

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

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The CHAIR — I welcome Professor Hal Swerissen from the college of science, health and engineering at the Bendigo campus of La Trobe University. He is also a fellow in the health program at the Grattan Institute. The committee thanks you very much for being here this morning.

I will just caution you that all evidence that is taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of Legislative Council standing orders. Therefore you are protected against any action for what you may say here today, but any comments made outside the hearing will not be afforded such privilege. Witnesses found to be giving false or misleading evidence may be in contempt of Parliament. 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.

Professor, we have allowed an hour for your presentation and questions this morning. I would ask you to make an opening statement of no more than perhaps around 10 minutes, and thereafter the committee will have questions for you. Thank you very much.

Prof. SWERISSEN — Thank you very much, Mr O'Donohue. It is a great pleasure to be here. I should say at the outset, as people in my position often do, that my views are my own today and not those of either of the institutions which I work for. I intend to make a short statement which really relates to work that I did last year on dying well, which some of you will have seen as a report which was published by the Grattan Institute.

In the beginning, let me say that around 40 000 people a year die in Victoria each year, and that is a little bit less than 1 per cent of the population, so about 6 in 1000 people die. Most of those people die from a chronic disease after the age of 70. Those diseases include heart disease and cancer. And most people die in a hospital or residential care facility — something in the order of 70 per cent.

That is very different than occurred about a century ago, when most people died from infectious diseases, often early and in childhood, and the rate was about twice as high as it is now per capita. Our health system was really designed to deal with that period of time, when people died relatively quickly from infectious diseases and trauma. In fact most of the healthcare system was designed to deal with military situations. In acute care, patients present with acute conditions, they are treated, they either get better or die relatively quickly. That is actually what the history of the healthcare system is.

Chronic diseases which we now die of are very different. They often take time to develop and diagnose, they are typically progressive, they are difficult to cure and they usually have to be managed by the patient in the early stages and often require considerable personal support in the later stages. They are heavily skewed towards older age, and often people have more than one chronic condition.

The change in the way we die is that we now have much more predictable deaths than was the case with infectious diseases or trauma, where you would be well one day and dead a week later. Now we often have long periods of time when people know that they are essentially heading towards the end of life. The exact prognosis, if you read the literature, is often a bit more problematic, but the reality is that people have a pretty clear idea of what trajectory they are on. The trajectories vary depending on the nature of the disease, so typically with cancer the trajectory is that you know you have cancer that you are likely to die from but you remain relatively well for a considerable period of time with the disease and then you have a fairly steep decline in maybe a month or so towards the end of your life. Dementia is a very different proposition, where you know you are going to die but you often have a very long period of time when you are quite unwell. Heart disease tends to bounce around with episodes and a gradual decline with chronic cardiac failure, for example. So we have a different trajectory for death than we did 100 years ago.

The acute care approach, when it is applied to chronic disease, often leads to fragmentation, confusion and distress. At worst it is intrusive and disabling. Treatment persists when there is little benefit, sometimes hastening death when treatment is overapplied. Paradoxically, palliative care often leads to longer periods of life than acute interventions, something which the literature clearly shows. Often realistic conversations about positive and negative impact of treatment do not occur, and people do not have the opportunity to clarify what really matters to them, including how they would like to die when time is short.

It is unlikely we will see dramatic improvements in the treatment of chronic disease in the near future. Notwithstanding all of the headlines in the papers about the latest interventions which have been developed,

average life expectancy is likely to continue to increase but with increasing disability, and it will be marginal increases over the next 20 or 30 years. Science and medicine have made great advances, but our unwillingness to accept their limits makes it more difficult to suggest that cure is improbable, that further treatment is unkind and that death is coming.

We no longer discuss the inevitability of death, and we do not prepare for it over the course of our lives. When pushed a little, most people say that a good death is one where you know what is coming, where you have some control of what will happen, that you will be comfortable and supported by family and friends and healthcare staff at home and that you will have an opportunity to say goodbye and to make sense of your life. That is what people would say is a good death. Most people say they do not want to have life prolonged when it is pointless to do so. If you go out and do the research on that, that is what people typically say.

We need a new approach to chronic disease and dying. To achieve a good death, we need to prepare for it. People now have limited experience and exposure to death. Most of us do not see dead bodies on a regular basis, do not see people dying and do not have that experience. A hundred years ago people died at home, so you saw it on a regular basis. You would go to people's houses and you would say goodbye and so on.

