

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Melbourne — 14 October 2015

Members

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Ms Margaret Fitzherbert

Ms Fiona Patten

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Staff

Secretary: Ms Lilian Topic

Witnesses

Ms Sue Hendy, Chief Executive Officer, and

Ms Janet Wood, Former President, Council on the Ageing, and Vice-President, International Federation on Ageing.

The CHAIR — I would now like to welcome Ms Sue Hendy, the chief executive officer of the Council on the Ageing and the vice-president of the International Federation on Ageing, and Ms Janet Wood, a former president of COTA. Thank you, ladies, for being with us this morning. Before I invite you to make some opening remarks I will 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 the proof version of the transcript next week. Transcripts will ultimately be made public and posted on the committee website. We have allowed 45 minutes for our session this morning, so I invite you to make some opening remarks, and thereafter the committee will have questions. Thank you again for being with us this morning.

Ms HENDY — Thank you, Chair and committee, for the opportunity to speak with you this morning. We certainly support many of the comments that were already made about the importance of this topic. We will make a couple of points and then welcome a discussion with you. Firstly, I guess the point we would like to make is that the diversity of the population of older people that are in Victoria and that this discussion impacts — whether that be religion, culture, geographic, sexual orientation, et cetera — underpins a number of the discussions that we have. There are a number of pathways by which we die. One of them is that we go through life and one morning we wake up dead. Most of us have that natural death, and we wish that we die at home. Statistically 12 per cent of us die at home; the rest are dying in hospitals and aged-care facilities or on the roads et cetera. There is a mismatch between our wish and the experience of waking up dead.

Obviously there are assisted deaths going on, whether they be by suicide or other ways occurring that are not within the legal framework of our community, but they are occurring. Of course we know through the work that we do in Seniors Rights Victoria around elder abuse that families do behave badly and will continue to, and there are probably people who are at risk of being murdered in whatever form we call that. Part of the system that exists does not necessarily support us in the way in which we want to die and the way in which our community thinks we should be able to die. Therefore the importance of choice and where we die, how we die, are absolutely vital to end-of-life choice and a quality of life to a quality of death.

One of the issues that we know underpins a lot of this and that we have certainly discussed in the previous presentation around what is informing the way in which the medical practitioners in the world in which we live, age and die is around age discrimination and ageism — the attitudes of our community towards us as we get old sometimes seem to shift at some magical age which varies depending on where we are. But we know that people walk into medical practitioner rooms and say, 'I'm 80, Doctor. I have a problem with my knee', and they say, 'What do you expect at your age?'. The response could be, 'A lot more than I'm getting from you at this point. The other knee is also 80, but it's not giving me a problem. Please help me understand: I don't know if it needs treatment, but I want to know what's going on'. Many circumstances are not dealt with or are limited to the way in which people are being supported in seeking treatment, information, et cetera, because of age discrimination. It is very pervasive, and we have connected age and capacity together.

We need to disaggregate those things, and therefore it will impact on the way in which we are perceived and treated as we get older, because one of the things that has been throughout the medical system and other parts of our community is the way in which the economics of the world impact upon that. We value younger people more than we value older people, so younger people can get treatment and older people cannot, and that will also impact on the way in which people's deaths, or the journey to deaths and their illnesses, are dealt with. That is a very important underpinning, and it connects very much with the rights of older people — the right to make choices, the right to make decisions and that link about capacity which was covered off well in terms of, 'If I have capacity, will my choices be listened to? If I have dementia, am I seen to have capacity? If I'm 80, will I even be asked?'. There are some strong connections between those things.

The other thing that obviously is going on is longevity. The consequences of longevity are that we are dying differently. I might hand to my colleague to talk about that.

Ms WOOD — She turns to me when she wants to talk about longevity because I am one of the examples, I suppose. I am of a generation which has seen, of course, our parents die much earlier, and I am even of a generation where I lost a younger brother, in 1942, to the diphtheria epidemic. So do not ask me about vaccinations, because you will get a very strong response on that!

