

The Policy Pitch – *Change to die for?* - Melbourne 19 August 2014

The baby boomers are reaching old age and in the next quarter century the number of Australians who die each year will double.

But dying in Australia is amongst the most institutionalised in the world – 86 per cent of Australians die in hospital or residential care. Many have deaths that are lingering, impersonal and disempowered and the cost of dying is high. With dying on the increase, this will become a much more significant issue for health policy in the future. The forthcoming Grattan report, *Change to die for?* argues that death is hidden and avoided and that most people have not discussed the services and support they would like when they die. How do we get people to discuss their preferences and choices for end-of-life care and what reforms are needed to ensure people have a good death?

This *Policy Pitch* event discussed the changes needed to improve the quality of dying in Australia.

Moderator: Stephen Duckett, Health Program Director, Grattan Institute

Speakers: Hal Swerissen, Health Fellow at Grattan Institute
Senator Jan McLucas, QLD.

BEN CLARK: Good evening everybody, my name's Ben Clark, I'm the Director of the Foundation and I'm delighted to welcome you here this evening. Our event tonight is held on the traditional country of the Kulin Nation and I wish to acknowledge them as the traditional owners and pay my respects to their Elders and to Elders of other communities that may be present this evening.

This evening's presentation is part of a broader series entitled *The Policy Pitch* which the Grattan Institute and the Library have partnered on and it's a really exciting initiative, it's probably about six months into its continuation. We often attract a very diverse and interesting crowd, and it's certainly testament this evening, but I'd particularly like to welcome and acknowledge members of the Library Board of Victoria, this evening's speakers, Dr Stephen Duckett, Professor Swerissen and Senator McLucas. I'd like to acknowledge members of the Friends of the Library who are a critical support mechanism for the work that the Library does, both conserving and acquiring parts for our incredible heritage collections, but also our extensive programming which covers things such as the Creative Fellowships Programs. If you have any interest in joining our Friends, I think their brochure's outside and I'd encourage you to grab one because it's full of rich and interesting content, as indeed are the benefits for those who join and become Friends.

We are delighted to be partnering with the Grattan Institute, as I mentioned, to present this series. *The Policy Pitch* brings to the Library a new audience, professionals and public policy makers in the fields of law, health, environment, energy, politics and higher education. This evening's topic is testament to that, *Change to die for?* I'm very pleased to introduce our participating chair this evening who is Dr Stephen Duckett. He's held top operational and policy leadership positions in healthcare in

Australia and Canada, including Secretary of what is now the Commonwealth Department of Health. He has a reputation for creativity, evidence-based innovation and reform in areas ranging from the introduction of activity-based funding for hospitals to new systems of accountability for the safety of hospital care. An economist, he is a Fellow of the Academy of the Social Sciences in Australia, and Stephen is also interestingly a strong supporter of the Library's Creative Fellowship Program and has endowed the Berry Family Creative Fellowship which actually investigates social history elements of this extraordinary city.

Tonight, Stephen, Jan and Hal are here to discuss the changes needed to improve the quality of dying in Australia and clearly we have a distinguished panel with impressive expertise in the field. I look forward to your insights for what I'm sure will be a fascinating discussion. Please join me in welcoming the panel.

STEPHEN DUCKETT: Thanks very much Ben, it's a real privilege for Grattan to be able to partner with the State Library in this event. It's part of getting ideas out into the public domain and tonight's event is also a part of that where at Grattan we're working on a report on end-of-life care and you are the lucky people who are being exposed to that report, in a sense, in its draft stage. So we really look forward to the questions and comments that you have at the end of the session.

We're very privileged to have two people with deep expertise in the health system and in the policy world.

The first is Professor Hal Swerissen. Hal has a long and distinguished career in healthcare, both as an academic; he headed the Australian Institute of Primary Care at Latrobe University and was subsequently Executive Dean of the Faculty of Health Sciences at that university. He's also worked in the policy sphere as an advisor and as a senior manager. He's been on the board of a number of health service organisations and is currently on the board of a Medicare Local. Hal is now working with us at Grattan Institute and is the lead author of this report on end-of-life care in Australia. So please join me in welcoming Hal to give his speech.