Death is an intensely personal matter. Each of us is going to have to figure out how we are going to face these realities ourselves. Most of us do not take the time to think about what that might mean. Public information and discussion about how people prepare for death needs to be promoted. It is a difficult topic, but we as policymakers — and that is why we are here today — need to have a sustained approach to actually promoting a discussion about death and dying and how we would like to do it. This includes information on how people die, the experience of dying, the services that are available, what you can do to have a good death and the choices you have to make. Public information campaigns should be funded. That is one of the things that we recommended in our report.

When it comes to expressing choices and preferences, it is important there is a systematic and ongoing framework for discussion with families and healthcare professionals. Currently advance care plans and directives offer the best option for that, and developing that framework is an important public policy agenda. Key elements include ensuring preferences and choices are clearly expressed. The critical thing is to make sure that people indicate what is important to them, that a medical power of attorney is in place so that in the circumstances where you cannot make decisions — in about 70 per cent of deaths people are no longer able to make decisions for themselves, so it is a very common situation — there is someone there who can articulate what the person's preferences were to the hospital staff or the community staff and the medical staff who are there, and that we have clear rules so that providers — the doctors, the nurses and the healthcare staff — know what their obligations are in these sets of circumstances.

The reality is that advance care plans and directives are very poorly used at the moment, and very few people have them in place. Very few people have medical powers of attorney in place. Even in nursing homes and residential care facilities very few people have them in place, yet 90 per cent of permanent residents in nursing homes or residential care facilities will die in the residential care facility. Conversations should occur as part of a systematic approach. We recommended that they happen at the over-75 healthcare checks — when people are in hospital and there is a high probability that they will die in the next year — and that they are applied in the discharge plan so that the discharge plan recommends that a conversation occurs with the general practitioner. We also think that on entry to residential care facilities it is important that people think about having the conversation.

In expressing choice in our preference to die, currently we can indicate a number of things that we do not want. These include things like resuscitation, intubation, catheterisation et cetera. We can say that we are happy to have terminal sedation and restrict nutrition — feeding and water and so on — but we cannot ask for active assistance to die.

In practice there is a fine line between legally accepted practices like terminal sedation and illegal practices like physician-assisted dying or providing the means for people to die, yet about 50 per cent of medical practitioners have had patients ask them for a quicker death, and around a third have hastened death, often justified by the doctrine of double effect, where treatment such as pain relief also leads to a quicker death. But when attempts are made to formalise voluntary euthanasia and assisted dying, potential risks for those who are vulnerable, young, have disabilities, mental illnesses or feel themselves to be a burden are raised. That is the typical list of things that get raised in these circumstances.

It is argued that it is not easy to determine when conditions are unbearable or terminal. Claims are made that too many people would choose voluntary euthanasia and assisted dying, that people will be coerced, that practices will become slipshod, the slippery slope kind of argument, and that the underlying principles of health care will be corrupted — you know, the notion of what it means to be a healthcare professional will be undermined by the idea that you might be able to assist people to die.

In practice, where voluntary euthanasia and assisted dying have been legalised, generally these concerns that have been raised have not been realised in the jurisdictions where that has occurred. Only a small proportion of people who die in these jurisdictions actually use voluntary euthanasia — less than 2 per cent generally. It is around 3 per cent in the Netherlands; it is much less in the United States. It does not vary significantly across those jurisdictions, and most people choose not to use it, but many find it to be a comfort that it exists as an option for them when they are in circumstances where they might have unbearable outcomes.

Some arguments are that all deaths can be managed successfully through palliative care. The reality is that not all deaths can be successfully managed through palliative care to reduce pain completely, to reduce distress and suffering and so on. There will always be a small group of people who have very difficult deaths, and people will be frightened of that or will not want to go through those kinds of experiences. Consistently where legal voluntary euthanasia and assisted dying have been available, the overwhelming majority of the population has continued to support those practices after they have been implemented. That is what the research indicates. Support for well-regulated voluntary euthanasia has been strong in the Australian population for many years now. Around 70 per cent of the population supports well-regulated, carefully planned voluntary euthanasia — not an unregulated set of arrangements.

The other thing I would like to comment on is that to have a good death we also need services so that we get people who are responsive to our needs. At some point when they are dying many people choose palliative care approaches, often in combination with other treatment. For people with chronic conditions, the burden heavily falls on carers if they want to die at home, and 70 per cent of people say they do want to die at home. We have a big mismatch between what people want and what actually happens. Currently services for people who want to die at home are inadequate, and as a result they have little option but to die in hospital or in residential care if they need significant support.

More competent, comprehensive and coordinated home and community-based services are needed for people who are dying if we are going to support them at home. Much of what is required is well-coordinated personal care to relieve pain and symptom management, as well as counselling, respite care and so on. It needs to be available seven days a week, 24 hours a day in order to work. Only a fraction of our estimate of \$5 billion worth of care in the last year of life is spent on community-based support, which is only a tiny fraction. Around Australia it is probably less than \$200 million.

