

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Shepparton — 13 August 2015

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Dr Margi Gould, General Practitioner, Yarrawonga Medical Clinic, Central Hume Primary Care Partnership.

The CHAIR — I declare open again this public hearing of the Standing Committee on Legal and Social Issues in relation to its inquiry into end-of-life choices. I would like to welcome Dr Margi Gould, general practitioner at Yarrowonga Medical Clinic. Thank you very much for joining us today. Before we start, I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded, and you will be provided with a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for our session today, so I would again like to thank you for joining us and invite you to make some opening comments, and thereafter the committee will have questions.

Dr GOULD — I just want to introduce myself and the working party I represent. I stress that some of the comments I make are on behalf of the committee, the working party, and some of them are my personal comments. That needs to be separated slightly. I also need to make a correction: the program indicates that I am a senior lecturer at the University of Melbourne. I no longer hold that position. I am now just a casual contractor at the University of Melbourne.

Basically I have been involved in educating and informing others about advance care planning and end-of-life care both at the medical student level, through to interns, registrars, overseas trained doctors, GPs and the general public. I also come to it from the situation of being a person, because I am also a daughter, a granddaughter, carer and friend, and that has influenced me and many members of our working party.

A few years ago we had the Hume region advance care planning working party, which was auspiced under the old Hume Medicare Local. It is a group of health professionals from across the border region, and we are very keen to make the committee aware of lots of issues that people on the border and in rural areas have with regard to end-of-life care and hopefully having quality end-of-life care close to home.

The group has been made up of members of various hospitals and healthcare networks, plus aged care, the ambulance service from both sides of the border, volunteers, GPs and nursing. So it is a wide group, and we remain open to other people joining us. Recently we have had people from the financial planning community and some lawyers join our group. It is quite an active group, and that is how we made our submission. I have provided you with a handout, one double-sided page, that talks about the group.

Ms PATTEN — ACDC?

Dr GOULD — One of the things we have come up with, which we have promoted amongst the community, is something called ACDC. It is a really easy way to remember how to do advance care planning, because you need to appoint someone to be a solitary decision-maker to communicate with others. That includes your family and those involved in your life. We use the word 'family' in the broader sense, because everyone's family is different nowadays. We need to document that hopefully, and we need to circulate it to make sure that those people who need to know about it do know about it at the appropriate time, because we firmly believe that having an advance care plan can help in the delivery of services no matter where you attend — what health service, what aged-care emergency service or GP, no matter what time of day and no matter what day of the week. So we see that as an important process.

I want to make sure I leave enough time for you to ask me questions, but I also want to emphasise some of the stories we have from advance care planning. Coming into this building I remembered a story that one of my interns told me from Goulburn Valley about a patient who had not had any formalised advance care plans, but when they had a heart attack in the middle the night the intern was able to phone the consultant and the consultant said, 'No, this lady is towards the end of her life. She has got chronic disease. She has expressed to me before and we have had the discussions that if something nasty happens we just keep her comfortable'. They managed to keep her comfortable and she died with her family around her. That is an excellent story of advance care planning where there was no paperwork. It is also a cautionary tale because, if that consultant had not been able to be contacted, that lady could have had her care escalated unnecessarily. Still she would have passed away, but it may not have been with the dignity and respect that she could have had.

Another story that I have concerns one of my close friends. I had the privilege of being with her when she passed away last year; and trust me, it is very different being with someone when you are their friend and not

their doctor. I had been her doctor in the past, but over the years we had become friends and so we had ceased being doctor-patient. It was a very hard at times seeing her go on that journey and some of the challenges she faced. She entered aged care when she did not really want to be in aged care; she desperately wanted to be in her own home. Being in aged care it is then declared that you are not a member of the community anymore, so you are not eligible for HACC services, so she could not have transport to transport her to see her oncologist and specialist in Albury. Her family had to do that and her family had to travel vast distances to be able to do that. One of the important things we like to express is that it is not just the health services; it is also the ambulance and the infrastructure and transport that are important in providing quality end-of-life care and leaving people their options open, so they can have as much as I want.

