

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 24 February, 2016

Members

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Dr Anthony Bartone, President, Australian Medical Association Victoria.

The CHAIR — I would now like to welcome Dr Anthony Bartone, the president of the Australian Medical Association Victoria. Thank you very much for being with us this evening. Before I invite you to make some opening remarks, I 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 proof versions of the transcript within the next week, and transcripts will ultimately be made public and posted on the committee's website. We have allowed approximately 45 minutes for our time tonight. Again, we very much appreciate you being available at this time of the day and at the committee's timing. I invite you to make some opening remarks and thereafter we will have questions.

Dr BARTONE — Thank you for the opportunity to speak with you tonight. Issues surrounding end-of-life care can be very emotive and elicit an extremely broad range of opinions from many different sectors of our community. Tonight I am here to speak to you in my capacity as President of AMA Victoria — the peak body representing doctors in Victoria. For a number of years AMA Victoria has been advocating for improvements in legislation and regulation of three key areas: the doctrine of double effect, the non-provision of futile care and legally binding advance care plans. AMA Victoria believes that legislative reform in these areas would provide much-needed certainty, reassurance and confidence to medical practitioners and to patients during very difficult times.

The doctrine of double effect refers to a situation where the administration of treatment or other action intended to relieve symptoms may have a secondary consequence of hastening death. The clinical practice of the non-provision of futile care is where medical practitioners are genuinely not obliged to provide treatments that are considered futile. The doctrine of double effect and the non-provision of futile care are accepted practice amongst the medical profession and are in line with ethics and good medical practice. There is significant uncertainty amongst doctors about the legal situation regarding the doctrine of double effect, with many medical practitioners concerned that they are not adequately protected by the law. It is commonly believed that doctors face legal limitations on their ability to manage pain or suffering when treatment needed to do so may have a secondary effect of hastening death.

This uncertainty exists because the legal principles that apply in such settings are not clearly articulated in legislation. There is no case law in Victoria relating to the doctrine of double effect. This means that medical practitioners who follow current best practice by providing whatever care is needed to alleviate pain and distress cannot be confident that they will be protected from criminal or civil prosecution. Although some believe that common law recognises the doctrine of double effect, this has not been tested in Australia. Other states have enacted versions of the doctrine of double effect, and it is time for Victoria to follow suit and exclude criminal and civil liability in appropriate circumstances. The AMA believes that all patients have the right to receive relief from pain and suffering. Doctors have a duty to act in accordance with good medical practice. This means ensuring that the care of the patient is the doctor's first concern and that they are practising medicine safely and effectively. Good medical practice is patient centred. It involves doctors understanding that each patient is unique, working in partnership with patients and adapting what they do to address the needs and the reasonable expectations of the patient.

The issue of futile care is a very personal one and an individual one. Each patient will have a different view on what treatment they do or do not want to receive. It is incumbent on the doctor to ensure that they are effectively communicating with the patient to ensure that they are aware of the realistic outcomes that could be achieved through any treatment. It is also important that the doctor is aware of the patient's wishes and goals for their care.

For one patient with end-stage cancer, a last dose of chemotherapy that gives them an extra few weeks may be extremely important, because they want to spend as much time with their family as possible or make it to a certain event, like a wedding. For another patient in the same position, the relief of their pain and suffering may be more important to them than an extra few weeks of life. It is about ensuring personal choices and values are respected at all times.

AMA Victoria believes that the principles in section 17 of South Australia's Consent to Medical Treatment and Palliative Care Act 1995 are appropriate and should be enacted in Victoria. The full details of these provisions are available in our submission to this inquiry, but I would like to highlight a couple of key points.

Protection should relate to measures directed at maintaining or improving the comfort of the person who is or would otherwise be in pain and distress, and there should be no civil or criminal liability if these measures are performed in accordance with good medical practice and with the intent of relieving pain and suffering.