It was interesting listening to Alzheimer's, because apart from wanting to say 'Ditto' to pretty well everything they said, I realised how personal this inevitably is. While vowing while I sat on the train this morning not to say anything personal, it is in fact a very personal journey, experience and so forth. I am a fairly typical COTA member, given my age group and particular interests, which are broader than just ageing but which are also about getting older and the experience of it. Longevity now means that we actually have a much longer time in which to contemplate mortality. It is different. Most of us, if we hit the age of 70, probably have 15 years and in that time you will probably be developing a chronic ailment, and that gives you time to think about, 'Oh, I didn't know I was going to die of that'. If I was presenting to you this time last year I would have been the absolute model of a healthy, active 75-year-old. Since that time I have been on what I call a pink assembly line and I have just jumped off that pink assembly line — still healthy-ish and active but now having a great sense of where I am likely to die. So although I want to die in my garden, it might not happen quite that way.

I think that extra 15 years to think about our own mortality changes the frame from where the debate starts — it absolutely does change it. It is not that we are all sitting down having our cups of tea and daily contemplating how we die; it is, though, that we all talk about it in our own peer group. Longevity is a major, interesting issue because we have now developed the capacity to live longer, but we have not yet got to living longer without chronic ailments. We might, although I am not sure I want to contemplate a world in which one never suffers anything.

The other thing that I think is changing the way in which we need to perceive how we can talk about these things is the change in language. I spent a day this week at the LASA conference on aged-care planning. The big buzzwords, of course, are about choice, positive ageing and consumer-directed care, and the Montefiore Homes, who do terrific policy work in aged-care things, are talking about consumer-directed living. I have been thinking about that, because I think it just means being alive, but I am not quite sure about that. But once we introduce this whole sense of choice — of flexibility, of people making their own decisions — then we cannot say, 'Oh, by the way, we are going to legislate or regulate or hand your decision-making over to doctors et cetera'. It changes the whole framework. So I think longevity and language, as I see it, are two of the major things that have happened that are different from my parents' generation.

I know today the emphasis is to be on advance care planning, and I suppose, again, language is really interesting, and longevity, in how we tackle this whole business of advance care planning.

The CHAIR — Ms Wood, can I interrupt for a second? It is completely up to you as to the focus of your presentation, so please direct it to whatever topics you — —

Ms WOOD — Okay. I am happy to do so, because I could be called an advance care junkie, I suppose, in that I see a lot of advance care plans that come from various organisations with which COTA has some connection or with other areas of my life that I am involved with, and I always fill them out. I have just filled out one from Barwon Health which has 60 questions. I am resilient, but an advance care plan with 60 questions for you to answer is too advanced. Then there are others. There is a lovely thing called *Five Wishes*. It is a book, almost. It asks you everything about what scents or scented candles you want.

I have been thinking about what would make a good advance care plan. As our good friends from Alzheimer's were saying, it ought not to be too advanced — that is, you can make one when you are 60, but it is not going to be the same plan you would have when you are 75. Had I made — as I did — one last year, it would be quite different from the one I would make now, now that I have intimations of mortality. So I think with advance care planning, we want some degree of standardisation, but it might mean that the actual document would look like a fairly standardised form for the medical part of it, another section which is the palliative care part of it and another section which in fact is for your family — part of it. One sheet will not fit all. That is what I have been thinking about there. Yes, okay. Back to you. I have lost my train of thought.

Ms HENDY — Grab it when you get it. I guess the other thing following on from that is the way in which some of those instruments that exist or are being developed further in terms of the advance care planning — the substitute content, the powers of attorney, all of those things — are valuable and useful but can also be powers of abuse. We know that in many ways powers of attorney are for evil and for good. There are some difficulties in all of those things, and being mandated, I think, would be quite difficult. What would you do if someone said, 'No, I'm not going to do one'?