A number of agencies have now demonstrated they can provide home-based palliative care services effectively, and those who have received these services are much more likely to die at home than in hospital. The research that we have looked at states that 60 or 70 per cent of people who are receiving community-based palliative care then die at home, as opposed to what happens in hospital.

The commonwealth has a well-established funding model for community-based support. It used to be called the home and community care program. It is going to be called community-based support in the future. Our report, *Dying Well*, estimated that on average home-based support for the last three months of life costs around \$6000 per person. Around 70 per cent of people who receive good quality palliative care at home will die at home, and savings from hospital and residential care would offset the cost of extending those services to all of the people who would want them. It is not an expensive exercise in doing that; it actually reduces the cost. The last hospital admission alone, if it were saved, would pay for that care. We think there is room for a significant expansion of community-based palliative care. Thank you very much.

The CHAIR — Thank you, Professor, for your presentation this morning.

Ms FITZHERBERT — I very much enjoyed your comments, and I was particularly interested in the attention that you gave to dying at home. I am broadly aware of the figures on this and that most people prefer that, as you say. My anecdotal observation is that it is often difficult to make the call as to when that transition should happen. Typically someone is in hospital, they are seriously ill and there are a range of discussions, but like life, death can be a very uncertain business. What sort of change could this committee make or suggest to

make that very imprecise process better? What could we do on a practical basis to say this is how we are going to make it easier for that really difficult move from usually hospital to home to happen and in a meaningful way?

Prof. SWERISSEN — The critical thing to think about in public policy terms is that — you are right — when people are in the situation where there is some uncertainty about when they will die, whether it is imminent or happening but will take some time, it is very important that, firstly, the conversations occur so that people are clear about what they want. It is very difficult if you are right at the end of life to have conversations like, ‘I always wanted to die at home’ or if you are very uncertain. It is very important that you are clear about your preferences early on and that those preferences are then built into the planning of how services will be provided so that people know what is going to happen.

Typically what will happen is there will be a moment when a little crisis or a major crisis occurs and it is likely that things are going to happen. If things are not in place prior to that happening, it is very difficult to organise it at the time. You are scrambling to do that. What is really important if you are going to do palliative care at home is to make the decision early, when you are still relatively well, that that is what you want and that the palliative care service is involved even when treatment is still progressing.

The idea that you go from treatment to palliative care is the wrong idea. You need to have the two combined early on in the process. One of the things that is important in advance care planning is to say to people that it is not either/or; they can do both. That is good information for people and it can be built into planning so people can express their views about what they would like to have happen, so you do not see it as, ‘Well, we’re stopping treatment now and now we’re going to palliative care’, but instead you say, ‘Well, it’s likely that you might die, but let’s continue with the treatment regime, and let’s also introduce the concept and start you being involved with a palliative care service’. Doing that is very important, and many palliative care services adopt that process — most, I think, in reality.

It is important from a planning perspective to put that into what happens with the conversations that people have. Many people do not understand that. I am not sure what it is in the community more generally, but it is important that that happens. In public policy terms, it is very important to have a very good planning framework for doing that.

The other thing that needs to happen is more availability of care around this and to get good coordination of care so that when people make these choices, that they want that option, there is someone who is responsible for making it happen. What often happens at the moment is you are in hospital, and they are not really responsible for organising these things. They will do palliative care in the hospital, but they do not really organise the other part of it. The GP is not really framed into this. What is important is that the planning framework on the side of the service providers has some obligations in relation to who is going to make this happen. We need to get the responsibilities clear, otherwise you bounce around. That is an important part of what needs to happen.

Ms FITZHERBERT — My understanding is what tends to happen is very similar to what you say, which is that at the point a decision is made that, ‘Look, there is nothing more we can do, it is time for this person to go home’ — and that is what is desired by everybody — the family then, all of a sudden, has to immerse itself in a world that it knows nothing about to make that happen.

Prof. SWERISSEN — Yes.

Ms FITZHERBERT — My question is that you have talked a lot about advance planning and conversations, and that is true, but I look at the number of people who make wills in this country. We all know we are going to die, it is just a question of when, but many people never want to do any sort of planning that anticipates that fact. Is there a limit to how perfect we can make this?

