

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Traralgon — 9 September 2015

Members

Mr Edward O'Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

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Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

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Secretary: Ms Lilian Topic

Witnesses

Ms Melissa Marr, Carer Mentor, and

Cr Dale Harriman, Coordinator, Gippsland Carers Association Inc.

The CHAIR — I would now like to welcome the mayor of the Latrobe City Council, Cr Dale Harriman, and Ms Melissa Marr, both here representing the Gippsland Carers Association. Thank you both for being here with us, and perhaps I will just put on the record what an outstanding organisation the Gippsland Carers Association is. It is very well respected by all sides of politics. Your longstanding president, Jean Tops, is well known to many of us, and the work you have done over many years is known and acknowledged.

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 proof versions of the transcript within the next week. The transcripts will ultimately be made public and posted on the committee's website. We again thank you very much for joining us. We have allowed half an hour for our session this morning. I invite you to make some opening remarks, and thereafter the committee will have questions. Thank you very much.

Ms MARR — I am the carer mentor at Gippsland Carers Association, so I deal personally with the carers throughout Gippsland. We cover all of the Gippsland area. With that comes a range of different types of family arrangements or carers that are caring for older ones as well as ones with disabilities or special needs, age frailty and those sorts of things. When we are talking about palliative care and those sorts of choices, many of the families that end up reaching out to us are quite overwhelmed with the situation. Sometimes I have been working with them before it gets to that point, so we have had a little bit of history and we have had some services in place, but many of them that might contact me at that delicate emotional time are quite overwhelmed and not sure where to get help and assistance. They might have been given a little bit of assistance through their local GP or through the hospital social worker team that have spoken to them, but with many of these ones I find there is a lot that want to bring their family member home and take care of them at home. They feel that that is the best care for that one, but at the time they need some assistance and some help to do that.

For many rural Victorians, when they are at home it is quite a distance to get service providers or assistance out there, and that can be a real challenge. It can also be a challenge if they decide to be in a palliative care facility. Being so rural and so far out, that means a lot of distance and a lot of time spent and a lot of cost. When you are talking about it at a very emotional time in someone's life, that can be a real challenge that they are not sure how to deal with or cope with at that point.

I try to link them into as many services and as much assistance as I can, but I can really see a need for more information to come through to them about where to go and what to do for help. Many service providers work independently. When it comes to Gippsland, it is such a wide and big area, and you have got different shires that offer different services. Some of the health providers also offer different services, so it can be real challenge for them to know what is available to them, what they can get access to and how best they can cope at that delicate, difficult time. So that is a real challenge for many of these carers. It is not only the distance, but I also really feel the lack of information and education and what is out there could really do with being looked at and worked on.

Cr HARRIMAN — I can contribute as well, not only from Gippsland Carers but also from a personal point of view, having gone through palliative care last year with my mother. Mum was diagnosed with terminal cancer in May, she died in November, and in that period of time trying to get services to her — she wished to die at home, in her own bed — was difficult. The disconnect between the different levels of government, even though I have got contacts and can navigate through that, still made it very, very hard. There were still weeks going by without services being provided or waiting on assessment of services.

I think part of that, from Gippsland Carers' point of view, because we deal with a lot of people caring in a palliative sense, it is very frustrating for the family. And I know it became frustrating for my mum. She looked at it that all of a sudden she had become a burden. I do not think in their final hours that people want that to be on their mind, the pressure that they are putting on the family.

I think that is something we need to look at and to work better. And I know it has been mentioned by people before about the options of easing pain and the level we ease pain. I think it was quite good that the doctors we had were quite open and up-front about that. They gave Mum the choice, and they respected her choice that, no, she wanted more time with the grandkids. Then towards the end she said, 'No, this has gone on long enough. The pain levels are too high', and they eased her pain. So I think within the medical fraternity there is that there already — there is that knowledge and understanding. I have to say from the local hospital point of view and the

local doctors' point of view, they were very empathetic about it. They were very kind in the way they put it. It was not put out there that, 'You know, it is time for your mum to go'. It was a case of, 'How is her pain? How is her pain management? How are we going to deal with your mum's final days?'