But from the conversations that we have been having, which we have highlighted in our submission, people are thirsty for the conversation, but they are lacking information. They are also lacking places where they can have that conversation. That goes to what our previous colleagues spoke about in terms of it often being the professionals who are not willing to have the conversation, but older people, we believe, are — given the opportunity. I guess the area of elder abuse is one that we are very concerned about in terms of the ways families can behave badly. Through Seniors Rights Victoria we have seen, not necessarily at the end of life but certainly in the process towards that, regarding people's capacity, that we do not often believe older people. We think that they are possibly making these things up. If we do not think they have capacity, because they are old, then when they start to indicate that something might be not quite right we do not often act.

Who do we make as our power of attorney, and are we coerced by family into having it be the son? I will slightly correct David. When he said earlier that sons are the most evil in the family, that is not quite true. We are seeing that it is not actually that much different between daughters and sons in our stats. That is not to say that that is 100 per cent correct, because there is no prevalence study done in Australia, but what we see through our stats is that it is slightly less daughters to sons, but it is not that much different that you could call it one way or the other.

Ms WOOD — I was just thinking that again one of the interesting things that we ask of older people is that as they think about advance care plans they write things down. We are a society where in a governance sense we want more and more paperwork. Now we do not live our lives and test our values all the time by writing things down, so in fact many older people find the writing of it down not only confusing but almost frightening. If I write this down, who acts on that? How is it acted upon? Who will I give it to? Again it is a slightly non-normal way of dealing with your life for end-of-life regulators to want us to write things down.

This I think causes some disconnect between the medical professional, nursing fraternity and the consumer-cum-patient, because what the patient wants to do is talk these things over, and what all those lovely nurses rushing around with their big files want is to write it down. In governance terms we have imposed on them the need to write everything down, but as people that is not really how we want to be. It is about how to balance the absolute need to make sure things are done properly with the need we have to live properly. It is that sort of balance. God bless you all for — —

Ms HENDY — Trying to get it right. Part of it is also that the workforce that are around older people are diverse as well and come from different cultures and religions, so many of these things are impacting. Certainly the drivers for the system do not necessarily meet what older people need, and the clash of those two things can sometimes feel a bit Pythonesque in terms of, 'You've said on this form that you want your kidneys donated, but didn't say you had to be dead'. That was a Monty Python. It feels a bit that way when you are actually saying, 'I don't want this'. 'Okay, great, you've said you don't want it — you don't get it. Oh, you don't have to be dead'. There is that kind of sense of, 'What am I handing over if I actually do this?'.

The CHAIR — Thank you both for those, again, insightful observations and remarks. If, Ms Hendy, I could take you to a comment you made — and I think this is pretty close to what you said: 'there are assisted deaths going on outside the legal framework' — could you expand on that, because I think that is — —

Ms HENDY — We have experiences of that whether that is in the medical system, helping people along with the extra morphine and that fine line between whether that is an assisted death or not versus circumstances where one of our peer educators — we have older people who work as our presenters, and we call them peer educators — had breast cancer return after some years and did not want to go through the full extent of that death, but could not get assistance, so she took a huge amount of medications and her husband put a plastic bag over her head and a pillow over her head because she did not want to come alive after this medication. He was charged, and I think he got a nine-month good behaviour bond or something. Imagine what his life was like, that that was the only choice they had. So there are examples. Sorry.

Ms FITZHERBERT — That is all right. It is usually my job to get upset at these hearings. You have just done it for me today.

Ms HENDY — Good-o, we can tag. So there are examples where people, because of the lack of choices, are having shocking deaths, and people around them have to go through that experience.

The CHAIR — We did hear evidence to that effect from the coroner in a very factual sort of way. I am not sure if you have seen what the coroner said to us in the last sitting week, two weeks ago.

Ms HENDY — Yes.

