

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 16 September 2015

Members

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Ms Nina Springle — Deputy Chair

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Mr Cesar Melhem

Mr Daniel Mulino

Ms Fiona Patten

Mrs Inga Peulich

Ms Jaclyn Symes

Participating Members

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Secretary: Ms Lilian Topic

Witness

Dr Natasha Michael, Director, Palliative Medicine, Cabrini Health.

The CHAIR — I would now like to welcome Dr Natasha Michael, the Director of Palliative Medicine at Cabrini Health. Doctor, thank you very much joining us at this hour of the night. We very much appreciate it.

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 a proof version of the transcript in the next week or so. Transcripts will ultimately be made public and posted on the committee's website.

We have allowed half an hour for our session tonight. I invite you, Doctor, to make some opening remarks, and the committee will have questions.

Dr MICHAEL — Wonderful. Thank you very much, Mr O'Donohue. I am going to try and keep my statement short so that we have a little bit more time for questions and discussion. I am grateful firstly to the committee for the opportunity to present and contribute as a representative of Cabrini Health. Cabrini Health is a Catholic not-for-profit healthcare service. It is unique in Australia in its provision of palliative care by being the first private inpatient palliative care service; it was built in 1999. It is currently the only privately funded community-based service in Australia.

Over the last two years our service has rapidly expanded to effectively provide a service without walls to all of our patients. We integrate acute consult services, inpatient services, community services and more recently an ambulatory service, which is an outpatient service, throughout Cabrini Health. Importantly we do this at no cost to the patient as part of Cabrini's mission. My views represent that of the organisation, as an affiliated member of Catholic Health Australia as well as that of a professional who has worked, trained, researched and taught internationally in palliative care in Europe, Asia and now Australia.

The provision of palliative care is directed to those who are diagnosed with a life-limiting illness, with a major impetus to reduce suffering and to ensure the care of the person in their totality, in conjunction with their family. We are a specialty that arose out of a deep philosophical belief that no man approaching the end of life should suffer, in pain or otherwise. We have demonstrated since the inception of modern palliative care in the 1960s, started off by Dame Cicely Saunders, that through the application of rigorous research, training and scholarship and the judicious use of pain medications and other interventions — that is both pharmacological and non-pharmacological — the ability to improve the quality of end-of-life care for patients and their families through the attention to physical, psychological, psychosocial and existential factors. More recently scientific evidence has demonstrated the improved survival and quality of life of those exposed to palliative care early in their illness trajectory, thus promoting the development of services within acute hospital environments and ambulatory care.

Palliative care has no place for amateurism. We are effectively dealing with the sickest people in society. Australia has demonstrated professional leadership in innovation and quality in palliative care through the development of academic programs in most tertiary universities, national quality assurance programs such as PCOC and NSAP, multi-site international clinical trials through the palliative care clinical trials collaboration led by Professor David Currow, and teaching and training in Victoria, particularly through our leadership in the Victorian Palliative Medicine Training Program at the Centre for Palliative Care, an affiliated body of the University of Melbourne.

As a professional who has worked internationally in this specialty, I am proud to be part of the Australian palliative care community. Nonetheless, there remain considerable deficits in the provision of care across Victoria to those who need it, particularly within the community setting. Many continue to suffer as illness threatens their wellbeing and personal integrity. The misconception of many issues pertaining to specialist palliative care continues to prevail. This includes inadequate information on the use of medications at the end of life; how and where to access specialist care; how to obtain adequate support in the community; how to interpret issues surrounding complex ethical issues and decision-making; and how to understand complex grief, distress, despair and other psychological issues that contribute to suffering.

Advocates for legal reform and legislation for physician-assisted suicide and euthanasia make frequent reference to the experience of poor end-of-life care. Many, though, practice outside of the scope of their training and experience and neither have the knowledge, experience or skill to assist those who suffer. The ongoing

under-resourcing of psychosocial support to patients and family needs urgent attention in palliative care and in end-of-life care. The association between the expression of a desire for death and depression, anxiety and demoralisation is well-documented in international research. However, there remains poor availability of key staff in clinical psychology, liaison psychiatry and social work services in our populations.

Many patients and families simply fear a bad death — that is, death with pain, death alone and death in an institution. These are commonly articulated fears. Early and coherent conversations are necessary. Staff must be trained and skilled in articulating and leading discussions in an empathetic and sensitive manner, and this has been shown to improve health and psychological outcomes.

The recent promotion of advance care planning in Australia is to be commended, but must be accompanied by a mature debate beyond that of simply having discussions on life-limiting treatments. Open discussions on values, wishes, end-of-life contingencies, preparation for place of care and place of death as death approaches add to the richness and substance of how we consider the welfare of those who are approaching the end of their lives. The uptake of advance care planning in Australia is currently less than 20 per cent, and less than 10 per cent in the cancer population. There is limited research in behavioural and societal issues on how we influence uptake, as opposed to the North American setting, where much research is done in this context.

