

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 21 October 2015

Members

Mr Edward O'Donohue — Chair

Ms Nina Springle — Deputy Chair

Ms Margaret Fitzherbert

Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

Participating Members

Mr Gordon Rich-Phillips

Staff

Secretary: Ms Lilian Topic

Witnesses

Mr Arnold Bates, Chair, Policy Advisory Group, and

Ms Vicki Davidson, Group Member, National Seniors Australia.

The CHAIR — I declare open the Legislative Council’s legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I welcome Mr Arnold Bates and Ms Vicki Davidson from the National Seniors advisory group. Thank you both very much for being with us this evening.

We have allowed half an hour for our session this evening, but before I invite you to make an opening statement 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 received your submission, and thank you very much for the information you provided. As I said, I invite you to make an opening statement, and thereafter the committee will have some questions. Thank you again for being with us.

Mr BATES — Good evening, and thank you for the opportunity. I am Arnold Bates. I chair the Victorian policy advisory group for National Seniors. We are all volunteers; we do not have any staff, if you like, in Victoria on policy. Does anybody need any background on National Seniors?

The CHAIR — I think we are good.

Ms PATTEN — No. Two hundred thousand members — wow!

Mr BATES — We are the largest independent self-funding seniors group in Australia. I will hand you over to Vicki, my colleague who chaired the little group we had working on end-of-life choices. The submission was largely her work, so I will ask Vicki to speak to the submission, and then we will move on.

Ms DAVIDSON — I add my thanks to Arnie’s for the opportunity to present to you this evening. Rather than repeating what is in our submission, I would like to talk about four ideas or principles that underpin the submission and underpin our recommendations. We believe, firstly, that we all have a basic right to control what happens to our own bodies. We believe that government has a responsibility to provide complete legal clarity for individuals, families and health professionals in this area of social policy. Thirdly, we think it important to move forward in a considered and strategic way to ensure that any change that does flow from this inquiry sticks. Fourthly, we think it is the right of the community at large to determine the appropriate framework for dying with dignity. I will elaborate just a little on each of these.

First is the right to control our own bodies. In our submission we are strongly supportive of advance care directives that are binding on family members and health professionals. Such directives would give legal force to the right of individuals to control what does happen to their bodies. Legislation for advance care directives should include the right to refuse food and water, a right we are currently denied. We recognise that there are issues to be managed, such as medication for pain, but good legislation can deal with such matters.

Second is the responsibility of government to provide legal clarity, and there is a real need in this area for families and for health professionals. We all do know that some health professionals and probably some families do take action when patients are close to death. The community wants this support from health professionals — wants it to be available — but the law lags far behind, leaving health professionals and families in limbo. We should not continue to shirk this issue. We are a mature community, and we can do better. We must provide legal clarity, rather than just sweeping the issue under the carpet. National Seniors is certainly very appreciative that this inquiry is taking place.

In our submission we also highlight the need to be clear about what is meant by ‘end of life’. Often it is taken as the last few weeks of a person’s life, when death is imminent, but many people know for years they have a condition that will lead to death. This needs to be recognised in legislation, and services need to be available for people in these circumstances.

Third is moving forward in a considered and strategic way. Our submission does propose a step-by-step approach to avoid the difficulties that occurred in the Northern Territory 20 years ago. We propose as a first step introducing a robust arrangement for advance care directives.

Then we can move on to our fourth underlying principle, that of giving citizens the right to decide. We believe there is a need for a plebiscite. Once legally binding directives are in place, we think a plebiscite about dying with dignity is the right approach. While our preference as set out in our submission is for the Oregon model, which I know has been referred to many times in other submissions, it is not National Seniors, it is not health professionals and it is not lobby groups that should determine Victoria's model; it is the people of Victoria. Citizens should have the right to choose the nature of the legal framework around this very important issue.

They are the four matters that we wanted to raise tonight, so thank you for that opportunity. I am happy to answer questions with Arnie.

The CHAIR — Thank you, Ms Davidson, for that, and Mr Bates. I will ask the first question by putting to you that a plebiscite is different — we have not had that proposed thus far — but isn't that the Parliament outsourcing its decision-making and outsourcing its responsibility in effect?

