

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Subcommittee

### Inquiry into end-of-life choices

Melbourne — 15 October 2015

#### Members

Mr Edward O’Donohue — Chair

Mrs Inga Peulich

Mr Daniel Mulino

Ms Nina Springle

Ms Fiona Patten

#### Staff

Secretary: Ms Lilian Topic

#### Witness

Ms Mary Hocking, Physiotherapist.

**The CHAIR** — I would now like to welcome Ms Mary Hocking. Thank you very much for your attendance today and for being available. Before I invite you to make some remarks, I will just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and is 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. The transcript will ultimately be made public and posted on the committee's website. We have a 15-minute window. Thank you for your submission. I invite you to make some remarks, and thereafter the committee will have questions.

**Ms HOCKING** — Thank you for the opportunity to speak today. I appreciate that a great deal of information and views have already been expressed, and I hope that I may help answer some outstanding questions which may still remain. My views are based on three contexts in which I have end-of-life experience: firstly, clinical; secondly, academic; and thirdly, personal. Firstly, I am a physiotherapist who gravitated to working in palliative care after working in rehab for over 15 years and in aged care as well. I do not need to work in palliative care, but I choose to do so because I believe that it is the best opportunity to improve people's end-of-life experience. However, I do admit that there is room for improvement in terms of providing palliative care — firstly, promoting palliative care to the public, and secondly, promoting early referral to palliative care to avoid, hopefully, all these negative end-of-life experiences which you have heard throughout the hearings. Secondly, as part of a masters of public health, I completed a literature review looking at the outcomes of advance care planning with respect to the quality of end-of-life experience. I went into my search with my white Anglo preconceived notion that advance care planning was common sense and made good sense. After two years of reviewing the literature I was left with a clearer view of the many limitations of advance care planning.

There are three important points that I would like to make regarding advance care planning. The first one — and I cannot stress this enough — is the absolute importance of taking into consideration the demographics of the people. Australia is a heterogeneous population — very multicultural — and the demographics of those engaging or not engaging in advance care planning is vital to the outcomes that are seen with the studies that have been done. A lot of the research is from overseas. The US has studied it extensively — multimillion-dollar studies looking at heterogeneous populations as well as homogeneous populations. The results that are seen are different depending on whether the population is like-minded or not. When the population is not like-minded, one with a conglomeration of many different cultures from all over the world, the results are different, and that is vital. There was one comment earlier in the day expressing surprise at a result that not many people indicated an 'unsure' response, and I would suggest the literature would say that that is because of the demographics of people who volunteered to do this survey. If you survey like-minded people, they will give you that kind of response. I think it is vital not to overlook that point. If the committee is interested, there is a US department of health literature review that looked at the evidence on a broad scale across the country, not just specific states that had more homogeneous populations.

Secondly, the notion or the question of allowing binding advance care plans has come up a number of times in the inquiry. My view is that it is fraught with potential unintentional negative consequences. You need to note that in the multicultural society that we are in, yes, there are those who will choose to limit aggressive treatment, but on the other side of the spectrum there are those people who will advocate for as much treatment as they can possibly receive or negotiate.

I will refer to a poster that outlines the risks of the different poles of people, depending on their view in society, and why it is important that advance care planning is not, and is not meant to be, a legalistic, binding document — or, if it is, the risks associated with that can be quite grave.

Thirdly, I would like to just point out that having an advance care plan does not guarantee quality of end of life. Regardless of what your stated preferences are, whether you have a good death, as it were, is more dependent on the institution that you happen to be referred to or if there are palliative care services available to you in the community and how early those are brought on board. I do not feel that advance care planning is not an important thing, but it is not a guarantee of quality end of life.

The third area or context that I have experience in is in a personal realm: I hold medical power of attorney for my husband, who has early onset dementia, so I know full well the dilemmas faced by substitute decision-makers. The point I wish to make is that my circumstances are probably not unique. My husband and I

did not discuss end-of-life choices in our thirties, when we were raising kids busily. I know the man my husband used to be, and I know he would not want to be the man that he is today; however, he is happy as he is the man he is today, which brings me to another difficulty with advance care plans, which is: whose version do we hold with or think is more valid? And I also caution the committee with regard to the possibility of substitute decision-makers, like myself, making third-party advance care plans for someone who has lost capacity. There is difficulty there.

