

# TRANSCRIPT

## STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Subcommittee

### Inquiry into end-of-life choices

Bendigo — 12 August 2015

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Dr Jason Fletcher, Staff Intensivist, Advance Care Planning Clinical Lead, and  
Associate Professor Marc Budge, Medical Director, Clinical Rehabilitation and Geriatric Medicine, Bendigo  
Health.

**The CHAIR** — Good afternoon, Professor, and thank you very much for joining us today. I will just issue the same caution I issued to Dr Fletcher. 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 proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website.

You are the medical director of clinical rehabilitation and geriatric medicine at Bendigo Health, and we thank you very much for your preparedness to be part of the hearings today. I invite you to make some opening remarks as well, and we will continue with the questioning thereafter.

**Assoc. Prof. BUDGE** — First, I would like to declare that I do not have any specific conflicts of interest today to declare. I am representing Bendigo Health rather than specifically myself in this undertaking, and I welcome the opportunity to do so. I guess my comments will naturally have a predominant focus on issues and services affecting those of middle and older age groups because of my long experience and involvement in geriatric medicine here in Australia and the UK, and also chronic disease management and community organisations such as Alzheimer's Australia. That is the background, if you like — a potted background — of some of my past relationships. I have also reviewed the background of those recently presenting to this inquiry. With regard to my current regional role, I thought I would primarily focus these brief introductory remarks on some of the briefing questions predominately in the community and medicine areas. I will try to make them brief so we have greater time to discuss things.

I think it may have been provided to you that I have provided six key points, and I might just go through those individually briefly. The first is to say that the provision of palliative care is but a small subset of end-of-life care and that I feel that more focus on discussion on end-of-life care in the community broadly and health professionals and service delivery planners more specifically should be facilitated. We could talk about mechanisms about that, but I think that would be a broad statement to commence.

The second is to date most state or territory government palliative care strategic plans that I have been involved with, either assisting with their production or worked within, have focused too greatly, in my opinion, on care for those requiring cancer-related palliative care at the expense of the at least equivalent numbers of those requiring non-cancer-related palliative care. I think that is quite an important point to underline, and I would like to expand on that if we have time.

Specifically, older adults dealing with terminal phases of common diseases, such as heart failure, chronic airways disease, dementia — and I could go on with a few others — are less well targeted and supported than those presenting with cancer as a primary diagnosis. We need to think very carefully about the design of resources as well as our strategic palliative care plans, as well as if we do develop end-of-life care plans or care suggestions in that regard.

For end-of-life and palliative care across these chronic disease-related conditions I would encourage us to explore also the interface between services that are already being provided for chronic disease — for example, HARP, HACC and HIP, the Health Independence Program — and see whether that interface is being optimised and whether coordination across those domains is ideal. I guess by saying that I am suggesting that I think they may not be or at least could be improved.

The next phase, which always comes after service delivery, is that which one provides in terms of education and training. I think we need to look at both health service and carer delivery domains in that regard, so that these areas of palliative care and end-of-life care can be delivered seamlessly across and independent of geographical location, especially since we are in a regional domain here today, and also be independent of the specific site of delivery — be that at home, be that in a nursing home, be that in a hospital zone or be that in a field in a caravan, where someone might happen to live with a singular electrical wire going to their caravan. We need to be able to do that across those domains.

Finally, I would like to explore end-of-life care and palliative care as what we are doing with respect to those as performance measures within the health domain, and more particularly: can we look forward to thinking about quality indicators that might be across both of those? This is not an easy proposition. In the UK they have been tussling for some years with this. Ontario in Canada is currently suggesting that is what they would like to

develop. I have not seen the evolution of what they have produced yet, but I think there are things we can start to think about.

I have just listed two very, if you like, nascent views: one about achieving desired place of care, which was mentioned earlier with the last questions — that is, if people wish to be helped to die or to be cared for within their home, then we should try to facilitate that. Of course many things interfere with that proposition, so designing a quality-of-care indicator related to that has to be carefully thought through. I would encourage the thought that those who work in the domain specifically are the people who really need to get down along with consumers to say: what do we think is reasonable, what do we think we can evaluate, and see what that delivers; and by defining these quality indicators, does it deliver a better process and outcome or not? Because often we design these things, they look good on sheets, they sit like tomes on a shelf and come to parliamentary inquiries as results, but are they actually delivering what people want in the community?