One of the good things about our working group is that we have responded to things that we have come across. Because of our structure we can be an ideas think tank, and recently we had a community talk at the Albury commercial club and one of the things that came up, which was brought up actually by the Centrelink presenter, was the issue of elder abuse and how common it is. And then amongst the aged-care staff and us who were sitting at the back of the room, we could all tell stories of people who had suffered elder abuse. That has really now become one of our focuses. When giving advice about making advance care planning, we have to have some protections for elder abuse, be that emotional, financial or any of the different forms it can be.

One of the other things about my friend who passed away was that her family got her to do all the paperwork again just to be sure it was correct. That involved seeing a solicitor and a huge amount of costs, and she was a lady on a fixed income. I cannot remember if it was \$300 or \$900, but it was something that was a very vast amount of money for her, and that could have been saved if we had talked to her earlier about doing her paperwork at no or minimal cost. So one of the things we are very keen to promote is that there needs to be a layer of assistance with performing advance care plans. People can do a simple plan on their own — it is a bit like do-your-own will kits and you can get your doctor to sign off on it — but when it gets more complicated, often people need assistance, especially if they have a lower level of health literacy or a lower level of literacy in general and they need help. Whether that is from a volunteer or a professional, there really should be a scale of people that can help, so that is one of our things.

Of course I would like to plug that we would love more palliative care resources in north-east Victoria. There are very dedicated nursing staff and experienced nursing staff who provide excellent palliative care services. We do liaise with St Vincent's Hospital in Melbourne, but it would be fantastic to have more services in north-east Victoria. I think I might leave it there and open it to questions, because I am sure you must have questions.

The CHAIR — Thank you very much, Dr Gould, for that presentation. Can I just ask you to talk further about elder abuse, because it is something which we have not heard much about as a committee thus far. It is obviously a significant potential issue in the community.

Dr GOULD — It is a significant issue. Lots of people are very vulnerable to being abused and there are different forms of elder abuse. It can range from neglect. I have seen patients where their family have not given them things to drink in the evening because they did not want to assist their relative with a stroke to get to the toilet. People are not changing incontinence pads because it was too expensive, and therefore people get urinary tract infections.

There is financial abuse, where people will sell people's belongings. People have been known to come home from hospital and their jewellery has all disappeared or their flat has been cleaned out and their furniture all sold. Some of the stories are just horrendous, but it is a scale of things, and it even be subtle pressure such as 'I think you should give your grandchildren \$10 000 each' or people wanting their inheritance sooner. The money involved can range from a small amount of money to a large amount. It is often very significant for the person involved. It is a continuum from the family violence situation. Family violence affects older people as well. Often they are still in relationships, but they may have been with someone who has been abusive all their life. That abusive person or demanding person can end up in an aged-care facility or in a hospital, and then the staff have to deal with that output.

Dysfunctional families can still be dysfunctional even amongst older people, and some children may be putting pressure on them. They will say, 'If you do not behave, Mum, I will put you in a home', and that is a very real, frightening thing for most people. There are probably a lot of people who are in these situations that we do not recognise, and part of our education process is to educate especially doctors and health-care workers to recognise it and offer people help and assistance. There are now helplines, and Seniors Rights Victoria has lots

of services with the objective of preventing elder abuse. It is a challenge. People are thinking about making enduring powers of attorney and giving people power over their finances or power over where they are going to live and sometimes who is going to see them in the nursing home, because the guardian will have those powers over who has contact with you, and that can separate people from their friends or family or support. It is quite a pervasive problem, and we have to be careful.

We want to have good communication between health-care workers and aged-care workers and both the person who is being cared for and their family, but we need to be careful not to be communicating with people who are abusive or giving more power to people who are abusive than they should be given. Some of the new changes with the power of attorney law that are coming into effect on 1 September are aimed at giving some protection to people and also being able to get money back when family or friends financially abuse people. So there is a lot of work in this space.

Ms SPRINGLE — Following on from that, how common would you say, in your opinion, this is?