I know in my circumstance I will be looking towards best medical practice to help guide me in my decision making. I think that is an important thing to consider, because I am of the demographic — I am white and educated — and I understand all of these things, and if I have difficulty making decisions for my husband, I can just imagine what it is like for people that do not have my level of understanding of my role as medical power of attorney, let alone the medical system. I know what is down the road, so if I find it difficult to make a decision, I can understand why — when they have done studies of substitute decision-makers in nursing homes trying to encourage them to make decisions for their loved ones — that is difficult for them. If I have difficulty, and I know what the decisions entail, for somebody who does not have my level of education it would be of even far greater difficulty.

I am happy to field any questions.

**The CHAIR** — Ms Hocking, thank you very much for your submission and the three pillars, I suppose, upon which you draw your views about this very important area. I do not have any questions, but I would just be interested in any of those studies that you referred to in the US about heterogeneous populations and the different views regarding advance care planning that exist in different communities. If you could point us in due course to some of those studies, that would be appreciated.

**Ms HOCKING** — Some of them are in the reference section of my submission — Wilkinson 2007 I believe is the US department of health literature review.

**The CHAIR** — Great; okay. Thank you.

**Ms PATTEN** — Thank you very much for making time for us.

**Ms HOCKING** — That is all right.

**Ms PATTEN** — When we were talking to Associate Professor Corke earlier this morning about his My Values advance care plan, one point he raised was that when they were looking at a patient with a brain tumour and the doctors were asked what they would do, they would do very invasive surgery and treat at all costs. Then once they saw the advance care plan they all agreed that it completely changed what their actions would be, and I was quite struck by that. Is that something that you have found in your literature review — different reactions by doctors or the medical profession to a plan?

**Ms HOCKING** — I can probably speak more from my experience working in palliative care and being the outsider. I am not a doctor, I am allied health, but I am happy to voice my opinion in team meetings and what not. From a clinical side of things, and from the experience in palliative care, I can certainly say when doctors are aware of patients' and families' stated wishes, and they are clear and not conflicting, then it definitely guides their treatment.

However, I work in palliative care; I do not work in oncology, where they are doing the treatment. The medical team is less likely to be instigating treatments — they will not be, other than things like antibiotics, or they may refer on for palliative radiotherapy, those sorts of things — so it is a different mindset working in palliative care.

One of the points I mean to make is that palliative care has had a bad rap, I think. People are afraid of being referred to palliative care. Most people I talk to wonder what a physiotherapist is doing working in palliative care. There is a lot that we do, especially if we can be involved early in community referrals and keeping people at home. I think there is great scope for improving our end-of-life care provision in Victoria by expanding community palliative care and getting people to accept that palliative care is not a death sentence. It is not terminal care; terminal care is a small part of palliative care. Palliative care just means we are making things comfortable, and sometimes that results in prolonging life because people stop worrying about being treated and they get on with doing what they want to do, which is what I love about my job.

**Mr MULINO** — Thanks very much for your evidence. Like the Chair, I would be looking forward to seeing some of the research around the complexities of providing a good advance care planning regime in a multicultural society. I just have one question: I was just wondering if you could flesh out a bit the challenges or the potential downsides of having binding advance care directives.

**Ms HOCKING** — Okay. Probably if you look at the societal views on planning for end-of-life care and then look on the right side of the spectrum, those people who hold strong views about treatment, currently it is my view — seeing the difficulty medical staff have in negotiating withdrawal of inappropriate treatments for those families, and they are mostly families, but some patients, who are insisting on more treatment — it is already difficult for doctors to withdraw and to become more palliative. If you allow people who have these strongly held views to write an advance care planning saying, ‘I would like this treatment continued’, and it is binding, then you are potentially making that situation far worse.

It is already difficult for doctors to stop treatment that is ineffective or no longer required and allocate the resources for treating other people. If doctors are held accountable to binding advance care plans where people have said, ‘We want this dialysis or all my medications or all my treatments kept going’, then I can see that just escalating the difficulty of rationing already limited resources, especially when there would be arguments that the treatment would be futile — that it is no longer serving benefit to the patient. That is the main concern. It is not such a problem when people say, ‘I want to opt out of medical treatment; I want less treatment’, but on the other pole — —

**Mr MULINO** — Right, where there is something very formal that says, ‘Do everything’.

**Ms HOCKING** — If you are going to allow people to say, ‘This is binding. I don’t want treatment’, are you also going to allow them to say, ‘I do want treatment’?

**The CHAIR** — Thank you, Ms Hocking, for your evidence today and your previous answers to our questions. As I said at the outset, a Hansard transcript of your evidence will be with you in a week or so. Thank you very much.

**Witness withdrew.**