HAL SWERISSEN: Thanks very much Stephen and let me also join with Ben in acknowledging the traditional owners of the land here tonight. This is an interesting topic for me because I'm broadly interested in the questions related to the limits of healthcare and in a sense there are limits, there are very significant limits to healthcare and they occur sometimes in the misapplication of healthcare, when we see services provided in ways which are not optimum, and in other cases where we just don't know what the optimal outcomes that we're pursuing might be, and I guess death in many respects is the ultimate limit to where healthcare can't solve the problems. So what I want to talk a bit about tonight is why we struggle with these issues and what some practical suggestions might be for going forward in relation to improving the quality of dying in Australia and the policy environment which might address those issues.

Firstly, it's important to recognise that the Australian way of death has changed dramatically over the last hundred years or so. Each year about 150,000 Australians die, two-thirds of those deaths are between the age of 75 and 95, two-thirds are from chronic disease, and what that graph is showing you is that mostly death occurs after the age of 70 in Australia. So we now have a much more predictable period where we're likely to die, we're much more likely to die from chronic disease and we're likely to have a longer period at the end-of-life when we're thinking about what our options will be. We're also likely to experience more disability at the end-of-life and much more intervention.

The other thing that's happened which is dramatically different over the last hundred years is the place that we die. A hundred years or so ago most people died at home; now most people die in institutions and what this is showing you is that about 14% of Australians die at home, the majority of people die in a hospital or in residential care. When you actually look at what people would like, the majority of people would like to die at home, 70% of people when they're asked say that they would like to die at home supported by family and friends and appropriate care and even when people are in the period when they're dying they say that they would prefer to die at home, so it's not just a survey result, it's when people have thought about it carefully they would like to have the option of dying at home. But the reality is that most Australians now die in institutions. As a result, we have seen much more intervention in relation to end-of-life. This slide is showing you hospital rates and the changes over time, so what we have here is the comparison over a period of ten years or so for males showing you the increase in hospitalisation rates and for females which show you the increase in hospitalisation rates. And across here you can see that as you get older you're much more likely to have interventions in hospitals and that's indicating that we have a high level of intervention when people are at the end-of-life.

What this leads to of course is questions about costs. The reality of costs in relation to dying is that they're significant, but manageable. Overall we spend around about \$4.64/4.7billion on hospital, residential care and community care for people who are dying. What this table shows you is that community care for people who are dying is a comparatively small proportion of all of our costs, in fact it's only \$77million out of the \$4.5billion that we're spending. So we spend only a very small amount of money on supporting people to die at home at the moment; the majority of costs are in institutions. The effect of all of this is that dying is going to become much more significant in the future because the Baby Boomers are coming and going over the next 30 years or so. So what this slide shows you is that the absolute number of deaths in Australia each year will double over the next quarter-century or so. And, although I don't want to be unkind about the audience, many of you will be in that group and you will actually have a very significant interest in what the policy outcomes are of the discussions about dying. So the effect of all of that is that we will see a significant increase in the number of people who are in the aged cohort because of the Boomers going through.

So that's the pattern that's occurred over the last hundred years, these are the trends that are there: highly institutionalised, much more predictable, much more chronic disease and so on. The question that arises is what does a good death look like and are we getting a good death? Well, the evidence suggests that we could do better in relation to death. A good death probably looks like this: people having much more of a say about what happens when they're dying; to know when they're dying; to have good symptom control and pain relief when death occurs; and to have a choice about who's present and when it's time to go. Also, to have the opportunity to come to terms with death and to say goodbye and put affairs in order; to have access to good advice, good services and so on; and to have control over the process. So most of the literature on dying includes that kind of set of criteria, but the reality is that in Australia death is often not discussed. In effect, we have a healthcare system which is focused on cure and prevention and treatment, rather than on dealing with the inevitable end-of-life, so the choices that are made to have the discussions about dying are difficult ones and they're not well-structured in our healthcare system. So very few people have their preferences and plans known in advance and, although we have well-developed systems for thinking about these things, relatively few people actually have plans for end-of-life well worked out. Even in places like nursing homes, only a tiny proportion of the people who are residents in residential care actually have plans and in part this is about the concern about hastening death.