Prof. SWERISSEN — Of course there are limits to how perfect we can make this, but at the moment it is very imperfect. The line that I use in relation to this is that all of us only die once, and so it is not surprising that we do not really do a whole lot of the preparations that we ought to do, particularly given that it has changed so much over 100 years. So what we have to do is create systematic prompts for people to do these things. The healthcare professionals, on the other hand, are involved in seeing people who are dying on a regular basis, so it is important that they have the obligation to prompt the conversations. If you ask people themselves to prompt

the conversation, you are right, you will have a level of imperfection at a grand scale, so what we need to do in a public policy sense is put the prompts in.

It needs to become a normal expectation of practice that medical practitioners and other healthcare professionals who are in the position to have those conversations have them systematically with people at the right points in time. We could do this in a variety of different ways. The mantra at Grattan is independent, rigorous and practical. The practical bit of this is: where are the practical points at which you can put these conversations in place? Those practical points are: over-75 healthcare checks; when you are in hospital and very seriously ill and the clinicians would not be surprised if you died in the next year; and when you go into residential care. They are three points at which really there should not necessarily be a plan, but certainly the opening up of the conversation to say to people, 'Have you thought about what you would like to have happen when time is short?'. That is then opening up that possibility for people to say, 'Well, no, I haven't thought about that'.

The other thing we need to do is to make this a firmly legally-embedded process but one which is relatively straightforward and manageable for people to complete so that they can actually do this. Medical power of attorney and advance care plans are not hard to do but you do need to go through a process and people need to be set up. At the moment it is a bit tricky because you have to get various people to sign off and so forth. It would be better if we cleaned that up just a little and made it a more routine process at the GP's surgery — that you could do that reasonably straightforwardly — so that you could come out with an advance care plan or an advance care directive and a medical power of attorney without too much drama. It needs to be legally well-regulated and all of that and it needs to be easily updatable, able to be put on the record and so on. So there is a bit of work to be done to get this in place in a more systematic way.

Mr MULINO — Just a follow-up on one of the points just raised, I was also interested in the proportion of people dying at home and the fact that it appears to be a lot lower than the proportion that would like to die at home. You suggest that a public education campaign is one of the steps we might take, among others, and I suspect that funding is also part of the picture there, but as you suggest, it might end up being neutral or potentially positive in the longer run. I was looking at the rate at which people die at home across comparable societies and it varies widely. There is a whole range of issues at stake here, I suspect, but I was wondering whether other countries have gone through a process where they have tried to facilitate people's options and where they have undertaken either a public education campaign or other public policy choices and where they have dramatically increased that rate.

Prof. SWERISSEN — Certainly in relation to public education campaigns there are a number of countries where people have effectively — and to some extent there is a bit of that in Australia already, but it is just a bit underdone. A number of countries have done that, where they have run public education campaigns with the outcome being to think about preparing for your own death and think about having advance care plans or something similar, whatever the jurisdiction has. It is probably fair to say that it is not fabulously done anywhere at the moment because of the nature of what has happened to death. So we have to work at it harder, but nevertheless there have been a number of places that have put campaigns in place.

In terms of the variations that have occurred, the trend now in a number of European countries is to start moving back towards dying at home, so increasingly putting services in place that start to address this issue. So the fact that you are having this inquiry and the fact that this is a live discussion and has been — —

The voluntary euthanasia bit has been something of a clouding of the issue around the bigger issues. Often the debate will end up being about voluntary euthanasia and assisted dying when the bigger debate is about dying at home, getting your preferences met and making sure that you can express what you want for that 98 per cent of people who will do that. The trend is starting to move back towards supporting people to die at home, and that is where it will go. That is because of the nature of how death is now.

Australia is a little behind some other jurisdictions in wanting to have that debate. It is struggling a bit. The nature of our federation and a range of other issues means that it is inevitably the Australian way. Sometimes we are ahead of things and sometimes we are behind, but we are probably a bit behind in that debate in some respects about dying at home, but in order to die at home you do have to have comprehensive services to allow people to die at home.

Mr MULINO — I am just looking at that table on page 4, and wondering whether there is a comparable table that I might have missed where instead of looking at the rates of people dying at home it looks at perhaps

the turnaround or the time series, and I am wondering whether, by looking at that, we might usefully be able to see a couple of case studies about what has worked, and that might be a starting point.

Prof. SWERISSEN — There is some literature — and it may be referenced in the report; I cannot recall exactly — which talks about the turnaround which has occurred over the last 20 years where it has been on an up. It is now turning, but it has not yet come back comprehensively. The best way I can run the analogy for you is if you look at the 1980s, the fundamental emphasis when you became frail and old was on going into residential care. We then moved towards an ageing-in-place policy, and we then put in place community-based care — home and community care programs came along. We have now dramatically reduced the extent to which people stay in nursing homes or residential care facilities, because we have put those services in place. The policy environment occurred 30 years ago now, and so we have changed that. We have not quite adapted that to dying at home, but that is the trend that is happening internationally. That is a broad-based trend which is happening everywhere.

