

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 25 November 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

Witnesses

Ms Kym Peake, Secretary,

Ms Simone Corin, Director, Health Programs Branch, and

Ms Jackie Kearney, Project Director, End of Life Care Health Service Programs,
Department of Health and Human Services.

The CHAIR — I declare open the Legislative Council’s Standing Committee on Legal and Social Issues public hearing in relation to the inquiry into end-of-life choices. I welcome the Department of Health and Human Services, particularly Ms Kym Peake, the secretary; Ms Simone Corin, the director of health programs branch; and Ms Jackie Kearney, the project director, end of life care health services programs. Thank you very much for appearing at relatively short notice, and also on a Wednesday night at 7 o’clock. We do appreciate it.

Before I invite you to make some opening submissions, I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege.

Today’s evidence is being recorded. You will be provided with 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 about 45 minutes for our time tonight. As you know, we heard from the department early on in our process, and obviously there has been a lot of water under the bridge, so we are keen to hear from the department again and also learn more about the direction of your own processes. Thanks again for being here. I invite you to make some comments, and we will have questions thereafter.

Ms PEAKE — Thank you, Chair, and thank you for the opportunity to speak with you tonight. I want to focus my comments on the work that is occurring within the department on end-of-life care, the costs associated with this work that I understand the committee is interested in hearing more about, and how we have sought to manage the interface with the work of the committee.

By way of context, I note that, when introducing the motion to establish the Inquiry, the Honourable Gavin Jennings, the Special Minister of State, indicated that the government would in parallel progress improvements in palliative care and undertake legislative reform for legal recognition of advance care directives.

I also note that the current policy framework for palliative care in Victoria concludes at the end of this year. It was in this context that at the national Australian Palliative Care Conference on 2 September the Minister for Health announced the government’s intention to undertake consultations on the development of an end-of-life-care framework to ensure all Victorians have access to the best quality end-of-life care, and a discussion paper was subsequently released on 28 September.

I understand that the minister wrote to you, Chair, on 10 October, outlining the work underway to progress this parallel work, which was described in more detail in the accompanying Victorian government submission to the inquiry. In particular, this submission outlined community and sector consultations underway, or planned and underway, to help guide the development of an end-of-life-care framework.

Over November and December I can update the committee that the department is running 25 consultations with services, clients and carers, and a website has been created to provide a platform to seek comments and input from the sector and the public. The focus of these consultations is on testing the policy rigour of the government’s work on advance care directives and palliative care service improvements.

The emphasis is very much on practical service improvements that can be implemented in the short to medium term, and, as identified in the government’s submission to the committee, four priorities are: firstly, improving the capacity of and access to specialist palliative care; secondly, better matching what people would want with what is provided; thirdly, improving integration across service delivery; and fourthly, increasing knowledge about end-of-life care amongst all clinicians and services.

We have also been regularly reviewing the publicly available submissions made available by the committee to make sure that we are identifying the key themes emerging from your work as a critical input to the development of the end-of-life care framework alongside that consultation process. The end-of-life care framework will not address the full range of end-of-life issues being examined by the committee. I would like to emphasise that the department’s work is not considering voluntary euthanasia and physician-assisted dying or looking at international legislative frameworks in these areas.

There is a component of the discussion paper that focuses on enabling genuine choice. That was meant in the very broadest context, such as supporting people to be able to choose where they want to be cared for and die and what services they want involved in their care. In not defining this more specifically there is a risk of

perceived overlap with your terms of reference, which is unfortunate, and I wanted to take this opportunity to apologise that the discussion paper has caused some confusion about the intent of consultation in this area. We have tried to manage this by providing clear information on the differences and the relationship between the standing committee inquiry and the consultation process, including through information provided on the consultation website and at the opening of each consultation forum. Despite this, there have been people who have expressed their views on voluntary euthanasia and assisted dying on the website, and if it would assist the committee, we are certainly be very happy to provide these comments to the standing committee in a document at the conclusion of the consultation period, which is 18 December.

I would also like to note that the policy framework will require an implementation plan, and this will become a living document that is developed over time, building on service improvements, successful service delivery initiatives and emerging evidence year on year. We would certainly value and envisage that the final report and recommendations of the committee will be a vital input into that detailed and ongoing work.