So the reality is that in many, many cases people have treatment withdrawn at the end-of-life, that there are decisions made to hasten death through the interventions which are actually occurring at the time, but there's a significant debate and concern about that. The reality is that even when we have circumstances where voluntary euthanasia or assisted dying are available, a small proportion of people use it but it gives comfort to people that they know that are options for the end-of-life when they're available, that's what the research is suggesting. But there are significant concerns in the Australian community about moving in that direction and that distracts the debate from the quality of services that we would like to have. The other thing that happens in dying is that there is pressure on carers because we don't have sufficient support for people to provide care at home with palliative care services or end-of-life services. There's only a very small proportion of care, as I pointed out earlier, which is available for people at home. And the other thing is, as many people will know, care is often very fragmented. Sometimes we end up with palliative care services being provided by one agency, home and community care by another; we end up with very different sets of arrangements being put into place.

So now we come to the policy pitch, which we'll be interested to hear your views about tonight.

The first thing that we would say and that we're looking at recommending is that we need to have a much more significant set of discussions about end-of-life and the limits of healthcare. And so there really needs to be a public debate about these issues and a public debate which promotes people having discussion about their preferences for how end-of-life should occur, and that debate needs to be promoted by government systematically. We've done it in a number of other areas – organ donation, transport and accident commission, campaigns to prevent people from driving badly – and we have a range of social media campaigns which are about changing public perceptions of key issues, and dying is a critical issue to have that sort of a debate about. So we're recommending that as a very important step we think that that should become a public policy focus.

The second thing is we think that there needs to be, in the promotion and development of end-of-life, discussions and plans. There's already a well-developed model for doing this which are called Advanced Care Directives and Advanced Care Plans and they are well-developed resources for pursuing those, but effective, as I said earlier, very few people actually have systematically had discussions about the end-of-life. So the approach that we're suggesting is that we put incentives and requirements in place for health professionals to have discussions around the 75+ health checks which are already in place, so that it becomes part of those discussions; that the discussion about end-of-life becomes part of chronic disease planning, there is a whole system for chronic disease planning which General Practitioners engage in; that it also becomes part of entering into residential and community aged care programs when people do have significant health needs that they need support for; and at discharge from hospital for those who are likely to die so that, as they go back out into the community in the period that they're likely to die, that there is a set of encouragements for people to have discussions about end-of-life planning.

The third thing that we're recommending is that there needs to be a greater emphasis on giving people choice about where they die, so we're suggesting that currently only 14% of people die in the community. If we took that up to the sorts of averages which are there for comparable countries like New Zealand, France and the United Kingdom we would see roughly a doubling of that percentage to 30% of people having the option to die at home. But in order to do that, we would need to provide much more support for carers and for families to manage that, so we're recommending that a very significant increase in support packages is required, which includes the elements which are in that list

there. Now in the end, the important thing to recognise about policy recommendation is that dying is a very significant but a comparatively small component of the overall care that the healthcare system provides. So it's important to try and have practical, focused measures which don't require you to re-do the whole healthcare system in order to improve the quality of dying. So the challenge in these discussions is where you put the emphasis.

And, in the end, I suppose I'd finish by saying that this is an issue which effects everyone and which is the focus of current debate and discussion in a number of forums and it's something which will inevitably have to come back into the policy discussions for a more integrated approach to how we manage end-of-life care. Thank you very much.

STEPHEN DUCKETT: Thanks Hal. If we're interested in changing policies on end-of-life care we have to look at the political dimension because it obviously is an area of some public contention. We're very pleased to have here tonight Senator McLucas. Senator Jan McLucas has been a Senator for Queensland since 1999. She was previously Minister for Human Services, currently Shadow Minister for Mental Health, Housing & Homelessness. Senator McLucas was also a local government councillor before she was elected into parliament. It gives me great pleasure in inviting Senator McLucas to give her comments on this contentious area.

JAN MCLUCAS: Thank you very much and I start by acknowledging the Kula Nation and pay my respects to their Elders past and present, and to other Indigenous people who might be with us here tonight. Thank you very much to Stephen and Hal for the opportunity to share with you today and I want to really congratulate the Grattan Institute and the State Library of Victoria for an innovative idea, to have a conversation about policy is I think a commendable thing to do. I really want to thank the Grattan Institute for the work that they have done to produce the document *Change to die for?* and that's the subject of tonight's conversation.

