then there was a lot of argument amongst the family, because they trusted the specialist and the specialist wanted to get the cancer out. Anyway, I looked after her for about another three or four years, and she died of something else. The kidney never got cancerous — it never grew. But that is one example. The consequence of having that kidney out, whilst it was the best management for the tumour, it may not have been the best management for her and what that meant for her. So there are those difficulties.

Another example we have got currently that one of the GPs spoke to me about is there is a patient in a nursing home of hers who is in his 90s having dialysis, so trotting along now. He might be happy doing that, and if that is the case, so be it. But it is a huge burden to be going three or four times a week to have your dialysis — at which point, as much as we get consent and education, a system of continually revisiting that documentation, your decisions, and being able to opt out at any point in time. One of the forms I have had is really long, and it says, ‘Do you want antibiotics if you’re sick?’. Well, come on; that is very difficult. I think you need more generic conversations than, ‘Do you need antibiotics?’. If you have got a skin infection, or you cut your finger, you want to have antibiotics for that and clear that up. If you have got pneumonia, and you are going to die, but you are quite happy to die — that sounds really bad. But it is a whole different treatment. I think we need to be much more focused on what people actually want rather than what they do not want and looking at that quality of life and what that means for them.

A lot of it is around communication and around education. Education has to happen across the whole community, so it has to happen with patients and with families. It has to happen with the medical profession and allied health professions and all health professionals. Also with legal and financial services, this is an opportune time — if someone is well and healthy, I do not get to see them for a long time. So if some bloke walks in

because his wife has made him come in because he has got a cold or something, or he is bothering her, and I want to say, 'Hey, let's talk about your end-of-life care plan', he is not going to come back.

Ms PATTEN — 'You've got man flu!'

Dr PIEJKO — Yes, that is right, 'You've got man flu; let's sort your care plan out. You're going to die'. That is why it has to be a much bigger picture in education, education about being open about it. I think it is changing. The fact this hearing is happening is a great example of how that has changed within the community. Bendigo Hospital, as many health services do, have appointed someone to work on this, and going out to GPs to try to encourage them to talk to people. But also at the time of writing, I do not expect the lawyer to sit down there and write it. It is cheaper to come to see me to get the end-of-life care plan written than the lawyer. I hope you are not lawyers; you probably are.

We need to raise that issue: 'This is something you need to go and do and a discussion you need to have', and to start thinking about it. Also, have health professionals thought about what conversations you use, what words to use, how do we relate that X number of years of experience and medical training we have got into language that is meaningful and relevant to the person sitting in front of you?

Because the gentleman I did today just said, 'I want you to decide and when the time comes give me a black pill'. I do not know what colour the pill is, but he wants me to give him a black pill, just, 'I want you to knock me off'. I thought, 'Well, I'm not going to do that'. But it is very difficult for some people to have that conversation, to be serious about it and to take it seriously. The more it becomes ingrained and the more financial advisers — as I said, you go and talk about where your money is going to go — are able to advise that.

Challenges as a primary health network was one of the other questions I was asked to look at. We are a big, enormous area. We are huge. We go from Wodonga to Mildura right down the Hume and across, right down to Woodend, so it is a big area with over 20 health services, over 200 GP practices, and I think we have got 500 000 people in that area, so it is a huge catchment. To be able to provide linkages between different community services, primary care providers and health services is a big challenge I think for the primary health network, because every area is going to have its individual needs. That is why I think coming back to some sort of standardised process that can be tweaked locally would be really useful across that, so at least we are all talking the same language or are on the same card.

One of the other challenges I guess we are having is the increasing corporatisation of different health services, so health services such as GP practices, health services such as the aged-care residences. What is happening with that is that you can talk to the individuals in that practice in your region and you can talk to the individual nursing home but they are sometimes not empowered to be able to make changes and change what is going on, because a lot of it is directed from a central organisation that might be outside our area, where we do not have a lot of influence. I think that is becoming a really big issue — the inability of the people working on the ground to be able to influence change and to make things happen.

In terms of that, you are also getting the transient staff. You are getting the transient staff on the medical groups, where they come along, they do their bit and they go. Less after hours, less continuity of care with transient staff in the aged-care facilities. We have already heard today how it is hard to keep them. As someone going in there, I see someone different quite often. I do not know who I am talking to, they may not know the resident, they do not know me, they do not know how best to contact me, things like that. That is a really big challenge that is happening across the board. I think we need to be able to add incentives to try to help encourage people to take that on.

Just talking about addressing that issue of aged care, statistics show that there are quite a lot of GPs in our area who do aged care and who look after people in the facilities, because if you have looked after someone for a long time and they go into a facility, they want you to look after them. The reality is that a lot of the GPs are not in that position of the doctor who has got 80 per cent of the residents in one place. We have all got lots of residents all over the place. That organisationally becomes very difficult. They just do it because they want to look after their patients and they do not want to let go, and the patient does not want to let go, and you are trying to do the right thing, but that is incredibly difficult to manage logistically. I have got lots of other things, but I guess you have got lots of questions.