Introducing such legislation in Victoria should effectively address doctors' main uncertainties. In providing greater reassurance and confidence to medical practitioners, patients can also be sure that doctors are focused on providing good end-of-life care instead of reacting to the fear of legal consequences. It is clearly desirable that seriously ill patients in terminal stages of their lives are able to have their pain or distress properly managed so they can remain as comfortable as possible for the time they have left.

Unfortunately current uncertainty in the laws relating to the provision of care during this time may mean that patients do not receive the care they wish to have because of doctors' fear of prosecution. This underpins the importance of having an advance care plan or directive that allows doctors, patients and others involved in their care the opportunity to discuss what really matters to the patient and why. I will use terms like 'advance care plan' and 'advance care directive' interchangeably here.

Every person deserves to have a good death. Advance care planning is able to provide a framework or a guide to ensure that a patient has a good death. A good death meets an individual's physical, psychological, social and spiritual needs. It upholds the principle of patient autonomy. It is the right of the patient to make decisions about their medical care with the support and advice of their healthcare provider. Advance care directives are consistent with the principles of patient autonomy and self-determination. They effectively ensure that a patient's wishes for their care can be honoured if a patient loses capacity to express those wishes — care that includes consideration of their values, beliefs, wishes and spiritual needs as well as their physical ones.

Advance care plans are not just a list of treatment decisions; they encompass wishes, values and beliefs of the patient. They should include everything that is important to the patient completing them. Do they want resuscitation? Do they want a religious representative with them at death? Would they like family photos or specific personal belongings with them? What are their goals for care? Is it important to them that they be pain free if it reduces their cognition, or is it more important that they continue to do a crossword every day? An advance care plan should reflect the person's wishes, and to the extent allowed by law it should be followed.

A completed advance care plan that is legally binding will mean that doctors and substitute decision-makers can make decisions in the best interests of the patient. Advance care planning has also been demonstrated to improve patient and family satisfaction with medical care and reduce the risk of stress, anxiety and depression in surviving relatives. Advance care plans should be legally binding in line with the Victorian Law Reform Commission's 2012 recommendations. AMA Victoria has long been calling for amendments to either the Medical Treatment Act 1988 or the Guardianship and Administration Act 1986 to enable enforceability of advance care directives and protection for health professionals who comply with them.

People should be able to make directives about the current and future care they wish to receive and have confidence that these will be complied with in the event that they are no longer able to express them. Amendments to existing legislation or new legislation should allow people to record their choices as to end-of-life care and recognise and clarify the rights and obligations outlined in an advance care plan.

Advance care directives should also enable people to detail their wishes for organ and tissue donation, and these wishes should be binding. Often when someone is approached about their loved one donating organs it is a complex and distressing time, and it can be very difficult to make that decision, particularly where the person who has died has not communicated their wishes. Detailing this in an advance care plan would ensure that the wishes of the patient are followed and would allow their organs and tissue to be used to save and improve the lives of many other people.

Consideration must also be given to the ways to support the advance care planning process. At a federal level an MBS item should be introduced to allow this to take place in general practice, and the state government should be advocating for this. The state needs to increase investment in allowing people to die at home whether this is in their own home or in their residential aged-care facility. Recent figures show that 70 per cent of people want to die at home, yet only 14 per cent do so.

The process of transferring a person to hospital when they are at their end of life is distressing for both the patient and their family. Hospital environments can be chaotic and confusing and are not the most appropriate

places for people to spend their final days if they wish to be at home. Every resident of a residential aged-care facility should be given the opportunity to complete an advance care plan. This would lead to fewer unwanted hospital transfers and a better experience at the end of life for the resident, carers and families. Advance care plans must be accessible. Research on translation of end-of-life wishes to medical treatment decisions has highlighted a need to improve availability of end-of-life preference documents. There is no point completing a plan if no-one is able to access it when it is needed.

The state also needs to invest in improving public education about advance care plans — about what they are and why people should complete one and, most importantly, about the need to discuss your plan and wishes with your family and anyone who might be involved in your care.