We found that to be really, really positive in the way it was put. I am Catholic and did not believe in euthanasia, until my mum had to confront it — change of mind. From a personal point of view, and hearing the stories of carers too coming in, and there are a lot that have the same point of view: you do love the person, but watching somebody in pain is a very, very hard thing to do.

I think the big point that we were trying to bring across is you need to make that last year, two years, last couple of months as easy as possible. It should not be a case of if a doctor has come out and said that this person is terminal, this is a terminal disease, or they are going to die, then we really do not need, and I have got to say it as a local councillor, our local council staff coming out and saying, 'We have got to do an assessment to see if you actually qualify for care'. That is the current system. We cannot get funding from the state government or from the federal government until we have gone out and done an assessment.

We short-circuited the assessment program because Mum was so far gone, but it still took two weeks for that to happen, and that was just two weeks of my sister, my brother and myself taking all that care on of washing Mum, feeding Mum and trying to organise breaks and to get an hour away, because mentally and emotionally it is destructive.

Ms MARR — I find that one of the biggest challenges for carers is the time factor to get these services and the assistance in, because it is a process. And I understand that processes work for a reason, but if you are dealing, especially when it comes to the palliative side of things, people do not have a lot of time and time is of the essence. So to get some district nursing in, to get some home help — some people to come in to shower, to dress — even sometimes they need some equipment to help them when it comes to lifting and movement and those sorts of things, and they have to wait, like Dale said, two, three or four weeks for that assessment to come through. They do not have that time, so then it is people taking time off work, family members trying to get in and trying to cope with the situation.

By the time I go and see them they are often in a real mess. I am on the phone to the providers because I know a lot of them and I can try and get things happening a bit sooner, but for the family, who is emotionally involved, that is really hard. And they do not have the time to follow through and make constant calls to various providers in that highly strung emotional state. They are not thinking clearly anyway to ask the right questions, to push for services, so that whole process is something that needs to be looked at and addressed and discussed.

The CHAIR — Could I perhaps ask, why are those processes so elongated, and how could they be improved?

Ms MARR — Timing sometimes. It can be the shire, the workload that they have got, the area that they are covering. Usually the first port of call is to get that assessment happening. That assessment will then allow a broader range of services to be involved and linked, but none of those other services can get involved until an assessment has been done. So whether it is a look at how soon we can get an assessor in, whether they need to have more written documentation from doctors saying, 'This is a palliative issue; it needs to be at the top of the list', but then where do you draw the line — who is more important than someone else? Whether there are more people in that department who do the assessments; whether they seek or listen to advice from people such as myself who go to visit these families, because I have the background on them already and the history behind them.

A lot of the time I find the carers, or the caring family, do not know the right questions to ask. They are not pushy, because they have been caring and they are used to looking after someone. They do not want to be a burden, but I am like, 'No, you are entitled to this, this and this', so I will ring on their behalf and I will be the advocate and I will ask the right questions. But you can imagine, Gippsland is a huge area to cover, and there is a lot involved to get those services happening over such a big area.

Cr HARRIMAN — A lot of it is bureaucratic too — it is boxes have to be kicked, processes have to be gone through. We now talk to a state person who will then organise something with the local department, so it is when they make that phone call, and three people trying to tie in two people to catch up is just —

Ms MARR — A bureaucracy.

Cr HARRIMAN — And a lot of the time the families get to that stage that they have been caring for that person for so long, they do not want to hand over that care. So it gets a stage where they can no longer cope, they are mentally and physically at their end, that they call out for help and then it is like, 'No, you have to wait another month, another two weeks'. And that is the most frustrating part. They are trying to do what they see is best for their family. They care about this family member, they love this family member. It is their responsibility to care for them, and when it gets too much it is then too much of a wait before they get that support.

Mr MELHEM — I am sorry to hear about your mum. What would you change? You talked about bureaucracy and what changes you would make there, in terms of a one-stop shop-type of thing, so funding. That is the first part of my question. The second part is: what sort of changes in the laws should we make for this sort of experience, from your point of view, to make life easier for everyone?

