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

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Witness

Mr William Darby, chairperson, Peninsula Advisory Committee for Elders.

The CHAIR — Before I invite you to make some remarks, 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. You will be provided with a proof version of the transcript within the next week, and transcripts will ultimately be made public and posted on the committee's website. We have allowed about half an hour for our time this afternoon, so I welcome and thank Mr William Darby, chairperson of the Peninsula Advisory Committee for Elders, or PACE. I invite you to make some remarks.

Mr DARBY — Thank you for those remarks. I take it that you are aware of our activity with PACE, but I will briefly say that I have been a resident of the peninsula for over 50 years, and in being here I have taken a fairly active part in public life in various ways. About 10 years ago I was asked to help set up the PACE committee. I was one of the inaugural members, and I am currently the chair for this year. When I got the request, I first thought, 'What could we do to assist you?'. I was not quite sure how to handle it, because, as I say in my submission, we had not really come to grips with the subject thoroughly — not in the usual way if we were to make a submission.

I should preface my remarks by saying that in the course of our 10 years advising the council, we have touched on all sorts of policies, ranging from physical activity, footpaths to public policy. We have also got involved in helping with positive ageing strategies, and we have widened our ambit on occasion to make submissions to things like the road safety committees of the government.

On this particular issue, if I could read my submission, we regard it as an important issue. As I note, it has often been made more complex by developing into a discussion of voluntary euthanasia rather than palliative care or the broader question of end of life, so with some of the issues that you might have expected would come up quite often, time runs out before you get to them, because you are bogged down. The other possibility which I have indicated is that we have sometimes had discussions which have not drawn everybody present out on the matter, and therefore my submission today is based on brief discussions during this week with some of our members, but not all of them.

As I say, earlier in 2015 we decided to invite a speaker from Medicare Local to outline the issues as they saw it related to palliative care, and for a subsequent meeting we called in a speaker from Peninsula Home Hospice, so we learnt a lot about palliative care and discussed some of the issues that were raised. As I say, we became aware of a variety of opinions during that discussion. We also became aware of a paper issued by the Grattan Institute which we thought gave a quite good, balanced assessment of all the issues that were in it, but we have not managed to put together a paper covering our own views.

Given those limitations, we support the government's policy in the 2014 advance care planning strategy, and in the course of looking at that we recognised that greater efforts are needed to raise public awareness of the benefits of advance care planning. I will not go into detail of my personal experience, but during the last 12 or 18 months I have had some experience in that area.

We believe safeguards need to be included to protect the rights of older people where there is a potential for elder abuse. I will not go into all the possibilities of elder abuse, but you are probably aware that they range over psychological abuse through to physical, financial and other things, which quite often mean that people are put under pressure to either do something or not do something, which I think is quite applicable in this area.

The medical fraternity's approach to asking somebody whether they have an advance care plan is sometimes met with a variety of responses in reality, and sometimes there is not an opportunity for the issue to be properly discussed, particularly as these issues quite often arise in a totally unforeseen, unplanned manner, and not all the parties will be aware of the issues, the background or the possibilities. There is also a question of whether people understand the term 'palliative care'. For some people it means almost the last rites, though obviously for other people it has a wider application.

The other question that comes up in relation to this in reality is that circumstances vary on how people find their progression. You might be in a nursing home, you might have an accident or you may have a chronic difficulty, and just with those three examples your path through discussing palliative care, if and when it arises, can be quite different in each of those situations.

Another aspect that we thought we should touch on is the documentation relating to end-of-life planning. It ought to be in readily understandable language, and I think every effort is made to do that, but sometimes it does not cover the case of those who have difficulty with English. On that particular point, interpreters in theory are available, but in practice very often they are under pressure. You cannot obtain somebody at the time. The other question is whether the interpreter is versed in the subject; medical terms vary from country to country. Individual attitudes perhaps may have some bearing, although I know that licensed interpreters take great care to avoid personal bias.

The last point I would like to make is that we believe, after our discussion, that palliative care has a place, but we certainly recognise that a lot of it at the moment is subsidised by personal effort, by volunteers raising funds or by supporting palliative care organisations. Ideally the care should be extended to services in the home and have continuity. I mention the possibilities of going in and out of care in various ways and in various contexts, which means that you may lose the opportunity — may never have the opportunity — of formally seeking palliative care if a particular medical person does not offer that to you. Depending upon the circumstances the care may or may not be readily available, and certainly not in some regional areas, or there may be limits to the service available due to the usual limitations of funding and capacity.

I think that is all I can offer you. It may well be that there is more that I could say.