To highlight the confusion and complexity of current laws, AMA Victoria and the Department of Health and Human Services commissioned a survey in December 2015 and January 2016 to gain a better understanding of doctors' current knowledge of legislation relating to advance care planning and end-of-life decision-making in Victoria. Some 389 doctors from a broad range of craft groups and geographical areas responded. The survey posed a series of scenarios and asked doctors which treatment path they would follow. Although it would have been more desirable to have a larger number of respondents to the survey, there is no doubt that the results show that doctors find the current laws complex and confusing and that there is a need for clearer legislation and better education and information for doctors. The full survey will be made publicly available in the coming weeks.

The results showed that where decision-making pathways were not clear, such as when there is no refusal-of-treatment certificate or no enduring medical power of attorney appointed, there was generally a low number of respondents who were able to identify the correct treatment pathway from the options provided. In most cases doctors responding to the survey chose the most cautious option. The survey also showed that there was confusion regarding the current role and legal standing of advance care plans or directives. Legislation that clarifies the doctrine of double effect, the non-provision of futile care and advance care plans will mean that a patient can receive the type of care that they would want, regardless of their condition.

The CHAIR — Thank you very much, Doctor, for that detailed submission, which has given us a great deal of material. We do thank you. I want to ask a couple of questions, if I may, around the doctrine of double effect. I think it is often enticing for legislators to codify a common-law doctrine, particularly if it has not been tested — as you say the doctrine of double effect has not been tested here in Victoria. But there is also a myriad of examples of where codification has generated unintended consequences. You cited the South Australian provision that has codified double effect in South Australia. Do you see any risks of unintended consequences from codifying the doctrine of double effect, adopting the South Australian model?

Dr BARTONE — As long as the principles of good medical practice are followed, and that I think is clearly spelt out in the South Australian legislation, I do not see any issues with following that kind of legislation. The principles are very clear and talk about the principles that we value — it is about communication; it is about understanding the wishes and desires and being clear in the expectations, likely or not likely, through treatment. So I think that really if we follow those principles of good medical practice, and remembering they are at the heart of what our regulators suggest as a code of conduct for us, there cannot be a situation where there would be unintended consequences.

The CHAIR — As a follow-up to that, do you see that those guidelines of good clinical practice and the basis upon which decisions are made by doctors, if double effect was codified, provide sufficient flexibility for doctors to respond to the individual cases that you described — the patient who is living for a birthday or an anniversary or others who have different motivations? Does that framework you are advocating for provide sufficient flexibility to deal with those individual cases?

Dr BARTONE — So remembering that we are calling for comprehensive advance care planning, which goes into understanding the values and the wishes of the patient, having a relationship and being very clear in communication, following those principles of good medical practice, I think that that would really ensure — and especially the conversation that goes in terms of ensuring the wishes are communicated to family members and other loved ones during the process of formulating the advance care plan would end up creating a situation where patients, families, relatives and doctors can all have confidence that the patient will be regarded, and well regarded, and respected for their wishes in those final days.

The CHAIR — We have heard evidence from doctors who have cited legal uncertainty as a cause for concern for them. Do you know of any AMA members that have been prosecuted either under a codified regime or under a common-law regime around Australia? I am wondering is this fear or concern, while legitimate no doubt, based on prosecutions that have taken place or more uncertainty or perceived uncertainty?

Dr BARTONE — I am not currently aware of any doctors that have had to submit to prosecution under those situations, but the uncertainty and the lack of clarity around the lack of legislation exists. While there have been opinions offered by various legal minds, it still leaves that potential for risk and uncertainty. While that uncertainty exists, it must form a potential barrier to providing the best quality of care.

The CHAIR — The final question from me: do you think is there a relationship between the provision of futile care that you have made comments about and this uncertainty? In other words, do you think that clarification or codification of the doctrine of double effect would help address futile care that currently may be provided?

Dr BARTONE — Perhaps there might be an interrelationship between the two, but I think the two can stand independently of one another and still need to be looked at entirely on their own, because the situations that one might envisage applying in one scenario may not really fall clearly or solely under the doctrine of double effect, so both need to be addressed in terms of legal certainty going forward.