Ladies and gentlemen, this is a valuable piece of analysis which will contribute to a better informed public discussion about how, where and with whom we die. The report confirms that what we want is not what we get when it comes to the end of our lives. The report documents a population survey that says that 70% of us do prefer to die in our own homes if we were facing a terminal illness. Only 19% of us want to die in a hospital and 10% in a hospice, but the reality is, as Hal has said, that around 14% of us die at home, 54% die in hospital and 32% of us die in hospices and residential aged care. The Productivity Commission came to a similar view in its *Caring for Older Australians* report in 2011. It looked at the quality of palliative and end-of-life care. The PC noted that the preference of older people is to die in familiar surroundings, but that – and I quote – “Too often, older Australians are transferred to acute care hospitals for pain management and to die due to insufficient expertise being available in the residential and home environment”.

Friends, the value of the Grattan Institute report in my view is two-fold. Its worth to health service funders and health services providers may very well result in some significant savings to the health budget, but the real benefit, the real benefit will be to those Australians who achieve a good death as a result of changed service delivery.

Hal and, with support from Johanna, have quantified the costs associated with the last year of life. They say in Australia about half of people die in hospital. Previous analyses of end-of-life costs in hospital suggest that about 8% to 10% of inpatient costs are associated with the last 12 months of life and particularly the last 30 days before death. The average cost of care in the last year of life in

2010/11 for acute inpatient costs was \$37,767. They note that in-home palliative care packages are available, but in quite limited numbers and vary hugely for a number of reasons, including the jurisdiction in which the services are provided and/or the diagnosis of the patient. The costs of these packages also vary but, by and large, are significantly less than inpatient costs. They found that 35% of deaths occurred in residential aged care and noted that virtually all – 91% of residents in residential aged care – die there. The Productivity Commission in the same report I referred earlier noted that, while it was acknowledged that some aged care providers provide excellent palliative and end-of-life care, the general view from many participants was that it was poorly provided in many residential facilities. For many years now successive governments have worked with our aged care services to provide a home, not an institution, for their residents, so it stands to reason that this should include quality palliative care as part of those settings but we do need to do more.

In my view, this report makes the economic case for a rethink of the ways in which we fund and deliver health services to people in the last months of their lives, but I think the human case is more compelling. The case that ensures that a 90 year-old with advanced dementia does not undergo extensive surgery to remove an ovarian cyst and, sadly, die three days later. Surely we, as a country, as a First World, wealthy nation, can do better than treat an elderly man with prostate cancer with chemotherapy and radiation that results in him never leaving the hospital and, because he was so personally embarrassed, would not let anyone, not even his wife, visit him in his last few weeks? We all know these stories. These are the stories that are the drivers for change in how we support people at the end of their lives. This is particularly so when we can predict the end-of-life for about 70% of deaths.

Over the last few years the principal of choice and control has been the driver in the design of major public policy reforms: the National Disability Insurance Scheme; the aged care reforms, Living Longer Living Better. In the '80s and '90s women demanded more choice and control over the way we had our babies. We need to bring the principal of choice and control to the policy considerations about end-of-life. For me, one answer, it's not a simple answer, but one answer is to improve the use of Advanced Healthcare Directives and I've had that view for many years now. In Opposition I was the Shadow Minister for Aging and I recommended that our states and territories move to ensure consistency in how ACDs are used across the nation. In government we saw the development of a National Framework for Advanced Care Directives in 2011. The Framework recognised the need for a national approach to ACDs and proposed a code of ethical practice and a set of best practice standards for consideration by state and territory regulators. But, despite Health Ministers agreeing to the National Framework, a level of uncertainty and confusion around Advanced Healthcare Directives persists.

The consumer group Choice has identified some of the problems. For example, they identified that it is still unclear if an Advanced Healthcare Directive is fully transferable across jurisdictions. They say there is currently a vast array of ACD forms with different names and protocols and it's unclear which ones will or won't be honoured across state lines. There are a number of policy challenges here. Advanced Healthcare Directives are largely regulated by the states and territories, but few of those jurisdictions have a Minister for Aging. We do have a federal Minister for Aging whose motivation to promote not only the harmonisation of the way we use Advanced Healthcare Directives in our country, but also the utilisation of those directives is high on that individual's agenda. But in our states and territories there are limited numbers of Ministers for Aging, but it is those states and territories that hold the policy levers.

There's been a change in the departmental structure following the change of government last year. Under the new system, aging services are now in the Department of Social Services and they've moved out of the Department of Health. It will be harder, not impossible, but it will be harder having to work across two separate departments to ensure that both the economic outcomes – who's going to save money, who's going to spend money - and who's going to champion not only the harmonisation but, more importantly, the uptake of Advanced Healthcare Directives.