We have a duty as a society to respond to the needs of the most vulnerable and voiceless. The concept of the common good requires that legislation and law reform protects those who are at greatest risk of harm. There is a fine line to be crossed in considering changes to legislation. The risk is to our patients. The risk is to our healthcare workers. The risk is to our communities, and the risk is to our society.

The risk is also to the future generations of Australians. We are now known and respected as a society who has invested greatly in health and care for our citizens, and yet we still have much to do. The next step forwards will define us as a society. I request that the committee consider the greater opportunity that lies before us to continue to provide excellence in healthcare, autonomy to our citizens to access choice through care planning and, most importantly, that we continue to display our humanity in society to those who most need it.

I take this opportunity to invite you to come and visit our service or any service for that matter. I just left work at half past six, and there is a full team of nurses, care attendants and cleaners beavering away and looking after the sickest in our society. It is almost like a paradox that I attend tonight to argue another point of the equation. You are all welcome at any point to visit us at Cabrini Health, Caritas Christi or any of the other palliative care services. Thank you.

The CHAIR — Thank you very much, Doctor, for your presentation and for your invitation to visit your workplace and see what you do. By way of opening, I ask you to comment further on why you think so few Australians have advance care directives or have those discussions.

Dr MICHAEL — It really mirrors what we see in North America. About 15 years ago a seminal study was done in North America called the SUPPORT study, which really demonstrated the concept of advance directives in terms of a didactic writing down of wishes was somewhat flawed. There has been a whole movement of trying to understand why.

Fundamentally, you are looking at a behavioural change process. When you ask people to think of these decisions, you have to think of how we make decisions. Making decisions involves precontemplation, contemplation and a whole variety of steps that occur in a very iterative manner before you can actually actualise a decision. Buying a house is a perfect example. You go to and fro, you look at multiple options before you actually actualise the decision.

Putting a piece of paper in front of somebody around end-of-life contingencies is not as simple as you think. We have done a whole body of research through Peter Mac and Cabrini looking in particular at how cancer patients make decisions, because you would think in this population everybody should have an advance care plan. Yet why are we not doing it?

We are not thinking of what it is like when you are 45 years old, have three children, a mortgage, a wife at home and you have a prognosis of six months. The last thing you want put in front of you is a piece of paper that says, ‘Tell me, do you want to be resuscitated, intubated or ventilated?’. What you are attending hospital for is for somebody to keep you alive for as long as possible to get your family through what they need to get through.

The process of conversations is more important — the process of timing conversations at the right time. We use the term assessing readiness. The most successful North American program is the Gundersen Health System Program in Wisconsin, USA, which talks about the first steps, the middle steps and the last steps. The first steps are that you appoint a substitute decision-maker. The middle steps might be, ‘Let’s talk about values and wishes about what things are important in your life that might direct how you consider care as you continue to get sick’. The last steps might be your end-of-life wishes. If you go in too early, too soon, nobody will sign a document. Many patients have said to me, ‘I am happy to talk about it, but I don’t want to sign it and I don’t want to write it down’.

Mr MULINO — One of the issues that we are considering is advance care planning and potentially the use of advance care directives. I think there is some reference to some of those studies in your submission, but it would be good to get any more references that you think are relevant in order for us to flesh out how that might work in practice.

Dr MICHAEL — Sure.

Mr MULINO — Because obviously if we are to consider something legislative, something practical, the devil is in the detail often. What you want is something that is going to be as consistent as possible with our understanding of behaviour.

Dr MICHAEL — I have just come back from Munich from the international advance care planning conference. It is wonderful to see how Australia and Victoria really have moved very much from a didactic directive approach to the Department of Health listening to a variety of stakeholders, including Northern Health, the Peter Mac/Cabrini cohort, Barwon Health, which has done work that has been somewhat different from the Respecting Patient Choices program

The work of Rebecca Sudore from San Francisco talks particularly about behaviour modification. The Wisconsin’s group program run by Bud Hammes is critical to look at. Work written by Billings, once again from North America, who talks about sometimes the danger of advance care planning and what he describes as the Goldilocks phenomenon — not too much, not too little, not too fast, not too soon. But how do you get it just right? So, assessing readiness before you get people to have these conversations.

Mr MULINO — That is very useful, thanks. I have one other quick question. One of the issues on which we have been hearing evidence on both sides is the extent to which protections that are put in place in relation to euthanasia can be effective and whether or not there is a slippery slope. We have had people make assertions on both sides of that. On the second page of your submission you have got a few references to, in some instances, practices slipping, people falling through protections. Do you have a general observation on that?