The other one I will just mention as a first thought might be that we could look at whether we have designed or at least delivered the capacity within the health system in terms of staff training and communication skills, as well as specific details about end-of-life care and a good death — if you like, delivering and helping to deliver a good death; because I believe there is such a thing to be desired. Can we measure that in terms of the preparedness of the systems within which we work — for example, the Bendigo Health system here or its outreach services into the Loddon-Mallee region? I think that is potentially achievable. What that then means in terms of translation through to outcome measures, desired or undesired, or more importantly how that facilitates delivering what the community wishes would be a topic of significantly more discussion than we have time for today.

Those are the preliminary brief thoughts I thought I might bring that are perhaps not quite just repetitions of what you have already heard.

**The CHAIR** — Thank you very much for that and for those succinct points. If I could take you to that issue of staff capacity and your observation that measuring outputs or measuring outcomes is quite difficult in this area. Do you want to perhaps explore further the work that has been done in the UK that you referred to or other jurisdictions that may have looked at this issue previously?

**Assoc. Prof. BUDGE** — I guess the thing that is being tussled with mostly in the UK is the first of those two points as to how you measure even just things such as simple place of care and whether you can deliver it where people desire to be cared for or to die, because of the complexity of things that influence that.

If we go to the second, which you have asked about, the staff training and education, there are certainly discussions happening at the moment about that, because at the moment as you would know, in the UK it is very much at the commissioning levels right down to the general practice level. It is not so much where we do it, which is at the state or territory level or at the regional level in terms of translation to what the state would hope for — often. I guess what I would say is that I think at least that proposition is measurable. You can measure for instance the percentage of staff who have received some form of, or have available to them for their own desire and training, information about optimal end-of-life care and optimal palliative care involvement. You can measure that for sure.

You can also then measure, by looking at patient surveys, what people feel about their care in those types of domains in terms of how the staff have delivered what they desired in terms of palliative care or end-of-life care. There are some measurables in there. Nothing is not fraught with a little bit of complexity in terms of the measurement of that, because the problem with any measurement, as you would be only too aware of, is that you need resources to measure — unless it is intrinsic to the process and built into the process technologically, usually, for efficiency. In other words if I am a palliative care nurse now going out to the community to visit someone in their own home and I have to log my activity, my number of minutes spent with that person and what it was about — was it about diagnostic issues, about terminal symptoms that are related to that disease — or just simple facts of whether anyone else was in the home, if I am doing all of that, that is not delivering care. What I am paid for is to deliver care, not to capture that resource and that measurement.

I think what we need to increasingly do is to have clever ways, so that for instance when that nurse goes into the home with her iPad under her arm or his iPad under his arm, they simply have to click on a button and it is recording already when they have started. They hit another button on the same screen, and that is when they have finished. Then they go 1, 2, 3 as to what they delivered in terms of the sectors of care or types of care they

delivered on that visit. It is captured. They do not have to go and write a report about it. It is done. Also that is more reliable as long as the technology is reliable. That is more reliable in terms of the capture of information, and if you capture accurate information, it might be useful for designing delivery of services. That is just a simple example.

**Ms SPRINGLE** — Thank you for that. You talked about palliative care being very cancer illness focused and how that needs to broaden out.