Cr HARRIMAN — I mean the first thing is that as soon as a doctor makes a diagnosis that a person's condition is terminal, then that should be the point that that is relayed to a department, and the department says, 'We send out an assessor now to find out what their needs are'. It should not be up to the family to have to ask, because we find a lot of caring families again who have been doing it for 30 or 40 years, it is just not in their mentality to ask.

Mr MELHEM — Sure.

Cr HARRIMAN — It is just not their way. But I think for the benefit of the person who has got the terminal condition, sometimes it is better that an independent person comes in on behalf of that family and says, 'Do you know what? You have done it hard for a long time, let's make their last couple of months or their last year or last two years as good as possible, these are the services we can provide'. So I think if a terminal diagnosis is made, then the department should be notified, and that is when we should start putting those processes in place.

Ms MARR — I have found too that some medical staff seem to have more information on services that are available than others. So I have got some carers whose doctor has worked really hard with them to get that process happening and the assessments done and helped and encouraged the carer, whom they have got the relationship with — they know the family and the situation. But then there are other doctors and medical staff who do not encourage that, who do not recommend services. And I do not know if it is that they do not know the information or what is available. There is a lack of education in that sense for them — I am not sure. But in some ways, if it was a bit more streamlined, a bit more encouragement maybe from the doctor — you know, that GP who might have been working with the family for 10 or 20 years and really has their best interests at heart — why not make the suggestion to get the assessment happening, get other services involved and make that suggestion when they have the rapport with them? Often when I come in we have got to build on that rapport.

I will tell them all the services but it takes a bit of time to sort of work with them to get them to feel comfortable to put up their hand to get help, whereas the GP at that level or the specialist or whatever who is working with them for some time would have that history and might have that rapport, and that would be a better use of knowing them and getting those services involved sooner.

Mr MELHEM — Just to follow up on that, and I am sorry to do this to you.

Cr HARRIMAN — That is all right. That is fine.

Mr MELHEM — Your mother wanted to spend time with the grandkids, and she got that, but then you said something about at a point of time where, 'Okay, it's time for me to go now'. Is it part of the process to put an advance care plan in place with these sorts of triggers, which include the point of 'Time to go'?

Cr HARRIMAN — I think it does. I think with Mum's case she got that message to us just before the medication for the pain relief affected her mental capabilities and her abilities. But she was quite adamant that the pain management was really good, and I think that is something that was different to what I had seen with other family members who have passed away. Even though Mum had refused radiotherapy — she had it once and just said, 'That's it, I'm not going to prolong it and drag it out' — the service of pain management was then

stepped up, whereas in the past I had seen if they refused medical care, then pain relief was withheld as well because that is medical care.

But I think in Mum's case it was really good. With the hospital, the doctors, people across the board, pain medication was considered really good. Mum got to the stage just before when she said, 'Enough's enough. I know I'm starting to slip, I know I'm starting to lose it mentally. I'm not going to have quality time with the grandkids. Enough's enough'. I think she probably lasted a week after that. But I think the hospital staff were quite aware of her wishes, and we were quite aware of her wishes, and it was good.

Ms MARR — I was just going to say, many families — I find some are really open and have put processes in place for the future of what is going to happen, and they have discussed end-of-life type issues as a family, whereas for many it is a very taboo subject. They do not want to discuss it — it is too hard. I run a couple of support groups for carers, and I usually make it a subject that we try and talk about, to get it out there, so that people can start the ball rolling to start discussing. I think, like you said, if there is a plan in place and some sort of action plan, it goes a long way to helping that transition run a little bit more smoothly, or at least the patient's needs are considered and the family understand what the patient wants and are more likely to work in with that and get the right service providers to get in and help with that. But then, where does that start? Does that start, again, with the local GP talking about those practices and getting that in place and thinking about it ahead of time, rather than waiting until they get to that terminal state? Because there is not a lot of time to discuss those needs. I am just putting it out there. It is another thing to consider I guess.