We still have a policy challenge with Advanced Healthcare Directives around the adoption by the medical profession of the wishes of an individual. It is true that the AMA's position statement on Advanced Healthcare Directives states that a doctor is under no legal obligation to follow an Advanced Healthcare Directive, for example if they have a conscientious objection or believe it does not reflect good medical practice. The AMA argues that the circumstances that existed at the time a Directive was first written may later change, or patients may use language which is ambiguous or open to misinterpretation, or that future scenarios which may arise are not predictable by the patient. But I am sure that those concerns can be overcome. I agree with Choice which argues that Advanced Care Directives can be designed to stand up to legal scrutiny, they recommend a series of criteria that could be met to protect against legal uncertainty.

In many respects, ladies and gentlemen, it does come down to the strength of the relationship between the patient, the patient's family and his or her treating medical professionals. It is yet another argument for improved health literacy in our community. Time prevents a full discussion on the needs of Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, and for those who live in regional, rural and remote Australia. Unsurprisingly though, these groups access palliative care services and Advanced Healthcare Directives at a much lower rate than other Australians. Less than 1% of Australians aged over 70 has an Advanced Healthcare Directive and a recent online survey by Palliative Care Australia of the recently bereaved found that just 5% of those surveyed had some form of advanced care plan in place. There remains an urgent need, in my view, to increase public awareness around the role of Advanced Healthcare Directives and end-of-life planning more generally and the report, as Hal as indicated, makes specific recommendations to that effect.

Any discussion about improving the quality of death will always lead to a debate about euthanasia. Our parliament has debated this issue on more than six occasions in the last 15 years and we have another Bill currently with the Senate's Legal & Constitutional Affairs Committee. As we prepare for the public discussion that we will have in the months ahead, I do encourage participants to conduct the debate respectfully. Of course, positions on voluntary euthanasia are based on very fundamental and very personal ethical beliefs. For many of us our views are strongly influenced by the death of a loved one, a family member or friend. Euthanasia has been described as a wicked problem characterised by conflicting and divergent definitions of the problem with no easy solution that will satisfy all; they are immune to resolution by appeal to evidence or facts; are cross-institutional; are unbounded in scope with broader policy implications; and require action by individuals and organisations as well as government.

It is argued that there are three basic requirements for dealing with such a wicked problem. Firstly, there needs to be time to engage the public in an open, depoliticised, iterative discussion where different perspectives are understood and that allows a shared understanding of the issue. Secondly, reliable evidence and data needs to be available to support the debate, although it is true to say that evidence alone will not resolve the matter. Thirdly, appropriate mechanisms will need to be developed

for public engagement in an informed and safe debate. We must take care not to reduce such a complex discussion to a contest about who is more caring, more compassionate or more loving. My Party invokes the conscience vote for the progress of these debates, respecting the different views that are held in the Party.

So finally, again, my congratulations go to Hal and the Grattan Institute for this contribution to an informed discussion that will provide better deaths for those we love. I thank you for the intelligent analysis of the economic data that can deliver better end-of-life services for those we care for. More of us I think will have a better death if we learn from this work. Thank you.

STEPHEN DUCKETT: Thank you very much Jan. We've deliberately structure this evening so that you have an opportunity to comment, ask questions and so on. I'd appreciate if when you're asking a question you keep it brief.

AUDIENCE: On your slide you mentioned that other countries have 30% to 40% of people die at home. How are they achieving that objective and how could we adopt some of the lessons from overseas countries?

HAL SWERISSEN: The reason that Australia has a comparatively low rate of home deaths is because it has a less holistic, less integrated approach to providing care at home than happens in places like New Zealand and the UK, for example. And part of what needs to happen to address that is to put much more emphasis on home-based care services which actually make those things possible and to bring those in a much more integrated way. The general direction over the last 30 years or so in aged care has been to support people to live at home as they grow older and develop higher levels of dependency, and really we need to extend that into the last period of life to the end-of-life so that that happens. But in order to do that, we're going to have to shift the culture of the healthcare system about how death occurs and the sorts of things that Jan's been saying about having conversations and having discussion about that and being clear about what we want is a critical feature of that, as well as having the services that can then be brought into play to support people once they've made a decision as to what they would like to have happen.