The CHAIR — Thank you very much, Mr Darby, for your considered evidence. We appreciate it, and thank you for consulting with your colleagues and members as well to draw on their views about this. You made some remarks about doctors who request if their advance care plan exists, and I was not quite clear about what you were saying. Are you saying that perhaps sometimes that communication between doctor and patient is not as good as it could be or sometimes that it raises questions that are awkward and difficult? Is that what you were — —

Mr DARBY — There is that possibility. I have noticed that, if you go into care or into hospital at the moment, one of the first questions that is asked is, ‘Have you got an ACP?’, which usually means the next question is, ‘What does that mean?’. You may have discussed the possibilities and may have decided that you do not want extreme measures, but you have not been able to vocalise it in clear terms and you may not have had a discussion with other members of the family, so the response when a doctor asks that question or a nurse asks that question can be difficult.

The CHAIR — I think what has become clear over today’s evidence — one of the things — is that the Mornington Peninsula community is very engaged. There is a strong sense of volunteerism and a lot of great community groups such as yours that are engaged in various issues across the peninsula. Are you aware of any similar committee or organisation to PACE in other parts of Victoria?

Mr DARBY — I am aware that there are advisory committees. I think that probably we are one of the few that operate the way we do. I do not know whether it has been explained to you, but very briefly we tend to set our own agenda. We have administrative assistance from the shire, but generally speaking we set our own agenda, except in the cases where a matter is referred to us. We get regular referrals of plans for aged-care facilities. We are starting to build up a bit of expertise in looking at plans, sometimes with great difficulty when they come over the internet and are very hard to read.

We have tended to — how shall I put it? — cover whatever ground appears to be needed, so if we see an article in the newspaper, we may ask a question and circulate an item for discussion, and we may put that on an agenda for a meeting and invite a guest speaker to come along to tell us more about it so we are better informed. We very often consider whether we should respond to invitations to submit papers on various subjects. There is a fair bit of work involved in that, and it is difficult sometimes with volunteers to put all that together and truly represent the view of the committee. Our meetings usually go on for a couple of hours, but they are not the place to develop a policy, so this work is done outside of our normal meetings.

To that extent, we have met with a couple of committees from other places, and the remark has passed that in most cases their committee is chaired by a councillor and the agenda is directed by council and is somewhat more formal perhaps than ours. We allow a pretty wideranging, fairly easygoing discussion usually. The rules of chairmanship are fairly lax, and over a period of time it has been possible for us to develop a rapport amongst the members of the committee. I think those who have joined us in recent times find it a bit difficult to understand, but those who can, assist us greatly, because we try to keep a broad cross-section of the community.

We try to draw people with useful backgrounds, located in different parts of the peninsula and with an interest in or a community connection with a community group of some sort, but we hasten to tell people when they come that we welcome their views but do not welcome anyone grinding an axe on behalf of a particular viewpoint or a particular organisation. We wish to operate as a coherent committee.

Ms PATTEN — I really like the idea of PACE. One of the previous witnesses — I think it was the woman from the shire — was extolling the virtues of your organisation and telling us how brilliant you are.

Mr DARBY — Sometimes we find it hard to live up to some of the things they say about us.

Ms PATTEN — So far so good. She also mentioned that you have a lot of contact with the Probus groups and Rotary and those sorts of organisations. I was just wondering: with advance care planning and end-of-life choices, are you starting to see it on their agendas more now than it was a few years ago, or have we still got a lot more work to do to get it out to those groups?

Mr DARBY — There has been the occasional issue of documents, like taking control in relation to medical powers of attorney, and you are probably aware that has been revised recently. On each of those occasions there is usually a bit of a flourish of publicity and so forth and then everybody goes off again. You can still go to a meeting and ask the question, which is difficult, ‘Who’s got a will, and what have you got in the way of a medical power of attorney?’, and find that there are at least one or two people who come up to you afterwards. They do not want to talk about it publicly, but they say, ‘What should I do?’ or ‘Where do I get it?’ and ‘Why should I?’.

Younger people seem to ignore what we have to say, and by younger I would say practically up to the age of 50 you can still find people who do not have a will, even though they have a family. As I say to younger people, if you own a house or a car, what do you want to do with it? If you have a bank account or a superannuation fund, what do you want to have happen to it? The average person has not thought about it.

The same situation applies with aged care and I think to advance care planning. Many people say it is too complicated and it seems to keep changing — ‘I’ll wait until I need to know’. When they need to know, it is invariably a bit late, because it is hard to get all the information you need and it is hard to make an assessment, partly because you do not know where to go and who to ask and partly because you are under stress. Those who are under stress cannot communicate as well. There is always somebody with perhaps a stronger viewpoint who may control the situation and others who feel unhappy or uncertain. So there is still a lot of room for this to be discussed among the community.