**Assoc. Prof. BUDGE** — Yes.

**Ms SPRINGLE** — Can you give us some sort of idea about how you think that is possible?

**Assoc. Prof. BUDGE** — I think it requires several things. The first is a mindset change. Having been involved in at least two if not three strategic care plans over a five-year time frame for various jurisdictions in the past, the committees tend to be dominated by those related to cancer care or palliative care related to cancer issues. When one has tried to introduce as a geriatrician the proposition that over the last 10 to 20 years in fact the numbers in the category that is non-cancer — that is, other conditions I have mentioned — is greater than those with cancer, they have sort of swept it aside, saying, ‘Oh, no, we need to focus on what we have traditionally done — deal with pain, cancer, the things we understand or that we are used to delivering services in’. If you then say to them, ‘What about the person who comes along with early dementia that is advancing rapidly but happens to also have heart failure and is increasingly breathless, and the symptom of breathlessness is troubling them greatly and perturbing even more their dementia and behaviour?’. In other words there is greater complexity there, but that is a common situation for me. In terms of the people I see in geriatric medicine over a 30-year period, I see much more of that. In fact 70 per cent of my work, I would say, is management of chronic disease during its middle-age phase or its terminal phases. Increasingly, dementia is the other focus in terms of both diagnosis and its impact on other disease process management, as well as intrinsically its own issues. Of course there is such a thing as palliative care in dementia as well. People need to recognise that, and I would refer them to the Alzheimer’s Australia reports done in recent years, which are quite extensive and very clear about their suggestions from a review of the literature and experience.

**Ms SPRINGLE** — Just so that I have a better understanding of what you would suggest, is that around mandating a set of criteria tied to funding? If you are talking about culture change, that can be a challenge, so how would you instigate that?

**Assoc. Prof. BUDGE** — I think you are talking about two things with culture change, one is the carrot and one is the stick. The stick is of course to prescribe that you would have an expectation that palliative care services would not just be provided to those with cancer. You might want to set a number around that; that can be difficult. You may first start with an expectation that there would be specific, targeted disease processes or conditions that might be looked at in the first instance for provision specifically of palliative care. Having done that, you then need to examine the people who are being trained and educated to work in that field and look at what is embedded in their programs of learning and education.

To my mind, and I say this quite openly, over the many years there has been a shift towards people recognising the need for non-cancer-related palliative care, but there has not been as great a shift to making sure it is part of the mindset of those training or being educated to work in palliative care. So they come through that process, if you like, with a particular view, then when they are met with the workload they have, they tend to steer towards the one they have been educated towards, not the one that is in fact a greater need in terms of the numerousness of its need.

**Mr MELHEM** — Palliative care, from what I have been hearing, is still at the end of the road. At the end of the line, that is where it is sort of — —

**Assoc. Prof. BUDGE** — Yes.

**Mr MELHEM** — Over the weeks, months, that is where the advance care plans come into action et cetera. But you talked about other diseases, and I think you are right. I mean, cancer is clear cut. In most cases, you know where you are heading.

**Assoc. Prof. BUDGE** — Sure.

**Mr MELHEM** — Would you then talk about having triggers, for example, where it is time to have a plan, whether it is an advance care plan or a plan? We have heard from other professionals about the age of 75 being the trigger. Another trigger is aged care — when you go into aged care. What triggers would you like us to see heading into palliative care?

**Assoc. Prof. BUDGE** — Let us look in order at your questions, so pathway first, then process and then triggers. In terms of the pathway, yes, I agree completely that palliative care tends to focus on the very terminal part of the life's journey. And the end of life is actually a broader and longer phase, which includes the gathering of disability and inability to function in terms of what people would like to have as independent function. So if in a sense, for instance, someone has gross osteoporosis and osteoarthritis, and that in fact is limiting their life span and their lifestyle significantly, then that to me is something that needs to be palliated — those symptoms — and that might be 5, 10, 15 years before their death. I think what I am really saying is that you need to look at what people have as disability, as interference with their functional ability to do what they would like to do in life, look at the level of that symptomatology: is it more than can be handled with standard measures in terms of what would standardly be done via, for instance, a primary care practice? Then look at how we, if you like, intervene in that. That is the hard part — knowing when and how to intervene, if you are asking for trigger points.