Mr BATES — You could look at it that way. The difficulty I think for members of Parliament is that there are going to be emotional conflicts. If it is passed down to the individual — the public — those conflicts are taken away.

Ms DAVIDSON — I think also that members of Parliament may be required to vote in accordance with a position taken by their party and may not always have a conscience vote. With all due respect to members of Parliament, they are subject to extensive lobbying by all sides of the debate. I think with a plebiscite, where if opinion polls are any indication you could see 70 to 80 per cent of people supporting a particular framework for choice around death, it would be very difficult for parliamentarians to ignore that very strong message, whereas we have seen in other states how difficult it is to progress some of this legislation.

Ms PATTEN — Following on from the Chair's position, we have received over 1000 submissions, so I would have to say that I think that community consultation has been very successful with this committee. A plebiscite, while I appreciate that it again puts it out in the open, it does not have any legal holding, unlike in Oregon, where it is more a citizen-initiated referendum in the way that they introduced their legislation. Given that your other notion was an exposure draft and given the over 1000 submissions we have received, I wonder if you could just talk more about how you think a plebiscite would tease this out and tease something out that this committee is not teasing out in the way that it is conducted.

Mr BATES — That is down the road. I think first of all we have to get advance directives and living wills in place, respected and acted upon, and that is what we do not have. That is the first step. This follows going through from that. Once we get the community, especially the health, the aged care and the palliative care community used to the idea of a consumer choice then we can perhaps move on to the very difficult subject of medically assisted termination, which is the Oregon model. But I would hate to cloud this first step with that plebiscite.

Let us get this out of the way. It is badly needed. We do not have respect of directives around Australia, they are not nationally respected. We need that legislation, but that is not for here. Victoria needs to catch up, we think. We just had an amendment to the powers of attorney on 1 September, but it still isolates the enduring medical power of attorney. It is still stuck with the Medical Treatment Act 1988, effectively. That is ridiculous in this day and age.

Ms DAVIDSON — We have only looked at some of the submissions, you have obviously looked at 1000 submissions, but it does highlight the extent of interest in the issue, so I am sure this committee would be as well informed as any in Australia on the issues that are involved in this area of social policy. It does seem, in purely scanning the website, that a lot of the submissions have come from the palliative care sector. While palliative care, improvements in palliative care and improvements in funding are obviously important, we would not want that to swamp the importance of the right to choose. If we may ask you a question, is it possible for you to give us a feel at this stage about the balance of the submissions that you have received?

The CHAIR — Probably at this stage we are considering all of the submissions. We have had a broad range of representations, and we will reflect the views of the committee in our ultimate report.

Mrs PEULICH — Thank you very much for your presentation. Obviously community consensus is never going to be complete, but it is very important when dealing with social policy issues where there are very

divided opinions. If you had an informed, full and comprehensive debate — and I believe that there is a lot of confusion about what end-of-life care means, about euthanasia, about various models, so I do not believe there has been informed debate — I do not believe the numbers would be 70 or 80 per cent, but nonetheless I take your point about the merit of a plebiscite. Unfortunately we do not have plebiscites for capital punishment — if we did, it would probably come in as law, which is something I do not support. I think we all advocate mechanisms that we think are going to favour our side.

My question goes to how your organisation, which is obviously very significant and very large, formed its position. Did you take a plebiscite vote of all of your members or has it been formulated in some way? I also noticed a slight difference of opinion between Mr Bates and Ms Davidson on the position of how to advance the case. Are you able to comment on how you actually formulated your position and what consultation occurred with the members?

Mr BATES — There is no difference there. We want to get this first step through first and not focus on later. Our opinion has been formed really through the membership. I think you have already had a session with Dr Rodney Syme. He came to speak to us in Victoria way back in 2007. Based on what we heard, the board agreed in Victoria at the time to just survey the members.

Mrs PEULICH — So you did a survey across all your membership?

Mr BATES — It was a dying with dignity question. I cannot remember exactly how we phrased the question, but not a lot different to the one that was put out in the dying with dignity survey. We had 80 per cent-plus in favour of assisted termination.