Dr MICHAEL — Yes. One of the questions I am always asked is: do patients ask you to kill them? The answer is: yes. I do not use the term ‘request for euthanasia’; I use the term, ‘They express a desire for death’. Many might have heard me use this terminology or expression before.

People say one of three things to me: ‘I want to die’, ‘Let me die’ or ‘Kill me’. The people who are saying ‘I want to die’ are people who are saying: my suffering is so unbearable at this point in time, with my pain, my distress or the burden I am placing on my family, death has to be a better option. The answer to that is not injecting them with a drug or providing barbiturates; the answer to that is saying, ‘How can I help you with these factors that are making you feel that death has to be the better option?’. The ‘Let me die’ are saying, ‘You know what, I have fought this fight. I have run the course. I am 85 — or I am 63 — I have had six lines of chemotherapy. I have had enough. Let me die’. The ‘Kill me’ is from a really, really small minority. Most health professionals are not trained to unpick these things. They lump them together in a singular cohort, so you think of the danger you pose when people come to you and express a desire for death when actually what they are saying is, ‘My suffering is so unbearable that I just want you to help me’. The risk is phenomenal.

I think any of us who watched *Dateline* last night and the use of a drug in a lady who was profoundly grief-stricken from the loss of her daughter — that is complex grief. Issues of grief and despair and demoralisation and depression are very difficult. After 15 or 17 years in this profession, I still have to call on my colleagues to assist me. I draw from psychology and liaison psychiatry, because these patients need very skilled specialists to work with them, either pharmacologically or through the use of psychotherapeutic procedures.

If you have an unskilled practitioner, you do not have the ability to distinguish these complex psychosocial phenomena. The risk is too high, and you have to think of the risk to broader society. I have seen too many people express a desire for death when actually all they are asking for is help. All of us when we are vulnerable want to feel safe. Having and knowing that the drug is there that you can take is feeling safe. There is another option to that: you provide services to people that are accessible so people feel safe.

Ms SPRINGLE — I am curious to hear your response. Some of the testimony that we have heard has talked about the fact that sometimes advance care directives are not actually followed by a whole host of people. They may be medical practitioners and it may be emergency services, and sometimes it may be at the behest of the family. Have you got any ideas around how that could be countered?

Dr MICHAEL — An advance care directive is one component of an advance care plan. If we look in terms of research terminology or even the academic literature, it is described as a complex intervention. A complex intervention is when there are many components that form something so that it is actually difficult to know what is the crucial ingredient that is going to lead to the crux of a positive outcome.

Completing a document is one step of it. People must need to know where the documents are kept, families need to know what they say and health systems must have procedures in place for these documents to be accessible. That is probably one of the greatest areas that we need to work on in terms of systems implementation. It can fall between two stools at many, many, many different levels, so it is not uncommon for patients to arrive in the ED department of the organisation that I work with with no documentation. You get a reflex action at 3 o'clock in the morning, and somebody is put into an ambulance. The following day, following interventions, you discover that they have an advance care plan. Families in a time of crisis never think of mentioning it, patients in a time of illness do not talk about it and hospitals do not have documentation.

The UK system has advance care planning embedded within the Gold Standards Framework, which is a national framework for excellence in end-of-life care. It is an excellent system. You actually get a gold card — a GSF card — in your wallet, which talks about the fact that you have an advance care plan. These are system-level implementations that we have to look at.

Ms PATTEN — Thank you very much for your submission and your information. Having listened to Mr Mackenzie, our previous witness, I am wondering whether there is a time when we can be more proactive — a time when you can manage the pain, but can you manage a 96-year-old man not wanting to be fed, not wanting to be lying in a bed and in a very severe existential condition? Do you think that the kindest thing is to be more proactive in that circumstance?

Dr MICHAEL — I am not here to say that we are the answers to everything, because we are not. I think the humility of being a health professional makes you say that none of us are perfect and none of us have the answers to everything.

I think people underestimate the extent that you have to go to sometimes. You use the term dignity all of the time. What does it inherently mean? Harvey Chochinov, a psychiatrist in Canada, has done extraordinary work in looking at the different domains of an inherent human being that defines dignity — so the care of your physicality, the care of your family, the loss of your privacy as you deteriorate. Many elderly people talk about that feeling so vulnerable, the loss of your autonomy to be able to control different things.

A hospice environment allows for the care of certain aspects of these things. Today we rugged up a lady who was preterminal, and we pushed her bed out to the courtyard so she could feel the sun on her face and feel the warmth on her skin. That takes a tremendous amount of work and effort and commitment from staff who are underresourced and under pressure. Yes, if you leave a patient lying in bed in a nursing home, of course you lose dignity, of course you feel unwanted and unheard.