Mr MULINO — I have a couple of questions in relation to the recommendation that there be codification of the protection of medical professionals in the non-provision of futile or burdensome treatment. Does the AMA believe that doctors are currently providing such treatment because of a fear of uncertainty or prosecution.

Dr BARTONE — What we can say is that that obviously becomes an issue that needs to be addressed and, hopefully, through discussions, information and communication between patients and the substitute decision-makers has not arisen as a particular issue, but it always remains a concern.

Mr MULINO — Similar to the question that Mr O'Donohue asked in relation to double effect, I am just interested in whether you are aware of any actual prosecutions in this area in other jurisdictions in Australia.

Dr BARTONE — I am not aware of any other prosecutions, but I am aware that the only legislation that we have referred to is the South Australian. The only other state that has anything closely approximating it is Queensland.

Mr MULINO — Just a final question, which is on a totally different topic and is a broad-ranging question is: the previous evidence related in part to the need for more training, for more skills across health professionals generally in relation to palliative care. I am just wondering what your thoughts are on the need for or benefits of some kind of mandating of palliative care skills in undergraduate or postgraduate tertiary courses and/or continuing professional development.

Dr BARTONE — I am not sure about the need for mandating, but what I can say is that all courses already take into account issues such as good medical practice, and that is clearly a foundation stone around which the courses are formulated. In terms of mandating those principles of delivery of care really go to the foundation of all the other standards and training modules that go in there, so already it is there. It is about, though, how ongoing, how comfortable and confident you feel and how complex any framework that you have to work within is. So from that point of view, any training or any information or education that can assist to navigate through the current framework is obviously a good thing, and, furthermore, anything that reduces that complexity is also a good thing.

But going forward I do not see the need to mandate that because the principles that underpin that are key to good medical practice and the provision of good quality care. It is about everything we hold dear and in terms of a doctor-patient relationship. To mandate that you need water and bread to live on is losing sight of the argument or the issue, and that is that we need to communicate with patients, we need to have an understanding of each other's goals, desires and expectations and we need to be able to explain it and communicate what our treatments are. And that is fundamental to everything we do.

Ms PATTEN — Thank you, Doctor. With advance care planning, obviously it is something that has been discussed greatly, and I appreciate organ donation being included in that. I had not actually heard that before.

One of the questions that we have had raised is: when does someone do an advance care plan, and if they do one, as many of us had a go at doing one a few months ago, do you need to renew it? I must say that what I say now is probably quite different to what I might say in 25 years time. In that system of mandating advance care planning, would you have a time frame in it?

Dr BARTONE — A couple of things to say on that. There probably are many times or many opportunities to initiate or prepare one or to review and refresh. Significant life events become an opportunity to discuss that; significant diagnoses become an opportunity to discuss that; the attainment of certain milestones in age or the milestones that occur in general practice — in terms of an over-75 check, a health assessment which begins at 75, or a general practitioner management plan — these are all opportunities to initiate or have the discussion around when to have an advance care directive.

Secondly, because there are multiple opportunities to have that conversation, together with the department we have developed a series of resources to begin to assist doctors in understanding the opportunities and how to initiate that discussion about: ‘Have you got an advance care plan? Have you thought about an advance plan? What are the things that you should put into an advance care plan?’, and begin that conversation. If you have got an ongoing relationship with your GP, it is a conversation that will become refreshed and ticked.

As we know, there is a shared electronic health record being developed, and one of the key components of that is, ‘Tick the box if you have got an advance care plan’. We have mentioned that everyone going into a residential aged care facility should have an advance care plan. You can probably draw up a very long list of when you should be thinking about it and when you should be thinking about changing it. Obviously we could spend a long time discussing it, but we have put out some resources which clearly go to explaining the ‘how’, the ‘if’ and the ‘when’, which we were able to launch at our advance care planning day with the department in November last year.