Mrs PEULICH — Following on from that, just in terms of navigating through the bureaucratic mayhem — not only obviously in this area, but more complex in this area because of often the shortness of time and the vulnerability of the people involved and family and so forth. In this day and age you would think that eHealth, the IT platform, part of it may have a segment where you may have, I do not know, prenatal/natal-related services. So if you are six months pregnant, you are going to need entry into a hospital at nine months, you are going to need some visiting nurses in the first few weeks, you are going to need a 10-week group session on this and that and whatever, and you can plan it. Obviously terminal illnesses and end of life are not as linear, and we understand that. But would it not be possible to have a comprehensive IT platform that has modules pertaining to stages of life, including one segment which has the advance care plan, which can actually integrate the needs of the three levels of government and triages and sends off, with the appropriate privacy checks, notification to the city of —

Cr HARRIMAN — Latrobe?

Mrs PEULICH — Latrobe — that Mrs X or Mr Y is going to need a visit from home and community care or whatever for assessment and so forth. Is that not viable? Is that the sort of system that we need to be looking at in terms of streamlining and better coordinating our responses?

Ms MARR — In many ways I think yes. The idea of that sounds very good. Each situation is very different, so where do you draw the line at what triggers what process or what service?

Mrs PEULICH — There has got to be agreement — a consensus.

Ms MARR — Yes. Then it is a matter of, 'Okay, that's going to trigger an assessment, that's going to trigger this, that will trigger some other service provider getting involved'. But then for the family itself, they need some information on those service providers before they get the phone call and they go, 'No, I don't need this. What's this about?', or, 'I don't understand'. A carer will usually say, 'I don't need anything', because it is too hard, because they do not have time to think about it and fully understand. In their minds they feel it is their responsibility. It is their husband, it is their wife, it is their child, their mother, whoever. They love them. They feel it is their responsibility. The fact that they are not coping and that their own health is deteriorating or that they are not giving to their own family is irrelevant. In their mind they want to give the best possible care. So then they need to really understand those service providers and those trigger points. Then who explains that to them before the service provider gets involved?

Mrs PEULICH — It may well be that it triggers a flyer to be sent to so-and-so with a contact person.

Ms MARR — Yes.

Mrs PEULICH — I am thinking of an interesting trial that occurred at the Moorabbin police station; it was in relation to justice. What the police were finding was that often the same people interfaced with the local police. They might be homeless, they might have mental health issues or whatever, and it was a bit of a revolving door. A certain number consumed most of the police time, which prevented investigation of some more serious stuff. This triage was called PACT. It would trigger notification of the local mental health service or the local housing association that so-and-so needed follow up. Obviously funding is an issue always, but it seems to me that we need to coordinate things better. There is a way, but it obviously needs to be an investment into an IT platform that respects still the importance of that communication and that relationship between service providers, medical personnel, family and the person concerned.

Ms MARR — Yes, and some sort of assistance too for those who are rural, who have to travel for services. There are ones who live in town — Traralgon, Morwell, even Bairnsdale — but I have got carers who I go and see out the back of Korumburra, Leongatha, heading towards Wonthaggi, out at Lakes Entrance. There is a long way that they have to travel to get even into town to go see their GP or a specialist.

Mrs PEULICH — This is really sort of out there, but I am just thinking: so-and-so has been diagnosed, given a 12-month terminal prognosis or diagnosis. That might trigger a flyer to be sent out to a person in relation to whatever. Often people do not know where to turn. The fragmentation of services and this sort of notion that somehow we can make them seamless has been a longstanding goal, but we have failed to achieve it. Surely IT can play a really important role in trying to sort that out.

Ms MARR — Yes, I agree.

Cr HARRIMAN — I think at the GP level that if the GP hits that button and those services were then automatically rolled out and information was sent to the caring family, that they had an idea of, ‘These are the steps we’re going to go through, these are the people I need to contact’, or, ‘These people will be contacting me, I’ve got an understanding’, that would be a good way to go.

Mrs PEULICH — It will only be embraced by the GPs if it helps their job, if it is more efficient for them and if it is more professional.

Ms MARR — Exactly, yes.

Cr HARRIMAN — Yes. I think a lot of the time GPs get to the stage where the family keeps coming back with, ‘Oh, this has happened’, or, ‘This has happened, where do we go?’, and the GP is acting as a social worker, acting as a — —

Ms MARR — And a counsellor, a psychologist.

Mrs PEULICH — We know they have only got 15 minutes before their next patient.