We have not discussed the issue of continuous deep sedation, which we sometimes offer patients. People always bring in that debate as a proxy to euthanasia, but what they fail to appreciate is the complex ethical issues that you have to consider when you do these things and the guidelines that we adhere to.

Continuous deep sedation is sometimes instituted in people where we feel they have intractable pain that we just cannot manage. You have to be very clear in your mind around the issues of intent. I cannot be somebody else's moral compass; you can only be your own moral compass. As a specialty lead or a consultant, you have to also

ensure that you adhere to guidelines. The European Association for Palliative Care and the Canadian association for palliative care have very clear guidelines. The Australian and New Zealand Society of Palliative Medicine is currently developing guidelines, and we adhere to them to the T when we institute continuous deep sedation.

Ms PATTEN — I have a side question. It is just in response to one of the footnotes that you mentioned. You talked about a man in Oregon — an uninsured man with prostate cancer. In that documentary that was aired in the United States this man was offered in writing access to Nembutal instead of access to further treatment for his prostate cancer. That would never happen in Australia. We have Medicare, and we would continue to provide treatment.

Dr MICHAEL — Correct.

Ms PATTEN — I feel that that is not necessarily an accurate example for Australia.

Dr MICHAEL — Yes, I would agree with that. I think every context is different. It is interesting that Canada has passed legislation and the United Kingdom has not. The gold standard for end-of-life care in the world is the United Kingdom. That is where the hospice and palliative care movement started. If you look at who comes second in the world, it is Australia, followed by Ireland. North America is probably seventh to eighth in the world in the index of quality of end-of-life care provision. Last week, or a few days ago, the end-of-life bill was overturned in the House of Lords in the United Kingdom.

We have an opportunity to lead the way and show an example to society, and I think we should never let go of that opportunity. It would be a tragedy, because making a U-turn back would be extremely difficult, and I think the price we would pay as a society would be tremendous.

Ms FITZHERBERT — I was interested in what you said earlier about the quality framework in the UK helping to basically embed those end-of-life choices issues.

Dr MICHAEL — Yes.

Ms FITZHERBERT — We had discussed something sort of equivalent here, and the question we looked at — and we have not dug into it much yet — is whether we could embed end-of-life planning into the hospital accreditation process.

Dr MICHAEL — Yes.

Ms FITZHERBERT — I would be interested in your views on that. I have a second question as well, if I could sneak it in. You mentioned that in the index of quality of end-of-life care the UK was no. 1. Are you using that as sort of a generic expression, or is there actually something that compares how nations do these things?

Dr MICHAEL — There was a study done by the Economist Intelligence unit and commissioned by the Lien Foundation in 2010. They actually ranked quality of end-of-life care internationally, and Australia came second in the world. It was work commissioned by the Lien Foundation, based in Singapore, and in conjunction with a number of large international bodies.

I think your first point about making sure that quality end-of-life care becomes part of national accreditation is absolutely mandatory. The current Australian Commission on Safety and Quality in Health Care program is — I am trying to think of the term — calling for expressions or commentary on version 2 of the NSQHS Standards that we are all contributing to. Sixty per cent of Australians die in hospital. I always say we cannot have the lack of parity of services — that you get first-class care if you die in an inpatient palliative care unit, second-class care if you die in an acute hospital that happens to have a palliative care team, and third class care if you die in the community. We need to ensure that there is parity in quality of care, and quality standards are an important way of moving that forward.

There is also a huge movement now towards ensuring that rather than just focusing on advance directives we have the conversation about goals of care. So when someone comes into hospital, particularly somebody who has a very serious illness or somebody who is elderly, the question you ask is, ‘What are the goals of care here?’. Are we going to be looking at life prolongation? Are we going to be looking at comfort care only? Are we looking at what we call time trial treatment’, so where we say we might give somebody a course of antibiotics for a week or two, and if there is no improvement we then take a palliative approach to care? That is

particularly important with our ageing population. Our hospitals are full of elderly patients who sometimes get ongoing inappropriate aggressive care and finally death is the outcome.

Sometimes with our interventions we make very little difference to the outcome. We might move by a millimetre forward or a millimetre backward, but what we can really influence is the experience of care between now and the outcome. That is what families remember. They are the ones who are left with the legacy after somebody dies. That is what they remember. They do not remember if I gave somebody three courses of antibiotics. They remember the nurse that comes and turns the patient, wheels them out so that the mother gets the sun or the air on her face. They remember those things. They remember how we care.

The CHAIR — Dr Michael, thank you very much for your evidence and, as I said at the outset, for your preparedness to come before the committee this evening.

Dr MICHAEL — Wonderful. Thank you very much for the opportunity, and once again, you are welcome to come at any point.

The CHAIR — Thank you so much for the invitation.

Witness withdrew.