The CHAIR — We had better keep it to a few questions too, unfortunately. I am interested in particular in your point about assessing competency. Is that something that you are taught through medical school? Is there any training in that or is it something that you basically learn on the job?

Dr PIEJKO — Not when I was in medical school. I do not know whether now they do. We do discuss it, so where it has come up for me is both in my work day but also in discussing it. For example, I do a lot of tutorials for GP registrars in training, so it comes up there and we have discussions around it, but there is no clear answer. That is what I have discovered, and that has been in the last six months. We have looked into different guidelines, we have talked to our medical defence organisations, we have looked at different state health structures and there are no clear guidelines or a checklist for what is competency. What does that mean?

Ms PATTEN — Thank you. It is fascinating, and unfortunately we do not have time for millions of questions, but about the black pill comment. I can appreciate that they are trying to say, ‘Well, just give me the pill’. Do you think that that conversation about physician-assisted dying or that sort of thing could be something that doctors would be willing to have that conversation about as part of an advance care plan?

Dr PIEJKO — I think it is a very difficult conversation, and I think that overall we are probably far more wanting to have conversations about what we can do to allow you to die naturally but in a comfortable way. I think on the whole, from the doctors that I have spoken to, there are mixed views. It is a very controversial area, it is a very difficult area. But I think more often we want to have that conversation out there that you do not have to die in pain and suffering. It does not mean it is assisted, it means it is about allowing things to take their course, but to provide as much care, support, palliation and comfort as possible. I think that is much more the stronger conversation that doctors would feel much more comfortable with. But it is variable.

Ms SPRINGLE — Sure. We have heard a lot of commentary around the lack of education and the need for education on all sorts of levels within the health sector but also within the community. I would like to link that with the idea of treating for treating’s sake. You talked about that and said how that is a default position for most health practitioners and emergency services. I think we have ascertained that. How would you address that? Would that be in education issue?

Dr PIEJKO — Absolutely.

Ms SPRINGLE — How do you think we could change that from a default position to become a bit more nuanced?

Dr PIEJKO — I think where the difficulty lies is the time factor and the criticalness of the time factor. But it is important to be a bit more aware of people before they come into the situation where it becomes acute so we know what they may want to have and where they are at. Family conversations are really important, particularly around people with chronic illnesses and cardiac disease. Heart failure is one of the big ones. I think people underestimate the morbidity of heart failure and when we need to stop and just let people’s hearts do what they do — keeping people alive when they cannot leave their chairs or things like that. I think we have to have the conversation before it becomes acute and make people more comfortable with those conversations. So we need education around how to have those conversations. I think that is where the education needs to come in, and put some boundaries in place.

Ms SPRINGLE — Is it just about education? We have heard from some people who think it should be mandated, that it should be something that has some sort of compulsory framework around it.

Dr PIEJKO — I am very wary of making something compulsory when you cannot enforce it. I do not know. If you are talking about a lot of us physicians, there is so much stuff that we have to do. It is not that we do not want to do it; it is not that we do not want to do the screening, the prevention and the conversations; it is around time constraints and abilities. I think it would be something difficult to mandate. I do not know how you would mandate it.

Ms SPRINGLE — So would it be more about looking for trigger points where you could perhaps weave it into your practice?

Dr PIEJKO — Yes. But I do think that overall medicine is changing, and in looking back over the 28 years there are a lot of things that we are not treating as much as we used in some ways. In the high-tech areas of

cardiological interventions and some of the cancer treatments we have probably upped the ante a little bit, but in some things we are being a little bit more cautious.

Mr MELHEM — Regarding the advance care plan, which we all agree is an important thing to have, would you include voluntary euthanasia as part of that plan; and in what circumstances and what safeguards would you put around that if the answer to that is yes?

Dr PIEJKO — I think that would be very difficult. It would be very difficult. I guess currently it is not an issue because it is not legal. I have never thought of going there and I have never wanted to go there. Professionally I cannot speak on behalf of the profession because I do not know necessarily. Personally I do not know that it is something that I would want to be involved with. Again, if everything else is grey and we do not know and we cannot give informed consent, then I think it is an even harder area. For a lot of practitioners there will be a lot of other overriding personal views and religious views and things that might impact on that.

The CHAIR — Dr Piejko, we had better leave it there.

Dr PIEJKO — I talk too much, sorry.

The CHAIR — No, not at all.

Ms PATTEN — That was fantastic, thank you.

Ms SPRINGLE — Wonderful.

The CHAIR — Thank you very much for your evidence and for your contribution. It was much appreciated.

Dr PIEJKO — And thank you for inviting me along.

Witness withdrew.