

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Shepparton — 13 August 2015

#### Members

Mr Edward O'Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Mrs Inga Peulich

Mr Cesar Melhem

Ms Jaclyn Symes

#### Participating Members

Mr Gordon Rich-Phillips

#### Staff

Secretary: Ms Lilian Topic

Research assistants: Ms Annemarie Burt and Ms Kim Martinow

#### Witnesses

Dr Arup Bhattacharya, Divisional Clinical Director, Medical, Goulburn Valley Health; and

Ms Annette Cudmore, Clinical Nurse Consultant, West Hume Palliative Care Consultancy Service.

**The CHAIR** — I now ask Dr Arup Bhattacharya to join us at the table. We understand that you have taken time off your rounds, so if that is convenient for you we would be pleased to hear what your thoughts are on this issue. Before we do, I will give you the standard 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 you make 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. Transcripts will ultimately be made public. I understand that you are the divisional clinical director in the medical department at Goulburn Valley Health.

**Dr BHATTACHARYA** — I am.

**The CHAIR** — Thank you very much for joining us today. Thank you for being here. We look forward to what you have got to say.

**Dr BHATTACHARYA** — Thank you for inviting me, ladies and gentlemen, today. I am a specialist physician and geriatrician by trade and my special interest is in neurodegenerative disorders, particularly Parkinson's disease and Alzheimer's disease. I am very passionate about this topic and I thank you for giving me the chance to articulate some of my thoughts. For me, I think there are two aspects to this. One is the more philosophical aspect and the other is the operational aspect. You could see from Annette Cudmore's submission that she is an operational person and she has beautifully outlined what the constraints of good palliative care are in a regional setting, but I wanted to touch on the more philosophical aspect.

Palliative care by definition should be consensual. Consensual means between the patient and the treating team and the family. I just wanted you to think about the current setting and how much of this consensual thing is going on. Palliative care, since Cicely Saunders advocated it, has made great strides and it is one of the fastest growing specialties. A few weeks back I was listening to the *Q&A* program, and there was an oncologist there who said that in the next 50 years the future of medicine will be good communication and setting expectations. For that, I think the best thing we can do is to try to find out what our patients want for themselves, when they are unwell and what they are trying to tell us through their relatives.

Palliative care is extremely good at managing physical symptoms — and there is a wealth of literature out there on its effectiveness— However, there are issues for the dying patient in their terminal care beyond physical symptoms, beyond mental and spiritual symptoms, which really no discipline can adequately address. We should not be saying that we will adequately address every single symptom or every single problem that a patient is going through. It needs to be made clear and transparent to the community at large that palliative care is a very good specialty. It has really provided the best care that we have currently for the terminal patient and towards the terminal stages, but it also has got its limitations and that it does not address every single symptom or every single problem that a terminal or a dying patient has or might have. I think our community will thank us for that transparency when we offer palliative care.

Having said that, palliative care is not just terminal care, as Annette has said. Palliative care is good care of symptoms, and it comes from empathy. I think empathy should be at the heart of all that, and it is good clinical care. When you walk into a patient's room and meet a patient, if you are actually happy to see the patient as an individual and you treasure the limited time and interaction that you have with the patient.

We do ward rounds maybe two or three times a week. Yesterday I had a patient who is now so depressed he just wants to wither away and die, and he is not eating. He has not talked much for that one week that he has been here. He has not talked to any of the staff. I saw him one week later after having a life-changing surgery in Melbourne, and he made a joke with me because he could see that I was genuinely happy to see him. Maybe I could not help much with his physical symptoms, but the empathy, the genuine caring, is what our patients want from us, not just technological advances, but empathy – our eyes lighting up, our smile, our touch etc.

I am an examiner of the Royal College of Physicians, so I examine doctors who become fellows of the Royal College. I think in medical school and even higher medical training we talk a lot about communication but there is less of a focus on empathy. I know that perhaps cannot be taught, but I feel can be imbibed by repeated practice. I think if you show many cases of good clinical skills where empathy plays a leading part and if there is positive mentoring, our future doctors and clinicians will treat our patients with more empathy. I think there is a need to include this both in the undergraduate and postgraduate medical curricula.

I think the end-of-life choices and the palliative care has to have a much broader remit now. I have not had too much time to prepare a submission, but I understand that you are all aware that it is much broader than the hospitals and much broader than the health service. There has to be a political push to be at the forefront of the government's agenda, for the community to be actively involved in advance care planning. Unless we fully embrace advance care planning we will always fall short of good and effective palliative care because we will not know what our patients have wanted. Whether they want spiritual support or not is our assumption, and that is where the word 'consensual' breaks down, because we assume their needs at a time when they might not be able to communicate their needs. In many cases, particularly in a multicultural setting and when you take other factors (religious or otherwise) into account, these assumptions may not always be true.