Ms PATTEN — Thank you, Professor Swerissen. I agree with my colleagues. I was just looking at those triggers you mentioned on when we should have this discussion and that this discussion probably needs to be mandatory. There are two questions there. Do you think we should regulate that so that when people are going into aged care, they must set out an assessment plan, and when doctors are doing that 75-plus assessment, they must set out this plan? With advance directive planning most of it is about what you do not want. Do you think there is room in there to say what people do want and whether that might include something like physician-assisted dying?

Prof. SWERISSEN — That is a very good question. We had that debate internally when we were doing the research as to what we would recommend. I am sure, given your day jobs, you think very carefully about the words you use when you make public statements. We thought very carefully about whether we would go to ‘mandatory’ as a recommendation or not. The words were used are that it should be a ‘normal expectation’. We are a bit wary of mandating that particular set of arrangements. What we think is that ‘normal expectation’ would mean that when we look at performance requirements, good-quality care and so on it would be a normal expectation that those conversations should occur at those points in time, that people would be audited regarding whether that had occurred and they would then be asked questions if things had not occurred in that way. You might tie that to incentives. To go to ‘mandatory’ would probably be counterproductive because you would end up with a debate about the fact that there are always circumstances where it is not reasonable to have that conversation et cetera, and people have explanations for that. That is why we said ‘normal expectation’. That needs to be not just words; it needs to be backed up with audits, reviews and questions when it is clearly not happening. That is our view about that.

The second point in relation to whether you should have a more active approach — that is, saying, ‘This is what I do want’, as opposed to, ‘This is what I don’t want’ — the way to think about this in some ways relates to what has happened in medicine. Fifty years ago the idea was that medical staff told you what you needed. The current position is that we do not tell you what you need. We are not the decision-makers for you. We provide you with options about what you can do. Neither of those positions is very useful when you are dying, because there are not very many options, and being told what to do is not very helpful. What is more helpful is to be asked. Atul Gawande wrote a wonderful book on this recently, which I would recommend you read. He is a physician in the United States. He said the question you really need to ask people is, ‘What’s important to you as you are dying? You’re going to die. We are all going to die. What’s important to you when you are dying, and how can I help you to achieve what’s important to you?’.

I remember when I was a student we had this conversation, as you do when you are a healthcare student. Some people said, ‘I don’t want life to be prolonged’. Others said, ‘I want to continue to live until the last second’. We all looked at that person because that was unusual, but some people have those views. You need to be clear about what is important to the person. Some people will say, ‘What’s important to me is that I can see my grandchildren or that I can continue to watch the television. It doesn’t matter that I can’t get around anymore. As long as I can do that; if I can’t do those things, that’s the quality of life that matters to me’. You need to understand what matters to people rather than saying, ‘Here are six choices that you have as to what the intervention might be. We can do radio or chemo or whatever’. Those things are important when they lead to something. That is a critical thing.

In the conversation about advance care planning we currently do not give people the option of saying, 'Under those circumstances I would rather not continue'. The question then is that it is not so much about my personal view, but what is clear is that there are many people who say, 'Under those circumstances, I would like the option'. That is the reality of it. The debate then becomes about whether it is a reasonable option for people to have. Different jurisdictions have solved that in different ways in terms of saying what they would like to have achieved.

In Australia the view in the community is clearly that people would like that option to be there. We currently allow voluntary euthanasia, but we have it hidden. It happens all the time, in fact, that people are assisted to die. Sometimes people like Rodney Syme go out publicly and say that they do that. Oftentimes people are hiding it. We have an unregulated system of assisted dying and voluntary euthanasia at the moment. The question really is whether it would be better for it to be regulated and for us to set out clearly where it goes. There have been 30 years of debate about how that should be dealt with since the medical refusal of treatment legislation in the 1980s. There is a very fine line at the moment between terminal sedation, lifting the pain medication up, withdrawal of nutrition and so on. They effectively hasten death. There is a very fine line at the moment with these things. That debate has been going on for a long time.

Mr MELHEM — In your paper here you talk about 'Toward the Better Death' and you have got three options in relation to reforms that you are talking about. There is the public discussion, which you have touched on, the individual plan and the one that I am really interested in — and I think they are all good points — is the trigger point. You talk about 75 admissions et cetera. On these triggers, at what point do you turn the light off?