If I then turn briefly to the government's commitment to enabling statutory recognition of advance care directives, the government's submission to the committee sets out the principles that will guide assessment of legislative options to reduce complexity and better support advance care planning. I can advise the committee that the department is reviewing existing Victorian legislation to examine overlaps and differences between the Medical Treatment Act, the Powers of Attorney Act and the Guardianship and Administration Act. We have also commenced discussions with the Office of the Public Advocate, the Law Institute of Victoria, Health Issues Centre, clinical practitioners involved in the subacute peak body and the health services commissioner, but at this point I cannot comment on the possible or likely outcomes of the government's future policy consideration of what legislative options might be or the timing of those.

Finally, I understand the committee is interested in the costs associated with the government's activities. The total cost of producing the discussion paper was \$21 346.51, to be precise, and the total cost for the website is \$25 861, so together that represents a cost of \$47 207.51. The department also employed one full-time worker at a VPS5 level for eight weeks at a cost of \$16 000. Other program staff contributed a percentage of their time to assist with implementation. The palliative care team manager spent 30 per cent of their time and the branch director 10 per cent of their time over that eight-week period.

In closing, I would like to emphasise that from my perspective the relationship between the program staff in my department and the committee's secretariat is a positive one. I acknowledge that there is some overlap that was forecast by the Special Minister of State between the work of the committee and the work of the department on advance care directives and palliative care service improvements, but we really are committed to assisting the inquiry and working together to improve end-of-life experience for Victorians;. Of course, subject to the views of the committee, I would welcome that continued dialogue between department staff and the committee secretariat as the work of the inquiry but also the department's work on the end-of-life care framework and implementation planning associated with that and the work legislative options proceeds. I am happy to take any questions.

The CHAIR — Thanks very much, Ms Peake, for that presentation. Just to take, I suppose, the thrust of what you are saying, the government has two principal purposes with the statutory recognition of advance care directives and the palliative care framework. You are not able to comment on the timing of the implementation of the statutory recognition of advance care directives.

Ms PEAKE — That has not been confirmed, no.

The CHAIR — Are you looking at early next year?

Ms PEAKE — I really cannot comment. It is a matter before the government.

The CHAIR — The palliative care framework expires at the end of this calendar year.

Ms PEAKE — Correct.

The CHAIR — What is your timing on the refresh and renewal of that?

Ms PEAKE — Certainly, as I indicated, we are looking to complete all of the consultations by the middle of December and then have a final framework as soon as possible after that. As I mentioned, the framework will

provide the broad policy of the way forward to improve services and then the implementation plan will be a living document that we would see having more of the detail about practical actions that would be informed by the work of the inquiry.

The CHAIR — What is your target date for the framework to be concluded?

Ms PEAKE — Again, that will depend on government decision-making processes, but we are looking to have the policy framework and certainty for the community and stakeholders as soon as possible after the completion of the consultations in the middle of December.

The CHAIR — Do you envisage any legislative change from the palliative care component of what you are doing?

Ms PEAKE — The legislative options that are being considered are really those that are related to the advance care directive, as indicated by the Special Minister of State.

Ms SPRINGLE — Thank you for your time this evening. My question relates to the consultations that you are rolling out currently. It has been mentioned that there are some targeted, I guess, health sector consultations, but there are also some public consultations. You have also mentioned, which the committee has also noted, some confusion around the overlapping terms of reference of this committee's work and your work. I am concerned that if we were confused, the general public would be even more confused as to what the difference is between the two bodies of work and the risk of them having to double their input to two different government bodies. Can you tell me what has been done in terms of, I guess, damage control around that issue?

Ms PEAKE — Certainly. As I mentioned, we have sought both through the material on the website about the purpose of the consultations being on practical actions to improve services and in the introduction of the facilitators at each of the consultations to make those distinctions clear about the broader scope of work of this inquiry compared to the consultations for the policy framework. As I said, we have a website that enables free comments, and there are comments that have been submitted that go to matters that are more properly the remit of the committee rather than our consultations, and those we are very happy to pass on to you and to just keep working with the secretariat to make sure that we are sharing information.

Ms SPRINGLE — In your view there is no crossover in terms of public consultation between your work and our work?

Ms PEAKE — I think there is absolutely a relationship in looking at the services and how they can be improved and how we can build the knowledge base of clinicians and awareness of the service options in the development of a home-based model for patients. That is obviously a very close territory in looking at the full set of choices that someone might want to make about end-of-life care.

Ms SPRINGLE — Sure.