I think advance care planning, to give it a real thrust across the community and to make it a way of life among our patients — not only patients but among the community — is something I would really support wholeheartedly. Palliative care is doing great work. As you know, there are several facets of palliative care. Pain management and physical symptom management are doing well, but I am also mindful that beyond these physical factors there are so many other requirements for the terminal patient. Regional palliative care services are under-resourced to deliver that. We do not have enough psychologists. We do not have enough chaplaincy services. All these are different components of palliative care. The evidence for all these is limited, and interesting research is going on. I think palliative care cannot exist the way it is solely as a separate discipline; its principles have to be interwoven into the care of many chronic conditions.

There are good palliative care principles that span across the breadth of all medical disciplines. My vision is that palliative care will continue as a specialty, but principles of palliative care will remain a fabric in all other specialties of medicine, and it will be part of good clinical care with empathy and consensus — these two words — at the front and centre of all palliative care that I see.

**The CHAIR** — Thank you very much, Doctor, for that really insightful contribution. If you are both happy, we might put questions to either or both of you.

**Dr BHATTACHARYA** — Sure.

**Mrs PEULICH** — Only to clarify, taking on Annette's comments, I noted a New Zealand accent; is that right?

**Ms CUDMORE** — Yes.

**Mrs PEULICH** — An old English teacher — we pick these things up. You are saying that an advance care plan should be sitting outside end-of-life choices, that it should be something that every person contemplates with their doctor or their treating physician about how they wish to be treated should particular things occur in their lives.

**Ms CUDMORE** — And into the future.

**Mrs PEULICH** — Then, under that, you have end-of-life choices, of which palliative care is one subset; am I getting this right? Just to clarify, palliative care is only available to terminally ill patients.

**Dr BHATTACHARYA** — No, it is not. Palliative care principles, so I want to make a distinction.

**Mrs PEULICH** — Yes.

**Dr BHATTACHARYA** — I want to make a distinction. Principles of good palliative care is all symptom control or control of whatever is required for the patient. That spans across all stages of disease. If somebody after a heart attack has problems with chest pain or other symptoms, then palliative care principles can be woven into that. So it is not just terminal care; it is across the disease spectrum.

**Mrs PEULICH** — I am still wrestling with this because the common understanding by the average person on the street is that palliative care is predominantly for terminally ill patients. My father went through it. That was my summation. So with palliative care principles you are talking about the care of the whole person. Does that need a different term, a different concept, because I think the concept of palliative care is so deeply connected to the notion that it is actually the treatment of terminally ill patients that I am not sure that we can be successful in making that distinction?

**Ms CUDMORE** — I think the language in palliative care has changed. There are different terminologies. We talk about life-limiting illness, we talk about terminal illness and, as Carolyn was alluding to, there is probably a lack of consistency around some of that language. Historically with palliative care, if you go back 10 to 15 years, we actually had a time frame on how long people were allowed to live for. It was actually three months: if they were going to die within three months, they could access palliative care. We have moved forward from that a huge amount.

**Mrs PEULICH** — In which way?

**Ms CUDMORE** — I think because we have recognised that life-limiting illness can be many different things. For someone who has a life-limiting illness it means that their illness is going to shorten their life. We have stepped out of just that cancer scope into, as Arup is alluding to, other illness trajectories — things like our chronic diseases, our chronic motor neurone diseases and things like that.

Palliative care is not just around symptom management; it is around the person and their needs and their wishes across all of the domains. There are five domains that we work with, but there may be other domains, depending on the individual that we are working with. Articulating palliative care is just around good pain and symptom management. Palliative care is around looking after the person as a whole and their family, their carers and even their dog for whatever time they want.

**Mrs PEULICH** — I am going to ask a really tough question.

**The CHAIR** — I am sorry. We might just come back to that.

**Dr BHATTACHARYA** — If I could just make one observation on that.

**Mrs PEULICH** — I think this is a critical issue.

**Dr BHATTACHARYA** — About 100 years back we used to have infectious diseases and a quick and painless death. Now we have people with heart failure who are breathless for two decades. They should be receiving palliative care over those two decades. These are principles of palliative care. I understand that the man on the street, the community, understands palliative care as terminal care, but what I am advocating is that through community consultation, through more effective medical training, in a way we change that concept or we change that thinking and understanding in the community that it is not just terminal care.