Dr GOULD — The figures, I think, are currently about 5 per cent of people, but because it is a scale of things we do not know how many people are using those figures to label the most severe. There are an awful lot of people who are under pressure from their families — —

Ms SPRINGLE — Where do the figures come from? How is that data collected, do you know?

Dr GOULD — I know the data was quoted in a webinar I did from the Royal Australian College of GPs, so it is a reputable source. There is not that much data on it.

Ms SPRINGLE — But as you said, it is a pervasive issue, so one would assume that a lot of it is not documented.

Dr GOULD — And because it is a scale; it is incremental. Often the people who are in the situation would not describe themselves as abused; they just describe themselves as being in a bad situation. Often they still want to have that relationship with their son, daughter or whoever might be abusing them; they just want to be treated nicer by that person. That is why people are at such risk of being abused.

Ms PATTEN — Thank you, Doctor. I was interested in your submission around how you are working with ambulances here in Victoria but also what is happening in New South Wales. I just wondered if you could tell me how it is working in practice and whether it is actually is working?

Dr GOULD — In practice in small rural areas it actually works quite well, because the staff of hospitals have quite close links with ambulance services. When I started working at Yarrawonga I could name the ambos — it was either going to be Frank or it was going to be Steve. Now there is a larger ambulance workforce, which is fantastic, and also the ambulance often comes from elsewhere.

With our local ambulance workers, they have much more of an ‘acting in good faith’-type attitude. If they are aware that there is an advance care order or a patient is a palliative care patient, they would not necessarily resuscitate them. By the letter of the law and their protocols, if they do not have any documents in writing, they are supposed to resuscitate someone. That can be fairly distressing for an 84-year-old person on the bathroom of their house when they have collapsed. It is one of those difficult things because families should be able, if they are nervous or something happens, to call the ambulance for support, but the ambulance needs some guidance as to what the range of treatment options are. We have issues where ambulances in Victoria take patients into New South Wales and Victorian ambulances cross into New South Wales and bring patients to us, so there is a flow both ways across the border.

Mrs PEULICH — Thank you very much. In relation to elder abuse, are there other groups that may be subject to similar pressures, such as adults with severe disabilities?

Dr GOULD — Yes, and that is another issue, too, especially people with disabilities. Unfortunately they also have a very high rate of being sexually abused, so that comes into it as well.

Mrs PEULICH — I have one other question. Your lecturing and your teaching on advance care planning — can you just outline the range of courses or training that are provided, and where is it deficient and where do we need more of it?

Dr GOULD — Like all things, we want more. At the medical student level we do some talks. We have a 1-hour tutorial on ageing at the end of life, and we have another 1.5-hour interactive lesson on ageing through the life span and some of the legal issues. It is not very much. With the Murray to the Mountains interns in their orientation at the start of the year, we have Jenny Schwarz, who is a geriatrician from Melbourne, come and give some training on aged care and the legal processes at the end of life. Then with the GPs, up until recently it has often been me harping on at people, especially in my local town. I actually did a project with the Hume Region Palliative Care Consortium on educating GPs about advance care planning a couple of years ago.

Mrs PEULICH — How can we beef all that up?

Dr GOULD — That can be beefed up by encouraging it at the local health service level. Potentially you could use the stick approach and make it compulsory as part of people's VMO stays at hospitals — so in order to be a visiting medical officer at the hospital you should attend to advance care, but that is the ultimate big stick — or generally just make it part of the processes involved. There has been a lot of work done at the Austin Hospital and through Respecting Patient Choices, and they have rolled out the Decision Assist program, the training for which I attended the other week. I have been trained to be the trainer, and part of the deal is that I then have to roll out and do some of those projects locally.

I think it would be really important to also develop a module for it that is aimed at overseas-trained doctors, because on the last figures I looked at over 60 per cent of our workforce in the rural areas is overseas-trained doctors. They often feel very nervous, and so do junior doctors, about looking after people at the end of life. They do not want to be seen to make a mistake, and sometimes if they are not sure what to do, they will err on the safe side and tend to escalate care. Patients get referred off, in our case often, say, to Wangaratta, and if they are worried about them there, they then get airlifted down to Melbourne — so someone ends up in a tertiary-referral hospital, a long way from home, when maybe they did not need to. Sometimes it is appropriate; people do need to have those services. With end of life, it is just as valid to have both plans and pathways. It needs to be what is suitable for the person.