Ms PEAKE — As I said, we have tried to be very clear that we are really talking about the services piece, and that you are looking at the broader set of choices that someone might make.

Ms SPRINGLE — I suppose I am just concerned that a member of the general public, someone who is not involved in government, is going to look at that and not really know what they are looking for in terms of finding difference. For example, someone may have made a submission to this inquiry and then two months later see a different inquiry from the government asking something very similar, and that is very confusing, because I do not everyone thinks in terms of government frameworks. I guess that is what I am getting at.

I also have just a related question to that. Originally there was really not very much mention of this inquiry on the website. I am wondering if that has changed?

Ms PEAKE — I might refer that question.

Ms CORIN — Initially on the website there was reference to the inquiry. In our frequently asked questions section of the website there was a reference saying that our process was different to the inquiry, but we did realise through contact with some consumers and patients who were seeking to attend the consultations that that

perhaps was not quite as clear. So we did modify that and actually put quite clearly on the front page that our process was different to the inquiry, with a direct link to your inquiry website.

Ms SPRINGLE — And the other question, which was around the public consultation/confusion?

Ms PEAKE — Really I can just repeat that the government had been clear in its pre-election commitments through to the establishment of this committee that it would be proceeding with those two commitments around how to improve services and the work on care directives. So we have just sought to keep reiterating that through the website and through the consultation forums, but also importantly we say to people that ultimately wherever they provide the advice we would make sure that if there is input that is provided that is relevant to your inquiry, we would pass it through to you, so that it ends up in the right place for the right issue.

Ms FITZHERBERT — I have a few questions. Thank you for your time this evening. On the issue of recommendations regarding palliative care, do you expect that your recommendations will extend to issues like bed numbers? One of the issues that gets raised with us is the amount of infrastructure that is available and bed numbers is something that has come up in a number of regional hearings in particular.

Ms PEAKE — Certainly a particular focus is more on the home-based models.

Ms CORIN — Part of what we will look at is what we have got available in the system, what the system actually needs and how we can transition that to what people are looking for, which is an increase in home-based care. That is definitely the strong message that we are getting and so we will look at that. Whether we will actually come up with a recommendation about the actual numbers of beds or the distribution of those beds, I do not think that is the specific intent of our framework.

Ms FITZHERBERT — One issue that has come up with us in relation to advance care planning is how we accommodate informed consent. We have had some views raised with us about that difficult concept. I would imagine that this is something you would also be looking at. I was hoping you might be able to tell us how you think that might unfold and whether there is any capacity for us to share legal opinions or positions that you may come to in an effort to avoid duplication or reinventing the wheel.

Ms PEAKE — I cannot go to government deliberations on particular options. Nonetheless I am very happy to commit to there being ongoing dialogue about what is coming through in the consultations and certainly the piece of work that I have referred to about looking at what are the different frameworks under the three acts and how do they contribute to some of that confusion, both for practitioners as well as for the general public. I am certainly very happy to continue the dialogue about that and also the sorts of supports or informing choice that are coming through the consultations as ideas.

Ms FITZHERBERT — One more area, if I could. You mentioned earlier the costs of the work to date and the figures for the website and also for the report that had been prepared. Who prepared those two items?

Ms CORIN — The discussion paper was essentially prepared internally by the department's staff but was informed by a whole range of information, including some of the material from the inquiry to date. We did get that published. I am not sure — I will have to check — who did our publishing. We did get that published and printed.

Ms FITZHERBERT — Is the figure for that, which was \$21 000-odd, a design and publication cost but not a writing cost?

Ms CORIN — That is right. The majority of the cost actually is in relation to translation. We got that translated into the top 10 languages in Victoria so that we could get that spread and reach, and then printing costs. The printing costs were about \$3500 and the translation was about \$17 000, so that was the bulk of the costs.

Ms FITZHERBERT — Was there design work that was done externally?

Ms CORIN — Essentially layout, which was about \$550.

Ms FITZHERBERT — And was the website provided by an external party?

Ms CORIN — It was. That was through Harvest Digital Planning, a communications provider that was accessed through one of the government panels. They basically developed that. We used them based on essentially previous work that was done. They developed the 10-year mental health strategy and used essentially the same formula and approach, and that was \$25 000 inclusive of GST.

Ms PEAKE — That includes the construction and the hosting.

Ms FITZHERBERT — Going forward you have itemised staff costs and so on. Are there going to be additional communications expenses as you go through the process and at the end, and could you run me through what they might be?