**Ms PATTEN** — Thank you Doctor and Ms Cudmore. I really love the notion of consensus and empathy and covering that through all areas of medicine, and as we have become so clever, understanding the limitations of it as well is very important. Ms Cudmore, just taking you up on your comments about the submissions we have received, and you are absolutely right — so many of them, in fact the vast majority of them, have looked at physician-assisted dying or voluntary euthanasia. From what I am reading and from what we are hearing it is about actually the fear of the limitations of palliative care. That certainly is their fear.

With that in mind, do you see physician-assisted dying as part of an empathetic treatment? With someone with Parkinson's or with motor neurone disease, if their quality of life is at the point where they do not feel they are getting quality of life I think that is where the limitation of palliative care goes. We can get rid of their pain. We can deal with some of their symptoms. Do you feel that that is — —

**Ms CUDMORE** — You are trying to get the medical answer there.

**Dr BHATTACHARYA** — In my mind I have not reached that stage yet in which I can answer that question, predominantly because we have not thrown open the doors of the limitations of palliative care, because if you ask the average person on the street, or anybody, palliative care can take control or cure all your symptoms and can give you a very good, symptom-free dignified death. We need to be open and transparent and see what the community wants. When that limitation becomes transparent that not every person who has had excellent palliative care has died peacefully; it cannot be because of some of the symptoms — this transparency is not out there in the community.

Once it is out there, I think then the community will tell us what they want really, whether the physician-assisted suicide should be thrown into the mix of good palliative care principles. It might be, but in my mind I do not

think we are quite ready yet, because I do not think there has been that open discussion regarding the limitations of palliative care for them to make a judgement on this. Does that sound — —

**Ms PATTEN** — Yes it does. Thank you, Doctor.

**Ms CUDMORE** — Going back to what Arup has alluded to around empathy and connection and understanding, palliative care we are very aware that it does not solve everyone's problems. It is around connecting with people, empathising with people, understanding where they are at in their life and in their illness and supporting them through that. I have worked with numerous patients who have wanted to euthanase themselves and end it, and it is around not being afraid to have that conversation. So many times we go, 'No, that is illegal. No, we can't do that. Why do you want that? Have you got a plan? Tell me about it. Tell me more. Let us have a conversation around it'. I do not think there are many practitioners outside of palliative care who are comfortable with having those conversations.

**Ms FITZHERBERT** — Ms Cudmore, I was interested in what you said before about how a couple of years ago most people were dying in hospital but now most, if I recall correctly, are dying in their own homes, and I was interested in understanding how that change has happened. Also, what is the demographic that we are talking about? What sort of people are you looking after — their ages, their backgrounds and so on?

**Ms CUDMORE** — Okay. It is a little bit tricky for me to articulate that across three regions, but I might just break it up a little bit. The Goulburn Valley region, because of the model care with its community palliative care service, has always had one of the highest rates of home deaths in Victoria but also nationally, and historically that is around being able to provide a seven-day-a-week service with people they know, with experienced clinicians who have developed a relationship with both the patient and the family, and therefore there is that trust and that confidence, and also they are knowledgeable and have that level of expertise.

If you break that down into our other shires, Moira and Lower Hume, they are staffed basically by one palliative care nurse a day, and the district nurses or the general nurses do a lot of the care. They do not have access to after-hours support, and that is one of the biggest things that is happening more and more regionally. We used sometimes to have the capacity for the district nurses to go on call, but because of staffing levels often they will be working the next day, and if they get called out during the night, it is just not effective. At the moment the only access for after-hours support in the Moira and Lower Hume shires is the after-hours Caritas Christi number for phone support. If you have a loved one, who has developed whatever level of distressing symptoms — whether that be physical, psychological, social, spiritual or cultural — at 2 o'clock in the morning and you are struggling as a family to manage that, the only place you can go is hospital. That is the reality of it.

We need to be able to strengthen our capacity to care for people. People do not get sick Monday to Friday. People get sick seven-days-a-week, and things are harder and worse at 2 o'clock in the morning than at lunchtime on a Wednesday when you have got access to support. If we are going to support home deaths, we need to be real about how we are going to do that and how we are going to support people.

**Ms SPRINGLE** — I would just like to give you some feedback that we have heard in some of our other hearings in other regions about your palliative care program and how amazing it is and how it is held up as a model of best practice. I would like to congratulate you on that.

I would like to draw you back to the comments you made, Annette, just a moment ago about these conversations that physicians or healthcare professionals tend to shy away from — the fearlessness that would be involved in having conversations around voluntary euthanasia — and the fact that it does not happen when maybe it should be happening. Is that due to the legality of it or are there other reasons why healthcare professionals do not have those conversations with patients who may express a desire to utilise that as an option?