Ms PATTEN — It has certainly been raised with us that people have an advance care plan that they may have considered with their doctor 10 years ago but treatments may have changed in that time.

Dr BARTONE — Absolutely.

Ms PATTEN — That is right. So a decade later that person is in a circumstance where their advance care plan says, ‘Refuse all treatment. Do not resuscitate’. And, of course, we want to enter into an advance care plan with the confidence that it is going to be agreed to. Are there times when you, as a doctor, would say, ‘I would like to not agree to the advance care plan’?

Dr BARTONE — If an advance care plan is properly structured and really gives information and clarity about the wishes, the values and the beliefs of the patient and how they want their care to be — some of those principles are instructive regardless of any change of condition or any change of treatment. But you are right, medical treatments do change, and they are changing at a rapid speed at the moment. So that is the reason behind renewing certain elements of the advance care plan, but I think the foundations, the building blocks, essentially do not change, save for a patient undergoing a significant change in experience or change in beliefs, in which case that needs to be refreshed. But is there a mandatory longevity to an advance care plan? That is being debated and worked through currently by many different people in many different circles, but I think the principles, the foundation, underpin the quality of the plan and the instructiveness of the plan.

Ms SYMES — I just want to get an understanding of the doctrine of double effect, if it were to apply in practice. In your submission you talked about the delegated care. Is this a situation where a doctor would prescribe something and then it is actually administered by a nurse, for instance?

Dr BARTONE — A possible scenario would be exactly that, where the ongoing treatment required to maintain effective pain and suffering management needs to be given over a prescribed period of time regularly to maintain that care, and yes, it would be prescribed by the doctor, obviously, but the actual administration may occur by a secondary person. Is that what you are referring to?

Ms SYMES — Yes. So in terms of the current concern about doctors who are worried about or who have argued that it is hastening death, is it a situation where doctors may be reluctant to prescribe it because somebody else, another medical colleague, may say, ‘Well, I’m not comfortable on that level. I think that’s going to hasten death’. Is that another complication?

Dr BARTONE — Well, that potentially is another complexity or another issue, but at the end of the day it is about ensuring that the doctor has clarity and the certainty that he or she is performing the best possible care on behalf of his or her patient and ensuring that they are getting the quality of care and the respectful treatment that they deserve.

Ms SYMES — Right. Because there must be an existing doctor-patient relationship, are there any issues with that in terms of country patients coming down to the city or things like that? Would that be a problem in some cases?

Dr BARTONE — In that handover from country to city there is a handing over of care, and in that someone would take over the care. That person, he or she, would then take over the care and develop, as best as possible in that short period of time, an equal understanding and a relationship with the patient. So, yes, we do have our preferred go-to doctor that we respect and trust and seek an opinion from regardless of the situation, but he or she, in handing over that delegation, confers a certain amount of trust to that next person — it immediately improves their relationship with someone they may not have met before — and that carries that sort of additional trust and understanding that really underpins that relationship.

The CHAIR — I just want to ask, Doctor, about continuous palliative sedation. We have heard evidence from Peninsula Health and from others that continuous palliative sedation is applied and practised in Victoria. We are also aware that there are guidelines in Europe about the application of continuous palliative sedation. Are there any guidelines in Victoria, or is that an area that needs, perhaps, greater clarity?

Dr BARTONE — Look, I am not across that, but I am happy to provide the information back to the inquiry at a subsequent date.

The CHAIR — Thank you. That would be great.

Ms PATTEN — I just have one last question. I thought I had seen online that the AMA was revisiting its position on physician-assisted dying and that it had sought the views of its members. Is that correct?

Dr BARTONE — AMA federally is currently undergoing a review of all its policies, so that may be what you are referring to. But my presentation here tonight is clearly about advance care planning, the doctrine of double effect and the non-provision of futile care.

The CHAIR — Doctor, I just want to ask a question about refusal of treatment certificates and their ability to include future conditions, similar to the line of questioning from Ms Patten about advance care directives. Does the AMA support legislation to extend refusal of treatment certificates to include future conditions?