I guess as clinicians, Jason and I would actually see people frequently who are referred to us with exacerbations of chronic diseases. For instance they go into crashing heart failure, their lungs are all wet, they cannot breathe and they are very distressed. This is on the background of having chronic heart failure, which is limiting their life span probably as much for many of them as cancer would. In fact, sometimes in chronic heart failure their life span may only be one or two years, just as it might be with cancer. So the question is then how to support that, if you like, as a palliator. More importantly there are two sides of palliative care to me: not just cancer and non-cancer; the other is those where people can contribute, be self-managing and have self-response abilities for the care of their chronic diseases and those where they lack that ability to contribute but we can come in, not paternally but rather in a supportive way, to provide support in that. So for instance what I am really talking about, and what you are asking about, is chronic disease management.

Someone with heart failure, diabetes or airways disease from smoking — they are at home, they are very limited by their activity and they are someone who, for instance, as an example, needs oxygen during the day for their chronic airways disease. I can monitor them from my general practice or from my physician's desk at home. They can be self-responsibly putting their little finger into the oxygen monitor that day, standing on their electronic weight scales to say whether they have gained fluid or not in their lungs and in their body over the period of time, and I can say to them — that leads to an alert which goes back to them — 'Whoops, you've gained 3 kilograms in weight. Is that your heart failure or your airways disease going out of control again? Have you got any sputum? Are you sick? Have you got a fever?'. That could all be expedited. There are two ways to expedite that. Not only does it give them some self-responsibility for management as well, which also helps them feel that they are independently trying to help with their care, but secondly, it also links them into the system rather ubiquitously and rather seamlessly without too much resource being required for that at that earlier phase. Whereas when the later phase comes, the terminal phase that we were talking about, other triggers come in where they just cannot manage to live at home or they need to come to a hospital for acute care, subacute care or even placement because they just cannot cope with that terminal phase themselves — or those around them. So I think we have to explore those things.

**Mr MELHEM** — So just to follow up, to achieve that — and I agree with your proposition — do we change the law, for example, or is it just a matter of educating people? I am talking about the general population and physicians. Is that through a marketing campaign, for example, like the TAC when they talk about speeding, alcohol and all this? To achieve that, what do you think we should do?

**Assoc. Prof. BUDGE** — I think there are three levels. Firstly, you are right, education is the key, but it is across all domains. It is not just the health professionals or the carers; it is also the greater population — to understand that when you have a proposition like this, with a disease condition, you have the ability to assist with its management and to keep some control in your life with respect to that. However, what we also need, obviously, is to provide some form of structure and funding therefore, because nothing much happens in our system without funding, to provide care for those who need that support, e.g., the home monitoring of chronic diseases or something else, be that by individuals giving them a call — the simplest and cheapest — or home-monitoring gear at home, technologically involved but simply delivered, and it can be.

For instance, to give you one example, some years back there was a push to try to get that funded as an item for funding. What has happened since is that telehealth has been underpinned by funding initiatives and also bonuses to encourage it — for example, a 50 per cent bonus on the Medicare fee for that sort of item. But what we have not yet come to is support for chronic disease management in the home, especially when it is getting tricky and people are bouncing back into hospital and out of hospital. To expedite them getting home but also to stop them needing to come to hospital, we still do not have a mechanism in place yet, despite discussions with the minister from 2007 — commonwealth, I am talking about — in those days, almost achieving it; it has not really got there. So I think there is an opportunity.

Victoria has an opportunity because it has always been, to my mind, the jurisdiction that tends to lead in terms of health initiatives, despite resource implications and despite funding and budgets that are constrained, which we all recognise. But I think we are past now the pilot phase of these sorts of propositions. They are all done. I did them myself and was involved in research with those, funded by federal government — 2007, 2010. What we need to look at now is, ‘What is the proposition that, one, we can afford at the moment; two, that would have the most bang for the buck; and, three, that would also be the most acceptable to the community and to the people who really want that support in the community, because that is where they want to stay?’. They would rather stay at home than have to go to nursing care because they needed someone to watch how their monitoring was going. I think all of those things are critical, and one does not come without the others in terms of trying to achieve the outcome. I think they all need to be addressed at the same time.

**The CHAIR** — Thank you for that detail.

**Dr FLETCHER** — I think there is a big opportunity to actually save money by really focusing on this prehospital care. There is a lot of money spent on these patients in hospital that could have been prevented. It may be a lot of funding up-front, but it will probably save money down the track.