Prof. SWERISSEN — The triggers really refer to points at which conversations occur, and, as you said, we have set out a series of points of where that occurs. If I have got your question right, in relation to how do you make decisions about when you move from continuing to treat to saying, 'Okay, we should now move towards withdrawal of treatment or actively assisting people to die', there are two parts to that. One is that 80 per cent of people in intensive care end up in a situation where people say, 'Okay, we've about reached the limit of what we can do sensibly here. It's probably the point at which you, the family, need to make a very, very difficult decision, but there doesn't seem to be any point in going on, so we are stopping treatment'. That is a reasonably well understood kind of idea, and it happens all the time. There comes a moment right at the end of life where that happens reasonably straightforwardly. I do not think that is particularly controversial in our community anymore.

The other one, which is more controversial, is when people are still relatively well in the sense that they are not imminently going to die that day or that hour and they are still able to have that conversation, but they say, 'Look, I really don't want to go on in the circumstances which are facing me'. That is much more difficult, and people struggle with that. I am sure all of us, confronted by somebody who says that, would think that is difficult, if you were not used to having those sorts of conversations and thinking about what that might mean.

Typically the issues are: are the circumstances such that this is a reasonable request that this person is making? Are they making that request rationally and sensibly? Are there coercive pressures on them that might be leading them to make these decisions? And so on and so forth. It is beyond my scope to sort out all of the legal and technical issues, and one of the things that I would recommend that you think about, even if you do not proceed to legislation, is that there is a reference to the law reform commission to sort those issues out, and to look at the Australian circumstances to sort out exactly the question you are asking, which is: when is it reasonable to, as you put it, turn the lights off? They are not essentially healthcare issues. They are essentially legal, ethical and moral issues to be sorted out in a framework which is about when it is reasonable for people to make various kinds of decisions.

There are another set of issues which are secondary to that, which are the issues of what is the impact on the healthcare professionals and so on. But that is much less important than the issues for the people who are affected by this. The healthcare professionals' issues need to be sorted out, thought about and worked through, and there will be passionately held views amongst the medical profession and others who will come along and say what their view is about their role — the difficulty in providing care on the one hand and helping people to die on the other. That is a challenge. It is a socialisation issue within the medical profession and about the healthcare issues involved, but that is less important than the issues which are there for the people who are dying. The priorities of the people who are dying are more important than what healthcare professionals might need to struggle with in that space. I think that is something that needs to be sorted out within the Australian

context. You cannot just take the Netherlands or Belgium or Luxembourg or Oregon experience and say, 'Let's just translate that to Victoria'. You actually do have to create a framework which is uniquely for Victoria, which is why it is important to have inquiries like this one.

The CHAIR — Professor, I am interested in what you are talking about in terms of the coordinated role in our healthcare system. We are lucky to have an advanced healthcare system in Victoria and Australia, but as you have said, parts of it are disjointed, and you have state, federal, public, private and all sorts of other components to it that make coordination difficult. Could you describe how you would see in a perfect world what that coordinating role might be to take that pressure from families?

Prof. SWERISSEN — The critical place for coordination to occur ideally is with general practice. In a sense over a long period of time we have de-emphasised the role of general practice in actually helping to manage these sorts of processes. Often specialists end up taking responsibility for care, so a cardiologist or an oncologist will typically end up with the responsibility for people who are very seriously ill with the GP as a kind of adjunct to the process and what is going on. When that goes wrong, what tends to happen is we then bring in palliative care specialists to try to coordinate all of these arrangements, and that is yet another specialist coming in to try to deal with that. It does not always work. There are circumstances where you have palliative care people saying, 'When we have looked at this and we have asked people, it is not going well', yet the oncologist or the radiologist or the cardiologist will continue with a treatment regime, and there are mixed messages. The people in the middle are the patients and their families, trying to coordinate through that.

It would be better if we had a stronger role for general practitioners to help manage that and to coordinate that, but the way we pay general practitioners and the way we fund that part of the system is on fee-for-service arrangements, and it is expensive for them to then get on the phone and start to negotiate for people in the middle. We can change the funding arrangements for general practitioners — this is my next report, by the way — so that we give them a bigger role in trying to sort those issues out and make it more of their responsibility to sort those issues out so they can act as the patient's advocate in these sorts of arrangements. Working with palliative care teams where it is necessary, with the specialists, with the hospitals and so on to get the set of services which people really want. You do need someone who is reasonably articulate, capable and able to negotiate as a patient's advocate. Even I, when I go in and have procedures and so on, and I pull myself up to my full professorial height, discover how intimidated I can be by the nature of healthcare systems and so on. You need people who are advocates for you in that system, not who make decisions for you but who help you get your decisions implemented. So I think we need to strengthen that role because GPs are the people who we have the most ongoing sets of relationships with. It does not necessarily always have to be the GP; it can be a practice nurse or a nurse practitioner in the practice who does that, who works with others but who is close to that part. So I would put it there rather than otherwise. But there are moments when it needs to be from the hospital.