Publishing it in the local paper is not really the answer. Word of mouth and personal contact are probably better. We sometimes feel disappointed if we run a forum, say, on elder abuse or the legal documents and only get 10 or 15 people. You set yourself up with a hall for 100 and you only get 10 or 15, but if you have got through to 10 or 15 people and they understood it and were convinced, then maybe you have got 10 or 15 ambassadors, which perhaps might be the way to go.

At one point in my career I was a volunteer with Council on the Ageing, and they used the peer to peer idea, which means you train the trainer and it is a person like you, rather than a trained person or rather than an expert — an ordinary person. People can relate better to them.

Ms PATTEN — Yes, that is right.

Ms SPRINGLE — In your submission you talked about safeguards in terms of elder abuse.

Mr DARBY — Yes, I have drawn on the commissioner for seniors ideas on that — like when we are making submissions to support something that we have seen as being valuable rather than develop our own ideas.

Ms SPRINGLE — Absolutely. But for the record would you like to talk a little about your ideas around what possible safeguards could be put in place?

Mr DARBY — I find that question hard to answer for the reasons I have already outlined, that we have not put a lot of thought into this particular subject. I could only speak in general terms really.

Like I have just said, you need forums and so forth. You need to make it less threatening for people. I think the safeguards that I would have in mind are encouragements or removing barriers. Some people find themselves reluctant if they are the only member of the family, we would say, in this situation. Invariably it always falls to one or at most two people, if there is a situation in the family where somebody is approaching, say, a terminal illness or going into care.

I can think of somebody at the moment whose son is running around looking at accommodation. The son is probably going to make the decision rather than the other members of the family. The question then is: have the rights and wishes of the person involved been properly taken into account? That is where I think safeguards become important. The minimum I think is to get people to participate.

My experience in dealing with the medical profession over the last couple of years is that very often, because I was the capable person, they talked to me. I very often looked to my wife and tried to get the person who was addressing me to address it to my wife, because basically they needed her opinion or her answer, and she was the one who was going to get the treatment or not. But they were looking at me and asking the question and expecting me to answer on behalf my wife, which I found pretty difficult and distressing, but my technique was to keep directing them back to my wife. Now I do not know that that always happens, and consequently you have got a risk in all of these matters that you are not truly getting informed consent.

Mr MULINO — Thanks very much for your testimony today. I just had a question around advance care planning, and I think, like wills, a lot of people do not think about it until too late. One of the ideas that has been floated in a range of different ways is to have various triggers that might be used to prompt the discussion — for example, when somebody hits a certain age or maybe when somebody gets a certain check-up — or even just to have certain methods by which we might encourage families or friends to start discussions.

Mr DARBY — Yes, I am aware that if you have a 75-year-plus check-up, the nurse that is handling that will ask the question, ‘Have you got an advance care plan?’. I have had that experience.

Mr MULINO — Do you think those kinds of prompts — having a series of those — —

Mr DARBY — I still have not got a written advance care plan myself.

Mr MULINO — And I still do not have a will. I am not going to judge.

Mr DARBY — We have got all the legal documents, and I have made various appointments, yes.

Mr MULINO — It is a challenge, isn’t it, and some people find it confronting, but it does sound as though if you raise it in a way that is not overly formal — —

Mr DARBY — It is even more confronting, though, if an ambulance comes and the ambulance officer says, ‘Have you discussed resuscitation?’, and you say, ‘We’ll think about it’, and he says, ‘We might need the answer while on our way’. That has been my experience.

Mr MELHEM — On that point, though, should the government make it mandatory, for example, for various providers to offer? You cannot compel people — —

Mr DARBY — No.

Mr MELHEM — As Daniel was talking about, should we train our service providers, like ambulance, like doctors, like aged care, where people are terminally ill — it is black and white — so they can say, ‘Start thinking about advance care plans’, and various others. Should we make it mandatory for these providers to actually offer, including training? Is that something that could help?

Mr DARBY — I imagine so. The other thought that comes into my mind whilst you are asking me the question is that — we have done it a bit on the peninsula here — we have had a comedian act out situations involving aged care. *Mother and Son* — do you know that program? I think there has been probably an awareness. It is humorous, but it is also an awareness-raising thing, and it could well be that some careful scripting could be used to raise lots of the issues, a bit like *Neighbours* or something like that, where you pose various crises and introduce some of the things we have been talking about as community education. If you tell somebody to come to a forum, it does not work. As I said, you get the diehards or the hard cases, but you miss out on the hundreds of people that need to know.

The CHAIR — Mr Darby, before we conclude is there anything further you would like to add?

Mr DARBY — No, I think you have — —

The CHAIR — We thank you very much for your evidence, and we as committee members and members of Parliament thank you and your colleagues for volunteering your time to such a worthy pursuit.

Mr DARBY — Thank you.

Witness withdrew.