**Ms PATTEN** — Thank you. I am excited. I am ready for the implementation of that. I think that was wonderful.

**Assoc. Prof. BUDGE** — I am happy to talk further later.

**Ms PATTEN** — Thank you, Professor. Obviously we have been hearing about what a good death should look like, and I was really encouraged by what you had to say. You explained it very well. I just wanted to ask a question, going back to the advance care planning, and recognising, as you mentioned, our focus on cancer, do you think the advance care planning initiatives that we have now adequately cover the broad range of illnesses that we are seeing and that you are seeing in geriatric medicine?

**Assoc. Prof. BUDGE** — I think they potentially can but I think what we heard as evidence just before was that it is only a small percentage of people who still come to hospital with those in place. For instance, every person — no matter what they have come to me with in my outpatients — that I see I talk to them about: have they got a will in place? Have they got end-of-life decisions that they have discussed with their family? Have they got advance care directives and also have they got enduring power of attorney? Those are very baseline things for me to talk to them about, whether they are 50 or 95, as the last person I saw the other day was. He walked in, I might say, having just jumped off his bike to come to outpatients, which I was impressed by.

What I am really saying then is that we can encourage people, as Jason was saying, to get involved in the discussion about it, because it does require a pre-discussion before people will commit to a new thing, and this for many is a new thing, especially to older folk who have not conceived of having to think about these things and sign something related to it as opposed to discussing it. As we see every day in geriatric medicine, it is a difficult discussion at times, especially when people are unwell. It is not as difficult a discussion if people are having the conversation when they are well or as well as they can be.

We need to have it as a whole-of-community drive. It is a bit like immunisation — the herd immunity. If we had the herd immunity of 80-plus per cent or 90 per cent in terms of this situation, in terms of advance care planning, I think the system would work much better, and we would not have problems of people fronting ICU unable to express their preferences and us finding out later that we had actually not carried out their preferences that they had previously expressed. That would actually be a lesser phenomenon.

**Ms PATTEN** — Professor, in your 30 years of working in geriatric medicine, are you seeing that we are moving more of that medicine into hospital? Which way are we going?

**Assoc. Prof. BUDGE** — It is an answer I have to be a little careful about. In terms of what we have just heard previously as well what we are talking about today, the investment needs to be largely driven towards the community in terms of the provision of these things being in the community but being supported by the resources locally within hospital or primary care.

The difficulty is there becomes an expectation when there is a technology base within a hospital that everything will be provided in the hospital and not just the fancy tests and the equipment that goes whizz and bang or that takes an image of my brain — the CAT scan or the MRI. With that minor expectation you get a natural magnetism towards the hospital that should be reversed. It should be, in fact, that we can provide that by hubs in the community. Across the Loddon Mallee for instance, that is how we deliver stroke now, via the Victorian Stroke Telemedicine network, and it is a good example of what you might more broadly put into end-of-life care and palliative care. We have a hub here that provides a hub and spoke model to the outlying smaller places with smaller populations, but we still utilise the super resource of the metropolitan hospital and the academic health centres that have subspecialty resource that we can tap into at any time as long as we are officially connected.

That is the sort of hub and spoke model in the regional arena that should be connected to the super-specialised and very well-resourced metropolitan arena that I would like to see also in palliative care and end-of-life care in terms of what we do within the hospital. But once again I will underline what you said and that is, that we need to emphasise for the public, as well as for health professionals, that our expectation is — and it needs to be reflected in spending and funding — that most of this should be provided in the community. Where it cannot be provided because of technological reasons or resource issues, then of course it has to be provided in other zones, for example, the hospital.

**The CHAIR** — We will leave the questions there. Thank you both Dr Fletcher and Associate Professor Budge for your evidence this morning. You gave some thought-provoking suggestions and some good evidence for us to follow up on. Thank you both very much for your preparedness to be with us today.

**Assoc. Prof. BUDGE** — Thank you for the opportunity.

**Dr FLETCHER** — Thank you.

**Witnesses withdrew.**