**Ms CUDMORE** — I think it is probably two-dimensional. I am sure if we looked at that in the medical domain they would certainly be very mindful of the legal implications of that, and even in the nursing domain, we are very mindful of the way we look at the use of our opioids and things like that — that we are actually treating symptoms and giving appropriate doses for appropriate symptoms, so there is that concern. But I think the other area is that we need to be comfortable with our own mortality, and we need to be comfortable with supporting people to discuss their mortality. In my experience, a lot of people are not comfortable with their

own mortality, and therefore they struggle to have real and honest conversations about dying, how they are going to die, who is going to help them, and all that kind of thing.

**Mr MELHEM** — I have a question for both of you. What I take from what you are saying is that the focus should be more on education — educating the general public and clinicians — and training for clinicians, for example, about current options and advance care plans, versus looking at changing the current law. Is that what I should get from your presentation? Is that where the focus should be?

**Dr BHATTACHARYA** — As I said, on the two basic pillars on which I made my submission, one of the points was consensus. Under the current law any discussion, as Annette was referring to, takes the patient's choice a little bit off the table. If the patient knows that the suffering is immense and that while palliative care will control symptoms and, as I mentioned, other aspects to some extent, there may still be suffering and prolongation of the inevitable — of the remorseless progress of the disease — then the patient, despite your explanations and despite your assurances, might choose otherwise. When we have this discussion, it is a little bit difficult, because there is no consensus — because you know that in the end the law does not support that patient's choice.

The other limitation, I find, with advance care planning is that people can only make a refusal of treatment. At this point in time, the refusal of treatment document is the best that the patient or a person can actually complete that has got legal standing. While that relates to a current condition, or existing condition, it does not really give too much leeway or a free hand for the patient to articulate their wishes for any other condition. Even if they have seen in their near and dear ones what impact another life-changing illness can have. They cannot articulate their end-of-life wishes for that condition. I think that is a major difficulty in the current legislation which needs to be looked at urgently. I would propose that you, honourable ladies and gentlemen, really make a strong submission about that, because that is what we are seeing on the ground, and that is a major limitation to our advancing our advance care choices in a meaningful and proper way, because 'existing condition' is very limited in its scope and remit.

**Mrs PEULICH** — Amongst many who do not accept death, you are not going to change it through conversations; it has been a lifetime and centuries of cultural learning — and could I say I think it is almost an arrogance to think that you can. If such a regime were put in place, do you think it will destroy the trust in medical practitioners?

**Dr BHATTACHARYA** — It is a very good question. I think eventually all this discussion boils down to one thing — the expectation of society to uphold the sanctity of life and to prolong life, and that countered by patient autonomy. I think the legal and ethical position is that autonomy will trump societal expectations every time. I am cognisant of the fact that you have said that centuries of culture and tradition and religion and all that teaches us to assume in a certain way, but I again hark back —

**Mrs PEULICH** — It teaches some.

**Dr BHATTACHARYA** — that that is a mere assumption, and that unless all this has become transparent and is discussed openly with the patient, meaningful consensus can never be reached. This is a more philosophical argument. The operational side we have become very clever with, and it needs more funding regionally — resourcing — but the philosophical thing is what I would want you to be cognisant of and to grapple with. It is very difficult, and it is very difficult to even attempt or assume to change centuries of societal expectations, but that has to be balanced against an individual's autonomy.

**Ms PATTEN** — Thank you, Doctor, and Ms Cudmore. I agree with you, and I wish that we could write legislation that was, as much as possible, empathetic, consensual and allowed autonomy. Hopefully through this process we can find some path to that, which brings me back to advance care planning and the refusal of treatment care — the limitations on those. Would you support legislative change that made them binding, so they could be changed whenever it was required, but which made them more binding and gave them a little bit more legal power in the process. Would that encourage people to be more active in it?

**Ms CUDMORE** — I think we spend a great deal of time having conversations around advance care planning and choice and all that kind of thing, and if people are then articulate enough to actually put that into writing and to give other people decision-making capacity when they are no longer able to make those decisions, then putting a little bit more power and strength into that process and that documentation, I would

hope, would lighten people's burden. They could think, 'Well, I've done my homework and I've appointed my medical power of attorney, and when I do not have a voice they've at least got my paperwork and my homework that I have done that says what my wishes are'.

I think we need to be very mindful of such conditions as dementia and Alzheimer's and advancing neurological conditions that are incapacitating people at much younger ages, and then they are living with that chronic disease for a lengthy period of time. Yes, having some groundwork with their paperwork when they are well that will support them through that care journey with some power would be important.