With one of my registrars, I was with them at the nursing home and we saw a gentleman who was having some issues, but he totally still had capacity. He totally still had quality of life. The nurse was poking me in the back with a pen and showing me a piece of paper — 'Can we have this end-of-life care discussion and treatment plan?'. I actually took over from my registrar and had that consultation with him, and we negotiated. He was wanting to have his treatment there, because my registrar had previously called the ambulance to take him to the big hospital but he did not want to go. He was aware of the limitations of what could be offered to him, and we negotiated a plan that was suitable for him.

He is still going. He survived that acute exacerbation of his problems, and we kept him comfortable and kept him where he wanted to be. As I went out of the room I apologised to my registrar and said, 'I'm really sorry for taking over', because when I am teaching I am often supposed to be observing them. She said, 'That's okay, Margi, because I've never seen anyone have that conversation before. This is someone who has worked in hospital systems for many years and worked in general practice for a year, and yet she had never seen anyone have that end-of-life discussion and the negotiation with a patient before.'

When I talk with other supervisors of junior doctors, often we feel that people are unprepared to have those conversations. I know there are many mentors that I had when I was a junior doctor who showed me how to have that sensitive conversation with families. Sometimes it is challenging, but the more you can observe someone have those conversations, the better you can then start having those conversations yourself. I would be really keen, and the next people on my hit list to attack or approach for funding is Rural Workforce Agency of Victoria because they run an emergency training course for doctors, especially overseas-trained doctors going to rural practice, called a rural emergency skills course.

Having previously been an examiner in that course, our standard was: would I be happy to have a car accident or for my family to have a car accident in a country town where this doctor is? Because I want to know that they are going to look after me appropriately. We could potentially have a similar standard for: would I be happy to be in aged care or to have my end-of-life care managed in this country town by this doctor? I think the Decision Assist module of training could be adapted and expanded a bit to be suitable to train rural doctors and place the emphasis and importance on the fact that providing quality end-of-life care is just as important as providing quality emergency care.

Mr MELHEM — Thank you, Dr Gould. Do you think the existing laws are adequate to give people a real choice about end of life? I know you talked a bit about training and education, but I am interested in your view about the current laws and whether or not they need to be changed.

Dr GOULD — It is interesting, because whenever I attend education on this I get totally conflicting opinions on the law. The people who are very keen on advance care planning say that the law is there and it should be followed, whereas other entities say that advance care plan documents are not legal, are only a guide and cannot be enforced. It is a challenge because it needs to be simplified and clear what the law is for doctors to follow. Doctors will sometimes say, ‘I know there is an advance care plan in place, but I know better and think we should do something’. That does not pass the ‘best interests’ test — what is in the best interests of the patient and what the patient’s choices are.

Unfortunately not every patient has an advocate or a relative who is not upset at the time, because most of the time when you are in these situations the emotions are very high. If you have had these conversations with your family member beforehand, it makes it much easier for them to make the decision. It is much easier for the doctor making the decision to be able to say, ‘I have had this discussion with Mary over several years. I know this is not what she wanted, and we want to keep her comfortable’. But if they do not know Mary, then often doctors will say, ‘There’s a chance of cure. We should move on and do this and that’. That is not always appropriate.

Mr MELHEM — Just to follow on from that, with assisted suicide, for example, where would that rank in the list of priorities from 1 to 10?

Dr GOULD — Very low. I have had very few people ever ask anything, and I have looked after people with motor neurone disease and other diseases. My own grandfather at one stage said to me, ‘If anything happens to me, put a plastic bag over my head. I want to die’. That was quite a confronting conversation to have as a teenager with your granddad who you love very much, but it meant that later on when it came time he had talks with me and said that when he was lying on the floor at home after a stroke waiting for someone to find him he really wished he would die. He did not want to be found. He was embarrassed by being on the floor and being incontinent and all those sorts of things. But it meant that when it came time to make decisions at the nursing home about whether we would want advanced resuscitation for him, it was easy to say, ‘No. He is at a point in his life when he has not got much quality and he has chosen that if an act of God, so to speak, happens, he should be allowed a natural death’.