Ms WOOD — In our conversations we tend to call it the Pat Mabone effect — if you remember Pat Mabone, who wrote for the *Age*. At a relatively young age he was dying of cancer and obtained Nembutal, or whatever it is; he did not use it but found comfort in having it as an option. That is the evidence that is coming from overseas as well. It is not so much that we all want to rush out and swallow something nasty; it is just knowing that there is a capacity.

At COTA we have not taken a strong and direct position on medically assisted suicide. Our membership is diverse. Although I think if we did a poll there would be very strong support for the view, 'I'd like to have it if I need it'. But what we want to do is open up the conversation. We want to talk about it. Sometimes when the session is around palliative care there is a tendency to think, 'Let's not mention the elephant which is over there in the corner', but we have to talk about medically assisted suicide, or voluntary euthanasia, simply because it is there, and nearly all of us will think about it. I must say I have thought, 'Gee, if I got a diagnosis of dementia, that is when I would think about it. With all the other diseases, no, I do not think so'. We are all doing that sort of debate within ourselves quietly.

What COTA wants to do is have discussions, get it all out on the table, but it is not the primary goal to say, 'Does everybody have a little bottle?'. That is not the goal of any of this. It is to say, 'How will our community grow through having a capacity for its members to die well when the time comes?'. That is the big, interesting question.

Ms HENDY — I think what we are also seeing is that in some circumstances individuals are taking their lives earlier than they need because they do not know that they will be able to do it when they do not have capacity, that they will not be assisted. Our peer educator, for instance, died well early. But we have also seen it in the public domain, where there were two women not that long ago who could not bear the thought of living alone and one had been given a dementia early diagnosis. Both of them suicided together because they did not see any other choice. We know those sorts of things are going on — I have no idea about prevalence — but that is because there is not a sense of, 'There will be something to support us when we need it'.

Ms FITZHERBERT — It seems to me there is a tension, to use a really inadequate word, between the need to protect vulnerable people and the ability to give choice.

Ms HENDY — Indeed.

Ms FITZHERBERT — There is no magic answer to that, but I would appreciate any insight you could give, some practical direction, about how we can better balance those tensions.

Ms WOOD — From where we sit, we see our job particularly in terms of that conversation, because there is reassurance in having the spaces and the places to talk with each other, with our own peer group. We find that in the provision of a conversation area, if you like, a conversation pit, there is reassurance one to the other which is very significant and important. Then with that reassurance there is, 'Okay, I can handle this. Tell me how you handle that'. I think it is really crucial in a sense to have that conversation as a major part of anything about end-of-life issues.

Ms HENDY — We have been running gatherings, 'Dying to Talk', and that is giving the space for conversation and information. One of the things is that in our community, as has already been said, we do not think about this stuff until someone has a situation that brings it front of mind. It is often the conversation that is put aside, and often families will say, 'Oh, Mum, don't talk about that', and so it is not opened up. My mother has been talking about her death for as long as I can remember, and she is still alive, and I am very clear about what she wants and does not want. Whether I can fulfil that is another thing, but she has been a good example about, 'Here's the conversation we need to have'.

We have found that providing that space has been very valuable for hundreds of people because it enables them to get the good oil, like: what are advance care directives, what is power of attorney, what is palliative care? The research suggests that Australia rates very well in its palliative care service but not in the conversations about

it — we are way down on that — so it is about that area of enabling people to open up the conversation. I mean, just having this inquiry is a good start. People are going, ‘What’s all this about?’.

It is about enabling people to come together with both professionals and others to have the conversation in a way that is supportive and real, and then I guess you need to start thinking about how you protect the vulnerable person. Is it powers of attorney, or is it a raft of things, and who are the people who sign off or not? Can I just go, ‘Well, that’s it, I think in 40 years I’m going to have this, so I’m going to do it now’, or is it that at end of life there is a more restricted opportunity to have that discussion? I think what we see from the international work and what we hear from older people is that people do not want to take their life early if they know that at the time they will have the support — that is, even just the medication, the pain relief.