At the moment, just pragmatically, we do need to have hospitals taking more responsibility for people who are dying back out into the community as well just because our system is fragmented — just at the moment. We are now moving from the ideal to what is practically a reality in the public system: in the Victorian hospital system we do need stronger patterns of coordination back out for people as well. It can be a terribly confusing moment. Things take too long to get done when someone is very ill at the moment and you are going home again. The only option then is to say, 'Well, we're staying in hospital because there's no other option'. You cannot go home because it takes too long to get things done.

The CHAIR — You talked about systematic prompts. Also in your earlier presentation you talked about what I would perhaps describe as cultural change. We do not discuss these issues, and you are advocating for an education campaign. Could you perhaps give a bit more detail as to what that might look like and how we can perhaps address that cultural change?

Prof. SWERISSEN — At its crudest, we have had fabulously successful campaigns on a range of issues, including drink-driving, smoking, work safety et cetera. To some extent you have to get it into the public imagination. What we have sold people is this idea that the healthcare system is this marvellous thing, science is a terrific thing and we have made this amazing progress. So we have put our faith in this healthcare system. What we need to do is to get a more balanced approach. The reality of our healthcare system is that it is like trying to fix a Swiss watch with a hammer and chisel; it is imperfect. It is much less perfect if you work in hospitals — as I used to a long time ago. You realise just how limited our capacity to deal with things like heart

disease, cancer, dementia and so on really is and how humbling it is to be faced as a health professional with people who are dying when you really have no solution to the problem.

People need to understand that this is an inevitability that you do have to think about, and you have to make some sense of it. But we hide from it. We have professionalised, hidden and pushed away the notion of death to somewhere else, and so people do not want to deal with it. So we need campaigns which really get people just to think that this is something they do have to think about. So that is part of what needs to happen.

The other thing is that we do need to get health professionals to recognise that this is an important part of their job too, that they need to have these conversations. Lots of health professionals are not very good at this either. They struggle with this. They want to give people hope. If I walk out of here and fall down the steps and I am carted off to Royal Melbourne, I want them to do the best they can to look after me. But if I actually sustain a very serious head injury in the process and I am in a coma, I want them to get to the point where they realise, 'We need to have a conversation with my partner and my friends and my family', so that they see that as part of their role instead of it just being about hope pushed out unrealistically for people.

Most of the time the prognoses — what we give to people in the health system — are overly optimistic about what is going on. We do need to have more realistic sets of conversations with people. You see some very difficult situations when those conversations have not occurred, with people finding out that someone is dying who has actually been dying for months, as they are right at the end, and people say, 'You do realise your mum's dying?', and it is a shock because those conversations have not occurred, or they have been elliptical in their approach. So we do need to put more emphasis on it.

Ms PATTEN — You mentioned in other countries where there is physician-assisted dying and other jurisdictions, that less than probably 2 per cent of the people who die actually take that option. Do you have an understanding of why that is? I think people anticipate that if we offer it, everyone will take it.

Prof. SWERISSEN — There is a long, complicated story. The short version is that many people die quickly, so notwithstanding what I have said, there are a proportion of people who die quickly. The classic is a heart attack — 25 per cent of people die of cardiac failure in the great scheme of things. So you end up with strokes, heart attacks and so on that do not lend themselves to this kind of conversation. Cancer is typically the one which does lend itself to the conversation — probably 25 per cent or 30 per cent of deaths. Then you have got dementia. That is more difficult because of the notion of voluntariness. We immediately reduce the pool of people, so you have to look at the nature of dying. Then within that there are some deaths which are reasonably okay, and people say, 'Well, I'm willing to go through that process'. There are others where people say, 'Well, I don't want to', and then it gets down to personal preferences. Soon you get to a small proportion of people. A number of people like to have the option, and the reports are that they have the means or they have actually been through the process and could exercise their option if they would like to, but they do not.

Ms PATTEN — Do you have any idea of what the figures are for the people who take up the option but who do not exercise it?

Prof. SWERISSEN — Offhand I do not, no.

Mr MULINO — I just have a very quick one. I just wanted to clarify a statistic that you cited. I think you said that given the rising prevalence of chronic as opposed to acute conditions as the nature of death changes, something like 70 per cent of people at the end of life cannot make informed decisions.

Prof. SWERISSEN — Yes.

Mr MULINO — I just wanted to break that down a little: what proportion of that would be that people are not of a full state of mind, what proportion is that people might be unconscious and what proportion is that it happens too quickly?