Mrs PEULICH — What is the total number of respondents that you had vis-a-vis the number of surveys issued?

Mr BATES — Normally that is very poor. I think on this occasion we got about 25 per cent.

Mrs PEULICH — What is the whole number?

Ms DAVIDSON — That would be 25 per cent of 200 000.

Mr BATES — No, that was in Victoria. Sorry; Vicki was not with us then. That was just over 33 000 members in Victoria.

Mrs PEULICH — So 25 per cent of 33 000. Is there a similar position being taken by other states?

Mr BATES — I am not sure. It is not something that national seniors will advocate nationally. It can be divisive amongst the membership. They leave it to the state-based organisations like ourselves, and I think we have had some success with advance directives in other states — living wills.

Ms SPRINGLE — My question follows on from Mrs Peulich. Who are your members? You have many of them; 200 000 is an impressive membership list by anyone's count, but who are they?

Mr BATES — We are generally an over-50s organisation. The average age of our membership is about 62.

Ms SPRINGLE — They are just individual general public members?

Mr BATES — Yes, the general public.

Ms SPRINGLE — I am also keen to get a clearer picture of what you mean by a staged response.

Ms DAVIDSON — Approach

Ms SPRINGLE — Yes. Because you obviously have quite a clear picture in your mind about how it might work, but it is not quite clear in my mind how it might work.

Mr BATES — If we sit down and talk to the members, the majority will say, 'I don't want to be in a situation of' — to be blunt the word is 'vegetable'. 'I don't want to live like that'. It really flows from there how you address that situation, and we are not sure what the answer is. But now you bring in another aspect which

was never there back in 2007 or 2008 or even last year: the cost of aged care. It now seems that aged-care providers are able to provide palliative care inside the aged-care residency, and the palliative care has produced a model to do it in the home as an addition to home care. Now we are in a situation where the user pays. We have now got members saying, 'I really don't want pay to be kept alive in that situation and diminish our family assets'. That aspect comes into it as well.

Ms DAVIDSON — I think in relation to the staged approach, what we are promoting is that advance care directives are dealt with as the first step. Before our second step would have been a plebiscite, but we think dealing with each of these issues one at a time is a way to ensure that — —

Ms SPRINGLE — As per the list in the submission?

Ms DAVIDSON — No, sorry. I was not implying that. What we are trying to say is that the advance care directives need to be in place before you move onto really considering any assistance with death.

Ms SPRINGLE — Right. Okay.

Mr BATES — We would like to point out an issue that came up in further discussions after we made the submission. This is the activation of living wills. Quite a few people came to us and said, 'Actually, when they are pushed, our sons and daughters or our partners are reluctant to hand over the living will'. They feel like they are giving the health professionals a loaded gun. They feel very emotionally guilty about that, or they feel they are going to be in trouble with their siblings for being the one who did it. Given that emotive aspect of activating a living will, there needs to be a process in place that does not rely on a loved one notifying that there is a living will in place.

Ms SYMES — Thank you for your presentation. I will just come back to advance care planning and directives and your suggestion that there be mandatory compliance. I also note that you talk about community education. We can legislate to make them mandatory, but how do you increase the uptake of them? Do you want it to be mandatory that everyone at a certain age has to have them? When do you want people filling them out?

Mr BATES — No.

Ms DAVIDSON — No, I do not think so.

Mr BATES — Once written, abiding by them is mandatory.

Ms DAVIDSON — Yes.

Ms SYMES — So is your issue more the fact that they exist and they are being ignored as opposed to them not existing?

Mr BATES — Yes.

Ms DAVIDSON — Yes.

Ms SYMES — That is the bigger issue here?

Ms DAVIDSON — Yes. While we have not specifically discussed it, I think we would agree that it ought not be mandatory for everybody to make a directive. It is not mandatory to make a will for your assets, so that would be a matter of personal choice, I think.

Mr BATES — It is a choice.

The CHAIR — Following on from Ms Symes's question, I note that one of your recommendations is that there be a comprehensive education program. Perhaps could you comment on the level of understanding of your members about end-of-life choices and the pathways that exist under the current legislative framework and the current healthcare arrangements.