Dr BARTONE — What we are very clear about is that any future conditions are about future care, so it is about understanding the kind of care you want delivered. How can I best say this? A stroke — depending on the circumstances, depending on the timing, where you are in that process in terms of being close to a hospital or not, the time interval — there are so many things that could influence that, so I do not think it is really instructive to talk about conditions. But it is talking about outcomes and talking about the care that you would expect should there be a series of situations — so if it became clear that I would not be able to speak again or if I could not independently feed myself. It is about a better understanding of future conditions, rather than saying, ‘If I have a heart attack or if I have a stroke in the future, I don’t want’ — so it is about future situations involving the care, involving the outcomes, involving the type of situation that the patient would find themselves in and making the appropriate decisions.

Mr MULINO — I was interested in your discussion around all the possible triggers for starting a discussion around an advance care directive. We have had evidence from a number of bodies around which triggers might work best and some evidence of triggers that are used overseas. We know that in some instances there is a lot of behavioural inertia. For example, you might say that when somebody turns 70 and they go to their GP the next time, that is a good time to start it, but there are possibly reasons why the patient and/or the doctor might find that hard in practice in many instances. I am interested in your views on what triggers you think work best? What are the things that could be prioritised if anything was to be included in a regulatory framework?

Dr BARTONE — I think the triggers are a secondary issue here. I think that in an ongoing good relationship with a family doctor there would be multiple triggers, multiple episodes and that will become such an issue.

However, if we are looking for specific triggers, there is any admission into hospital, the change in life circumstances — so the birth of a child in a relationship, or a divorce or a break-up of a family relationship. I am not saying concurrently of course because there is a lot going on at some of those times, but they are the trigger points whereby you might think of having that conversation. But as a treating doctor, there are many reasons why I would ask Mrs Jones or Mr Phillips, ‘Have you thought about an advance care plan? If not, why not? Have you thought about renewing it? This has happened. Your medical situation has changed. You do realise that this has happened? Is there anything? You have got grandchildren now. Unfortunately you have lost your partner in life’. There are many reasons which would prompt that conversation in the consulting room.

Mr MULINO — I guess what I am really getting at is you can think of a lot of possible triggers. For example, you might say that some of them could become part of best practice. So you might say, ‘For all GPs we recommend that you consider this discussion at a certain point in time’. Do you think any triggers should be mandatory? Like you said, hospital admission might be one and admission to a nursing home might be one.

Dr BARTONE — Yes, and another trigger may be a health assessment that is routinely done from the age of 75 onwards. That is a government initiative that we take part in for general practice. And every time we renew a GP management plan, which is another initiative around chronic and complex disease management in family care.

Mr MULINO — Thanks.

The CHAIR — Doctor, I have just one final question, and it is in relation to the provision of non-futile care. It is a similar question to what I asked before. Noting the AMA’s call for legislative clarity, can you foresee any unintended consequences or any advice to us about how to mitigate unintended consequences when looking potentially to codify that common-law doctrine that currently exists?

Dr BARTONE — I do not think I can add any advice further to what I have already said: that is, as long as we follow accepted good medical practice, which underpins the code of conduct which influences our regulatory bodies in administering the standard of provision of health care in Australia, as long as we follow those principles and we are clear and concise in communicating our treatment plan and understanding and giving the patient the opportunity to voice and demonstrate their concerns or their input — and that is best done through an advance care plan, because it really does become quite instructive and becomes very broad when properly prepared — I think there will not be that situation. There are lots of regulations which will ensure that we cannot stray into unwanted territory to guard against any rogue element, if that is what you are — —

The CHAIR — No. That is not what I was getting at.

Dr BARTONE — No, but anyway — OK.

The CHAIR — Doctor, we sincerely appreciate your evidence tonight and your preparedness to respond to our questions and for being here at this time of the evening. Thank you very much.

Dr BARTONE — Thank you.

Witness withdrew.