Cr HARRIMAN — Exactly, yes. So I think that would be good.

Ms PATTEN — It certainly seems it is a no-brainer that GPs need more information at their fingertips to provide at the diagnosis point that can then set in place all of this. Last night when I was thinking about this I was looking at that you encourage support groups in an attempt to help with the carers. I was wondering if you could speak about how we could encourage that, with a chequebook and without a chequebook.

Ms MARR — We run two support groups. The area I cover includes six different shires. At the moment I have two support groups that cover two shires. There are some other support groups run in the other shires, but general specific as opposed to a broad range of carers can attend. It is a challenge, because that means people have to come away from their caring role in order to get together and meet with other carers. But it is a very positive experience. We talk about a range of subjects, and I like to make it educational as well as relaxing and fun. They ask me questions.

We discussed only last week in one of my groups that people wanted information on euthanasia and palliative care, so that is what I will organise for them. But like a lot of things funding is an issue, because people have to travel and that can be a challenge as well when you are talking rurally travelling on this side of Gippsland. And time as well, because people do not have a lot of time to spend an hour to travel somewhere; but they also want to be involved and feel like they are meeting others in similar roles to themselves.

It is an opportunity for them to get education, information and knowledge on services if they are in a position to attend; because if they are not caring, then someone else needs to be at home looking after the person they care for. Some of them I know get respite so they can come to my group for instance, which is good, but then that means they are not getting any time for themselves personally in another instance. Can there be some sort of funding that: yes, we will give you once a month so you can go to a support group and it is not going to affect the respite you are getting for your carer, because we feel it is valuable that you are getting information and support service help.

Ms PATTEN — Yes, so we call that something else, we do not call that respite.

Ms MARR — Yes, we call that something else. Something like that to think about.

Cr HARRIMAN — At the moment the support groups are run without a chequebook.

Ms PATTEN — Yes, right.

Cr HARRIMAN — Yes, so just making you aware of that. Even to the extent of what we can provide at the support groups, without a chequebook we can provide a lot; with a cheque-book it would take it to a whole new level.

Ms MARR — Yes, definitely.

Cr HARRIMAN — And make it accessible to a lot more people.

Ms MARR — A lot more. Yes, definitely.

Ms PATTEN — And make their lives easier.

Ms MARR — And the feedback I have had — I have got a new one that has only had two meetings — is already very positive. The community is getting involved, the word of mouth is spreading; so, you know, that is just from one group. The possibilities throughout Gippsland are endless. They are willing to support it if they are able to get there, if there is someone else looking after things for them.

Ms PATTEN — How many carers are we talking about then?

Cr HARRIMAN — In Gippsland there are 27 000 caring families, and if you went to any other region in Victoria, you would find the same sort of figures. We have had big discussions with carer groups right across regional Victoria and around regional New South Wales and the figures are the same.

Ms MARR — We have government funding for my role, but it is only 6 hours a day three days a week and I have to travel massive amounts. There could be three of me working five or six days a week for the amount of carers that need the support, need the help and would rather someone like myself come out and talk to them as opposed to having to deal with and go through the hoops of the system so to speak if that makes sense.

Cr HARRIMAN — Mel's position is philanthropic, because R.E. Ross have actually funded her.

Ms PATTEN — Yes, obviously there would be savings for governments.

Ms MARR — Yes, definitely. For carers at home to care for someone, as opposed to them going into a facility, saves the government a huge amount of money; and generally speaking it is more personalised care. The carer is happy and the person they are caring for is happy, but at times, you know, it is hard. They might have committed for a period of time, but the person they are caring for has lived a lot longer or it has gone a bit further or they are ageing now and their needs are changing. Things are changing all the time, and they do not necessarily want to give up. They just want help and assistance and support, and that is where the big need is throughout Gippsland. That is where we step in, get involved, and help them and support them in that way.

The CHAIR — We had better leave it there, but thank you both very much for your time today, and again congratulations on everything that the Gippsland Carers do. It is remarkable and a great group of people.

Ms MARR — Thank you.

Cr HARRIMAN — Thanks for coming out to the regional areas too. We really do appreciate it, thank you. It is nice.

Witnesses withdrew.