Ms PEAKE — I would certainly envisage that when the end-of-life care framework is finalised there would be a publication of that. The cost to put it on our website would be very minimal and the cost of hard copies again would be managed within existing resources. On the actions that then flow from that plan, for example, we have material that we just shared with the secretariat tonight that was released yesterday that has been in development over the last 12 months with the AMA about practical resources for clinicians. I imagine that there will be more materials like that that will continue to flow over time.

Ms PATTEN — Thank you for coming out this evening. On the face of it obviously there does seem to be considerable overlap. I know that you produced a paper that looked at a lot of our submissions in developing some of your work. Would you have a concept of what percentage of the submissions that we have already received specifically from organisations that you will also be seeking submissions from, or will you be using the submissions that they have given us, given that many of them were actually looking at palliative care — looking at that end of end-of-life choices? While we received a lot of submissions around possibly physician-assisted dying, I would say the vast majority of the organisations that responded to us raised issues around end-of-life care, and some of them only end-of-life care.

Ms KEARNEY — Thanks for that question. I think there are two components to that. The first is, as I understood it, are we getting any submissions from organisations that have already submitted to you. To date, last time I checked, we had one submission and that was from the Grattan Institute. So they have submitted to you and submitted to us, and very clearly in their submission to us delineated that they understood that there are two different inquiries going on.

In terms of how we use the submissions that are currently on your website, we have reviewed them and we continue to review them. In particular, we are reviewing them to make sure that we get the right information in terms of developing an end-of-life care framework and what the actions might be. One of the things we are really interested to confirm is the information that we are getting from particularly the interactive workshops we are having, what are the messages that are coming out of those workshops and are they reflected in your submissions, so essentially to get an understanding of where the majority of concerns or issues or solutions lie and start to align our priority actions with the feedback we are getting from the workshops.

Ms PATTEN — You say in your discussion paper that in seeking out information you have had only one organisation that has submitted to us that has also submitted to you, so not people like those at Palliative Care Victoria or Barwon Health. We have spoken to so many palliative care people.

Ms KEARNEY — You have spoken to so many people. Palliative Care Victoria and Barwon Health are participating in the workshops, so they have chosen their contribution to be as part of the workshops. We have particularly encouraged that because the approach we are taking is really a roundtable discussion about let us come together as service providers. What are the issues? Are there practical solutions that we can develop and start to expand and explore at the workshops? They have participated in that process.

Ms PATTEN — Great. So in looking at all the organisations that have taken part in our process, which is a submission process and also a lot of public hearings, and taking part in your process, would you say that the people that you are speaking to we have already spoken to or have already put in a submission into us?

Ms KEARNEY — Some of them, yes.

Ms PATTEN — But there would be others who have not submitted to us?

Ms KEARNEY — Some of them, no. Many of the people who participate in our workshops are direct service providers — the Royal District Nursing Service, palliative care nurses, local government, HACC providers, a whole range of aged-care facilities, a whole range of people who are providing care that also includes end-of-life and palliative care.

Ms PEAKE — It is worth saying that while it might be that organisations are putting in formal submissions to you, the point we are making is that it is the individual clinicians who are participating in our workshops. Of course you would expect their views would be generally aligned, but it is just the difference between the individual workforce.

Ms PATTEN — Okay. We have heard from lots of clinicians as well in our travels around the state. You are saying that there is very little overlap with those clinicians that we are seeing and that you are seeing different clinicians?

Ms PEAKE — I meant more in terms of submissions that you are receiving; I am sure you are talking to many similar people in terms of the discussions you are having around the state.

Ms CORIN — I think there is clearly overlap, that there are certainly clinicians you will have seen, such as Charlie Corke from Barwon and those sorts of people who will have participated in your process and ours. But we are certainly not seeking to duplicate in terms of seeking duplicate submissions. We are saying they are noted as having been provided to you. But I think the opportunity that our consultations provide is that there are then those clinicians able to work within a similar group within the regional area where the discussion does get to that practical level about what is the approach that might work within your region. How might you actually work with other health services to deliver? What might be the referral pathways? What are the governance-type considerations that might need to be made? I think that is a slightly different conversation because it is a conversation between clinicians and health services to inform us at a practical level about what needs to be considered in the framework.