Prof. SWERISSEN — It is a combination of all of those things. The first thing to remember is when you go into hospital for any serious illness, then often you will end up in a position where you cannot make decisions well for yourself anyway. So even if you are not dying, the nature of illness is such that it affects cognition, and so people end up in situations where decisions need to be assisted. They need someone saying, 'Yes, we will do that', or, 'No, we won't'.

If it is a straightforward thing and you are in a hospital, it does not matter, because the treatment is the treatment, that is what the protocols say, and we will continue to do that. Most people are not going to be a position where they can say, 'Well, I want my appendectomy done this way, not that way'. So it is only when you get to a point where you actually have decisions which are not essentially healthcare decisions, they are essentially decisions about wanting my preferences exercised that it becomes an issue. That is why it is important at the end of life.

The nature of the illness determines what that is, so cancer is a different trajectory from dementia, for example, in terms of what that is. In terms of the exact proportions, I do not know that there is a lot of breakdown of that. I have not seen a detailed breakdown.

Mr MULINO — It is probably rising over time.

Prof. SWERISSEN — It is rising over time — is it rising over time? I do not know whether it is rising over time, because I expect with infectious disease, for example, you also become incoherent at the end because of the nature of the disease, leading to lack of cognition. So in the end, when you are very seriously ill with an infectious disease, you also reach the point where you cannot make decisions for yourself anymore.

Mr MULINO — But the broader point is that it reinforces the importance of an advance planning regime —

Prof. SWERISSEN — It is absolutely critical.

Mr MULINO — whether that is legislative or through common practice or whatever it is.

Prof. SWERISSEN — That is right. It is not like most people at the end of life are able to still make decisions for themselves, so it is important that you have advance care plans and medical powers of attorney in place so that there is someone there who is helping. Otherwise everybody is standing around thinking, 'What would the person want? So it is important that you clarify that, because in many cases it is difficult for people.

Ms FITZHERBERT — Should people be able to choose exactly when and how they die and on what basis — leaving aside all of the forward planning you might do?

Prof. SWERISSEN — The only way to answer that question is either to answer it personally to say, 'I think', or to say, 'What does the research say that the community more generally wants?'. What I think does not actually matter, because all of our opinions will be our opinions. What I can tell you is what the community thinks, and the community thinks yes, there is a set of circumstances where it is reasonable for people to be able to make that decision. At the moment, as you know, it is about terminal illness, unbearable suffering, having a sound mind, blah blah blah. There is a series of criteria. It needs to be regulated. That is what people will say they would accept. They will not accept circumstances beyond that.

What I think is not so important. What is clear in the research over a period of 20 or 30 years is that is what people think. In jurisdictions where it has been possible to do that, people continue to support it. There is strong support in the Netherlands, Luxembourg, Oregon and so on where these things have been put in place. People support it. They have had experience of it; they have seen it happening. The approaches vary — legislative approaches in some places, decriminalisation in others et cetera. Regulatory environments vary in terms of how that is managed and the exact nature of that. But essentially it is the case that that is the experience.

As I said earlier, the reality is that assisted dying and voluntary euthanasia occur now in Victoria. It is just not regulated. As you know, people are not happy to go out and prosecute people who in good conscience and for the best of motives enter into the set of arrangements at the moment. We know that that is the case. We know that a very significant proportion of medical practitioners faced with people who are dying are asked to provide assistance, and about a third probably do or have, so it is a reasonably regular thing. They may justify it on the basis of the double-effect doctrine or other bases, but the reality is that it is occurring.

We already have frameworks to deal with decision-making: the guardianship legislation and so on, which are the Victorian approaches to try to deal with the issues. There is the medical power of attorney, and there is the refusal of treatment arrangement. As I say, it is really a blurred line now where that exists. The bigger issues we have talked about — I think on that particular point that the question is: is it a reasonable line at the moment, or should it be moved a little bit to actually make what is really already occurring occur in a way which is regulated and sensible? What is the next step?

All the history suggests that this is a trend which is progressing. Now, how far it progresses I do not know, and you are going to be in a better position than I am to deal with that issue. In a sense your opinion about whether it should happen or not is more important than my opinion.

Ms FITZHERBERT — I don't know about that.

Prof. SWERISSEN — All I can tell you is what the research says. That is what my job is, not to give you a moral view about that.

The CHAIR — Professor, the committee would like to thank you very much for your time this morning and for your evidence. As I said earlier, you will be provided with a transcript in the coming days, and we again thank you for your presentation.

Prof. SWERISSEN — My great pleasure. Thank you very much.

Witness withdrew.