Ms DAVIDSON — I do not know that we know, really, but we could speculate.

Mr BATES — That is what it would be: speculation

Ms DAVIDSON — We could speculate that it would probably be fairly low, I would think. I can speak personally; I have a 95-year-old mother. Even while trying to manage the issues with her or for myself, I became more informed as a result of being involved in this issue — much more informed. I think generally it would be pretty low.

Mr BATES — That tends to be the way it works. If you are exposed to it through a friend or family member, then you are probably going to react to it and sort something out. If you have your will put together by a legal professional, they will probably ask you, but if you use a do-it-yourself will kit, it is never going to happen.

The CHAIR — That is right.

Ms PATTEN — Your recommendation to define end of life was, I thought, a really interesting recommendation and one we have not heard of. We have talked about the need for greater definition of ‘palliative care’ because some people think that is end-of-life care, where, as you mentioned in your submission, palliative care can be something that can go on for years, if not a decade. Having read your submission, I am still unsure what we need an end-of-life definition for — if it is to get certain care — if you could elaborate a little bit for me?

Ms DAVIDSON — I think it is a little bit like the debate in the commonwealth at the moment on the introduction of new legislation about the purpose of superannuation. In a way, I mean, we all have our own understanding about what superannuation is and what it is for. So I think our suggestion in this regard was just to help everybody be on the same page in the conversation and be on the same page when it comes to the development of legislation or indeed programs and services that might help people at end of life. I think also using language that is quite clear and frank is also really important, rather than language that fudges the issue. They were the reasons; that was behind our thinking in defining end of life.

Ms PATTEN — Just following on from that, we have had various medical professions saying it is incredibly hard to define ‘end of life’ or even to say ‘terminally ill’. What does that mean? Generally doctors can tell you within maybe a few weeks of end of life but certainly cannot say six months or 12 months.

Ms DAVIDSON — No.

Mr BATES — No, I think it is realised where a condition is incurable — dementia, Parkinson’s and so on; you are not going to get better.

Ms DAVIDSON — I do not think we were suggesting a time frame. I think we were — —

Ms PATTEN — Just trying to get a good definition?

Ms DAVIDSON — A good definition, yes.

Ms PATTEN — That is an interesting idea; thank you.

Mrs PEULICH — I have an additional question. As policy advisory committee to the National Seniors Advisory Group, is your position the same as the National Seniors position?

Ms DAVIDSON — Our submission went through the head office of National Seniors, so we did not just make the submission from Victoria; it went there — —

Mrs PEULICH — It is taken as their position, the National Seniors?

Ms DAVIDSON — It is taken as their position.

Mr BATES — It was approved and submitted from the national policy office in Brisbane.

The CHAIR — I would like to ask: given the broad range of your membership and given that you have undertaken this consultation process, are there any other key facts or points you would like to make to us about the views of the membership, because you speak for a large number of people?

Ms DAVIDSON — That is probably you, Arnie; you would be better placed.

Mr BATES — Not really. I think the organisation wants to see uniformity nationally in powers of attorney and living wills, advance directives. That would be a nice starting point.

The CHAIR — Yes, excellent. Any other questions?

Ms PATTEN — Just a quick one. You noted that in advance care planning and directives we lagged behind other countries. For the benefit of our research, are there any countries that you think we should be looking at?

Ms DAVIDSON — I am going to have trouble answering that, I am afraid, Ms Patten.

Ms PATTEN — Maybe go back to your notes or something?

Ms DAVIDSON — Yes, I would be happy to do that and send some further information.

Ms PATTEN — That would be wonderful, thank you.

The CHAIR — Is there anything further you would like to add before we conclude?

Mr BATES — We noticed this week that there is a national conference in Melbourne in November on advance care planning and end-of-life care. Is that linked in any way to what we are doing here?

The CHAIR — No, it is not. We did notice the same thing, actually, but it is a coincidence. I am sure that will be an informative conference, but no, they are independent.

Mr BATES — Right, thank you.

The CHAIR — Thank you both very much for your significant submission and for your preparedness to appear before us tonight.

Mr BATES — Thank you very much.

Ms DAVIDSON — Thank you for the opportunity.

Witnesses withdrew.