The terminology we use around these processes is very important. Life is not like television programs; it is very different, and often, I think, using the term ‘allowing a natural death’ is important. For some, when you are older if your heart decides to stop or you stop breathing, depending on what you believe in, it is something saying, ‘That is it’. You need to be treated with dignity and respect, and you do not need to have someone jumping on your chest cracking your bones.

Ms SYMES — Thank you so much for your testimony and in particular your submission. I wanted to follow up on something. We have heard a lot about people in the health industry concerned about the community not being aware of the end-of-life options or access to advance care planning, and I note that you have some really good suggestions about how we can encourage more people to have the conversation. I was curious about the advance care plan champions and volunteers. What type of people would they be, and how would you see that working?

Dr GOULD — The thing is that advance care planning does not just speak to the aged population. They are the target audience, and we have tried to move it out of just the palliative care audience towards the broader aged-care community. There are a lot of volunteers in this space already, so a lot of these people are already trained in some respect in terms of volunteer training. Lots of organisations have a huge workforce purely based on volunteers. One of the things we did at a community forum was basically prompted by the volunteers at Mercy Health Albury.

Ms SYMES — Is this the one where 300 people came?

Dr GOULD — Yes, and it was really well received. I think that is because the volunteers put a huge amount of work into preparation. While I was one of the speakers, the volunteers went out and asked the questions —

basically asked the audience beforehand what they wanted to hear. We made sure our presentations covered and answered the things they wanted to hear. It just shows how interested people are in the process.

We can have talks in small towns, and people come along and say, 'I wish all my mates at the men's shed had come along to hear this talk'. A lot of people are interested, and we need to make use of our networks. Things like Rotary groups and Probus groups often all have those things. For some people, if they are volunteers, all they need to be trained up to do is to start having the conversation with people and then have the resources to know who and where to refer people to. Of course you have to have somewhere to refer people to, and that is where having some form of organisational structure — —

Ms SYMES — Great, thank you.

Mrs PEULICH — Is there software for advance care planning or perhaps an app?

Dr GOULD — There is an app that is produced by Decision Assist. Unfortunately it only works when you are connected to the internet, so it is not very useful for rural areas where internet costs and data costs are incredibly high and access is poor. Ideally, and I have fed this back to them, the app should have some features that stand alone so you download it and then you have it on your iPad and it will work when it is not connected.

The other important thing is to have it embedded in the software, and we have done a lot of work with hospitals and healthcare services to have alerts put on their things. This is an ongoing process, and, very importantly, it is in the GP software. It is still in the process, because you need to have a slot. You can type in free text anywhere but then you cannot search it, whereas if you have a slot in the program, it means you can search and find out: does this person have an advance care plan? Who is their substitute decision-maker? Most importantly, what is that substitute decision-maker's mobile phone number for 24-hour-a-day contact? All these things need to be worked on, and at the higher level if we demand that doctors have this in their software, then the software companies are going to provide it. Decision Assist is working on it. It is a challenge.

I developed some templates that can sit in the software and it can basically pull out information like a letter, but it is very clunky and very basic. Someone with more tech savviness could produce a very high quality document. After all, we can do TAC and WorkCover certificates on the computer. We can download templates from them, so why can we not have proper PDF files that self-populate? There are lots of forms you can get on the internet, but they will not populate with information from the data system that we already have. There is lots of integration, and health services often have multiple data systems and different data systems across different health services. It starts to become a bigger problem.

Mrs PEULICH — Thank you.

The CHAIR — Thank you very much, Dr Gould, for your evidence today and for coming here to Shepparton to be with us.

Dr GOULD — It has been a pleasure. Thank you very much.

The CHAIR — I just take this opportunity to acknowledge Wendy Lovell, a member for Northern Victoria Region, who is in the gallery. Thank you for joining us today, Wendy.

Witness withdrew.