There seems to be this thing, ‘We won’t give them the pain relief because they might get addicted to it’. What, for the next three weeks? If we think about it in the way in which older people are wanting the support, then I think it will actually move it right up to the end of life, not in projecting forward to the end of my life.

Ms WOOD — It means that the conversations that have to be had, have to be had with the medical profession as well, who should not be spooked by this 3rd century AD philosophical principle about the law of double effect. That is scary enough just to say it like that. But what it means, surely, is that in terms of the end of life the medico talks with you, you talk with the medico and say, ‘Okay, if I am having 10 mls of morphine today, what is the effect likely to be, and at what point am I tossing up a couple of extra days of my life vis-a-vis being pain free?’. That conversation ought to be able to be had between you and your doctor and not in fact be a hidden conversation that the medicos and the professionals have together; the consumer has to be very much part of that conversation.

It is about at what stage in medical training there is an introduction of that trust that they ought to have in us as well as us in them. At the moment the assumption is the trust goes one way: I have got to trust my doctor. How about the doctor trusts me? And then that conversation becomes one of, ‘I am willing to trade pain relief for a few extra days or hours, or whatever’, and then that notion of the law of double effect loses some of its spookiness. I do not know if you can put that in any legislation.

Ms FITZHERBERT — Just following on from that, you mentioned earlier that Australia does palliative care particularly well, and we have heard other evidence on that, seen the table and so on. But are you aware of anywhere that does the conversations particularly well?

Ms HENDY — No, but I can find out.

Ms FITZHERBERT — That would be great, thank you.

Ms WOOD — Do you mean in Australia or outside?

Ms FITZHERBERT — Anywhere.

Ms WOOD — The UK has some very good programs now. They are probably well ahead of almost everyone, not that I know so much what is going on in the Netherlands.

Ms HENDY — I would have said the Netherlands probably do it.

Ms WOOD — Yes, the Netherlands probably, but certainly the UK. I think one of the best papers produced recently is the Grattan Institute’s one with Stephen Duckett and somebody else. They mention in that I am pretty sure some of the UK programs. There is one in particular, the Marie Curie, which obviously has a cancer emphasis, but it is very good stuff there.

By the way, can I toss things in? We have this problem in a sense that we will say we want to die at home but most of us will not. I was thinking again coming down — trains are very good for thinking, and I was thinking coming down on the train — that in the UK babies are often born at home, and then they have a higher percentage of people who die at home. We hardly ever get born at home. It is almost as though it is a bigger question of what we do at home rather than just trying at the end of life to try and keep us all at home. Anyway, that is an aside, that is not central. You can think of that.

Ms PATTEN — Great, so we will expand this inquiry to the beginning-of-life choices as well.

Ms HENDY — You did not have enough to do, Fiona.

Ms PATTEN — That will help direct us into the end-of-life choices. I wanted to touch on families behaving badly. I was very sad to hear that daughters are just as bad as sons.

Ms HENDY — Nearly as bad.

Ms PATTEN — I was hoping to blame my brother for most things. With medical guardianship or power of attorney in that alternative decision-making, do you think there is some merit in that being a separate person to the power of attorney that has the financial decision-making? I suppose a lot of people who are concerned about this discussion are saying, yes, families will behave badly if they have the power to do so.

Ms HENDY — Some will. I think part of it is that the choice element needs to be retained. Also not everyone has lots of people to choose from, so that could be problematic. And what of those of us who do not have children? We have to find someone else. We will not all be able to have powers of attorney and/or the best choice. The other thing about longevity is that you go to more funerals than just about anything else if you live long enough, because you outlive everyone you know. But the area of trying to separate is a good idea, but I think also — and this talks to the power of attorney legislation — how are powers of attorney kept account of? Family members can be looking after bank accounts, and others, carers et cetera, are just taking a bit off the top, because they do not do annual accounts et cetera. There are some areas around the power of attorney that might help this end-of-life discussion.