**Dr BHATTACHARYA** — I think this whole exercise is being done to see whether any legislative change is required, and I think the first step for that would be to empower our patients with a bit more in the legislation to back them up, because currently all they can do is just refuse a particular type of treatment for an existing condition. The others documents are out there and should be consulted — it is good clinical practice — but the first step towards a legislative change is to see whether the patient's autonomy can be broadened and to increase the scope and remit of that refusal of treatment certificate. I think that is the thing that this committee is trying to do.

**Mr MELHEM** — Just to follow up, what safeguards would you put in place to stop abuse of that power or protect vulnerable people?

**Dr BHATTACHARYA** — There have been many discussions and many debates about the safeguards. I do not know whether you are aware of a Canadian Supreme Court ruling earlier this year. They have thought after much consultation that the safeguards would exist in determining medical capacity, in determining that there is a remorseless, inexorable and incurable disease, and for determining by various consultations that the patient choice is unwavering and not done under duress or coercion. Those three would be the main things to build any further safeguards on.. They thought these safeguards would be sufficient. I am aware that there is always that slippery slope argument, and there is always that argument that this could be abused, but if we first start with the patient making the choice, I think that would be a good step forward.

**Mrs PEULICH** — Just on the issue of safeguards, unwavering — so is it possible for any medical person or any person whatsoever to guarantee that faced with the moment of death that a person will not change his or her mind about their impending death? You talked about incurable disease. Is it psychological as well as physical? What sort of safeguards could be put in place in relation to the inarticulate? You have already mentioned the dementia patients, people who have psychiatric disorders, mental health issues and people with language and cultural challenges. Can there ever be a safeguarded system? Did they not do an audit in Holland and find that 1000 people, was it, were accidentally euthanased over a period of five years, since the introduction of that regime? How can you talk about a safeguard?

**Dr BHATTACHARYA** — So just answering your points point by point — —

**Mrs PEULICH** — And does your view also extend to experiential pain?

**Dr BHATTACHARYA** — Yes. That is a good point, and it is always a difficult discussion, but just answering your thing point by point, when you talk about dementia and psychiatric illness, I have already said that the person should have mental capacity, and that should be determined not just by one doctor. The Supreme Court judgement was that it should be determined by two doctors. That takes dementia and psychiatric illness where capacity is absent out of the equation.

**Mrs PEULICH** — Babies?

**Dr BHATTACHARYA** — Again, babies have a completely different thing, but let me just address the other things you said.

If we build mental capacity into it, I think that is an important safeguard for dementia and the severe psychiatric illness — that a person can only be regarded to be giving a reasoned choice when they have mental capacity or when they are mentally competent. The unwavering bit comes from the fact that you do not just ask them once but ask them a number of times and you see that their responses are consistent. You cannot ever be 100 per cent clear as to whether it will change minute by minute. I acknowledge that it can change very quickly when people

are faced with new circumstances — by the minute even. However, across a number of episodes, if the response is consistent, gives one more confidence.

Experiential it may be, but we need to be aware that experiences play an important part in our lives. Again it is an ethical debate, and I do not think it is a slippery slope, an abuse of the law or an abuse of power if experiences are brought into the equation, because that is what makes up the individual as well. If the individual is communicating a decision based on some mental, physical, psychological or emotional experiences, we need to be aware of that and not say this is experiential and colouring their choice or judgement. That forms part of the whole of the patient.

**Mrs PEULICH** — So can there be safeguards? You were saying that there can be.

**Dr BHATTACHARYA** — These are sufficient safeguards.

**Mrs PEULICH** — They are sufficient safeguards. How about babies?

**The CHAIR** — Doctor, if I could, I think you are citing the Canadian case, and I suppose I would caution you about reciting legal tests that do not yet apply. I appreciate your personal perspective in responding to this question. I just caution you, given we are being recorded by Hansard. Your perspective as a medical practitioner is the principal reason why we have sought to receive evidence from you today, and I think that is probably the most appropriate form of response and commentary from you.

**Dr BHATTACHARYA** — I just wanted to open up the debate. These are not my perspectives, and these are not things that I espouse or hold dear, but these are things that I just wanted to use to open the debate about.

**The CHAIR** — I think that is excellent, and it is important for you to make that comment too. Thank you.

Can I say to both of you, thank you very much for your insightful and thoughtful presentations this morning. You have given us much to consider, analyse and reflect upon, and we are very grateful as well to Goulburn Valley Health, which you are both a part of, for hosting us today.

**Witnesses withdrew.**