Ms PATTEN — Yes, I tend to agree with you about those groups talking together about how they can work together and obviously there is overlap in that. It seems that the separate part of our inquiry was, as you said, physician-assisted suicide and voluntary euthanasia. That, like your end-of-life discussion, was never put on the table for our end-of-life discussion either. We were looking at a much broader toolbox, as you are as well. Obviously when you raise that toolbox, a number of people want to discuss voluntary assisted suicide, as you are seeing.

I am still unclear though. Frankly, I do feel like all the work that we have been doing in the last six months in talking to all of these groups is a substantial overlap to what you will now be proceeding to do. I think it is great that you will have clinicians saying, ‘Well, we can do this over here if you can do that over there’. That is a very positive point. Is there anywhere else that you think that we might be doing something different or are we just travelling along the same path?

Ms PEAKE — The other point I would make is that I would certainly envisage that some of your recommendations will have more of a medium and longer term effect. While we are trying to have a broad framework for how to think about this, we are very focused on what are the very practical short-term actions that can be taken and how to organise for those.

The CHAIR — Ms Peake, I will just go to how we as a committee do our work from here on in. We have done the vast majority of the public hearings, and that has been most informative. The submissions have pretty much stopped coming in. We are at the conclusion of that process and will be starting to consider as a committee our recommendations. I appreciate that you cannot foreshadow here tonight government policy and the timing of government policy, but from our perspective we do not wish to spend hundreds of hours collectively analysing things that may already have been determined by government. Not that we as a parliamentary committee cannot have a different position from government, but we want to invest our time where it is going to deliver the most dividend for the Parliament and the broader community. Within the constraints that you have, and noting what you have already said about the end of the consultation process, can you provide any guidance at all about the timing of these two limbs that you are exploring because that will inform us about what we do and when we do it?

Ms PEAKE — I cannot give you any further advice on timing. What I can say is that the specifics of what we have been asked to look at around advance care directives is the specific terrain. The broader considerations around either what is other legislative schemes elsewhere for broader decisions or broader choices that people might make and the longer term more system changes — I think the work that you refer to around what are the strategies to inform choice, for example — are going to be ongoing needs to improve the system. That would be incredibly valuable from my perspective to have your perspectives on. I do think that what we have tried to emphasise tonight is that on the side of the ‘how do we improve services?’, where we are very focused on what can we do now and how do we best do that and in terms of the legislative reforms, we are very much focused on advance care directives. That is the best guidance I can provide.

The CHAIR — That leaves us in a somewhat difficult position. Without going over ground covered by the members, the committee was aware of the very narrow matters for government consideration that the Special Minister of State flagged in a very restricted and narrow way when he moved the motion that gave us this reference. His words and the two discrete things that he flagged in a very clear and narrow way are vastly different from the material that was produced by the department, which is much more expansive. While I note, and as been said by Ms Corin, that there have been changes made to the website and to the material, I think what has been put out publicly is very different from what was flagged by the Special Minister of State.

For me, this is not some sort of turf war. We have a concern as a committee for vulnerable witnesses — we have heard from many vulnerable witnesses — and confusion for them is a real concern for us. I just implore you to, wherever possible as we go forward in our respective processes, minimise any confusion for the general public, particularly vulnerable witnesses who find themselves looking to either of our processes to deliver them a policy change that will assist their particular situation.

Ms PEAKE — Chair, the other thing I am really happy to commit to as we finish our consultations is sharing, through the secretariat, the key themes that have come out that are relevant to our work and the key things that are relevant to your work so that you have clarity on where we are putting our effort.

Ms FITZHERBERT — I have one additional point leading on from what the Chair has been saying. I would imagine you have a work plan in mind and you have a fairly tight timeframe. Would you be able to give some sort of indication of when you might check in with us again so that we could possibly attempt to see where we are both at, respectively. Chair, would that be of assistance?

Ms PEAKE — Certainly.

The CHAIR — That would be of assistance, and I know the secretariat has been working closely with your team as well, so we do appreciate that. Ultimately we need guidance from government about timing and policy, and until we get that we are in a bind about where we spend our time and resources. Whilst a longer term focus will be a matter of importance for us, in relation to the hundreds of submissions that Ms Patten referred to that in effect overlap with what you are doing, we also have an obligation to discharge to them appropriate responses through our process. So the sooner government can provide us with some clarity, it will greatly assist us.

Ms Peake, Ms Kearney and Ms Corin, thank you very much for your time and for being here at this time of the evening.

Ms PEAKE — Thank you.

Witnesses withdrew.