I guess the other thing is that we know that the more someone becomes isolated or alone — not necessarily lonely but alone — the more they become vulnerable potentially, and that is when the predatory behaviour comes in. But also we know that there is system failure for other family members, which makes this whole thing more difficult. Son or daughter might have a mental health issue and a drug issue and have been discharged from hospital because they are okay and they have got a carer to look after them, which happens to be the 85-year-old mother. If that comes unstuck and the younger family member becomes abusive and they have got power of attorney, system failure can be a real problem. If we have got good supports across our community and we have older people engaged in our community, which comes back to our attitudes about older people in our community, then they are less vulnerable.

Ms WOOD — Some family members get into the abuse thing because they actually do not see it as abuse. We have argued through Seniors Rights Victoria for some years of the need for a campaign, an engaging one, which does just name abuse for what it can look like. You can just say, ‘Oh, Mum doesn’t need that anymore’, and it does not sound like abuse. It is just, ‘No, Mum, she doesn’t really need all that’. I think we need a naming more than we have had. There are also of course we have, as we said, diverse communities in Australia with diverse practices about who owns what within a family. That is too complicated for me, but there are lots of differences in how families in different cultures handle who owns what and how it is distributed and organised.

Ms HENDY — I think that the, ‘Mum doesn’t need that anymore’, or an extension of that conversation, is that many of us will be saying, ‘That older person doesn’t need that anymore’, and again that can be the whole health, in its broader sense, system. We had a couple of social workers who wrote a book about older people and what to do with mum when she needs care. Nowhere did it describe having a conversation with mum. You proceed and put her into care. Is that abuse? It is not giving mum any choice, any decision-making. We would see that as an abuse. It is not necessarily described as elder abuse in the formal sense of what the UN defines it as, but it is taking people’s rights away from making choice and decisions about their own life. Whether we call it consumer-directed care or consumer-directed living or whatever, that notion that we have rights as individuals, no matter what our age, and how we are engaged in those conversations is a really important underpinning of that right.

Ms PATTEN — Absolutely. With advance care planning, I think in the Netherlands a directive can actually be null and void if you are diagnosed with dementia. You might have made a decision when you were 70 but at 75 that decision does not count anymore. Do you think there is merit in that?

Ms WOOD — That is a really hard one, because to use what is actually an out-of-date directive maybe, it would depend at how many points does it still relate to that person’s situation. Maybe then you have a clause in an advance care directive which says, ‘If I develop dementia, then this is what I would like’. You can have a

more specific thing. The big killers, if you like, are cancer and heart attacks and dementia, so you could actually have more specific clauses, which would then stand depending on which of those you develop.

Ms PATTEN — Which path you enter.

Ms WOOD — Yes. But dementia is hard, because we do not want to be a society which then decides who is so cognitively impaired they need not live anymore. We cannot do that.

Ms HENDY — Advance care directives can often be, ‘In these circumstances, X’. Whether there are other principles; our values do not shift dramatically in short spaces of time. My mother has said always, ‘No matter what happens to me, I am allergic to oxygen. Do not resuscitate’, because she does not want to be resuscitated. Whether it is cancer or heart attack or dementia, that principle stands. In a sense, are there ways in which we can have our values enshrined in some of those things? But also, because I have dementia it does not mean that my values would be shifting.

I think it is difficult in terms of cognitive change. Dementia is one of the cognitive changes. There are others. If I have a car accident or an alcohol-related injury, then my brain is changing. What does that mean? Some of it we may never know. But who I am still continues through that in some essence I would think. It is a tricky one for you to consider.

The CHAIR — We are just about out of time. Is there anything else you would like to say before we close?

Ms HENDY — No. Thank you for the opportunity.

Ms WOOD — No, that is terrific. Thank you for having it, it is good.

The CHAIR — Thank you very much for your evidence today. As I said at the introduction, the transcript will be with you in the next week or so.

Witnesses withdrew.