AUDIENCE: I'm a medical practitioner and I'm absolutely appalled to hear you say, Senator, that the AMA's position is that it does not support Advanced Healthcare Directives. There is absolutely no doubt that in any medical consultation around the end-of-life, to know what your patient wants in terms of treatment is absolutely fundamental. You know, when we deal with children it's just beyond question that we provide them with an immunisation program which protects them from illness in the rest of their life. Seems to me just stupid that when we go to the end of their life we don't have the same sort of discussions with people who are aging, getting older, getting sicker, getting more chronically ill, that we don't have an automatic discussion as a doctor with what they want for the end of their life.

JAN MCLUCAS: I totally agree with you. I think what I'm saying is that we need to encourage those conversations with people, perhaps at the 75+ health check, perhaps at an event that may occur that the doctor would then be able to predict that a person may be approaching the end of their life. I think that's what we need to be encouraging the medical profession to do. All I was referencing was what the AMA policy statement on Advanced Healthcare Directives was.

HAL SWERISSEN: I think the issue is important. The problem is that often the conversations don't occur and often they don't occur because the healthcare professional, the medical professional themselves is uncomfortable about having the conversation. Notwithstanding the fact that you probably aren't in that camp, the reality is that many of your colleagues are. So what we have to do is recognise that and then create some systemic incentives for people to have those conversations. We can keep talking about that it should happen, but unless you actually have some policy leaders which say, "Well, at this point there's actually a requirement that it happens" and that there's actually a trigger for it to happen, it's very difficult to actually see that shifting.

So I'm essentially in the policy camp where you really need to have leaders to encourage people to do that through regulatory, financial or other incentives, backed up with education and training and so on. And there are very good resources for assisting people to have conversations about dying which are already available. If you go on the web now you can do a training program on how to have the conversation, that's available here and now. But the reality is that often in the vast majority of cases there are no formal conversations and there are no trigger points, and that's what the policy environment needs to start addressing.

AUDIENCE: Thank you so much for some really interesting presentations, I'm both overjoyed and very excited to see a cohesive policy analysis of this issue. I just wanted to note a word of caution, I guess, which is the increasing emphasis we are seeing on dying at home rather than in institutions. I speak from the perspective of someone who was a young carer and a sole carer of someone who wanted to die within an institutional context and for whom that wasn't actually a valid possibility because of lack of hospice care in a regional area.

So while I really commend the change - and it is an important change to emphasise increased resources being spent at home and I understand that the last federal government actually made that policy change and it's being implemented by the current government - I would suggest that a note of caution needs to be implemented with that alongside those changes and to make sure that we don't move towards a stigmatisation of people that go into institutions. On the basis of the numbers you gave Senator McLucas, that's actually one in three who would prefer to be in an institution context. And the other factor of course is changing demographics, more single-person households, less actual ability to care within the home; we need to be conscious of those issues as well. But thank you so much.

JAN MCLUCAS: I think you've made a very important point and that if the choice and control of the person is that, "I want to go to hospital" that should be their decision and we need to respect that. I also think we've got to have that decision-making within a family unit - I take your point though, if it's a very, very small family unit, that's hard to do. And the stigmatisation, when you said that the first thought that came to my mind is yes, we want more choice and control about how we have our babies, so if you have a caesarean section nowadays everyone says, "Oh, she's a not a very good mother", you know? So we've got to be careful there about putting people in pigeonholes to say that if you didn't die at home there's some sort of failing. It isn't. The person's wishes need to be respected and supported.

AUDIENCE: In a more implementation sense, if we take a view that now the advanced Healthcare Directive has an item number or is a component of a healthcare check, how can we be sure or how would you suggest we best get that healthcare check to the hospital before something invasive is done?

HAL SWERISSEN: It's a really good question. One of the things that happens, and we haven't had time to talk about, is that once you do have an Advanced Care Plan it often doesn't get implemented. So you need a system to ensure that it actually gets followed through, so it's very important that it's built into records and that it's built into the system of following the person through care wherever they are. The other thing is the report will say that it's important that somebody is identified as the coordinator of the plan so that if you don't have any responsibility assigned in the system for someone to make sure that the person's preferences are actually followed then the person themselves has to manage it through the system, and that's much more difficult.

AUDIENCE: Senator McLucas, the research we've done at Respecting Patient Choices has shown that it's fantastic to think we can get doctors to have all these conversations, but our research has shown that in fact it takes between 60 and 70 minutes to have a proper discussion with a patient or with a person about their wishes that they want respected at the end-of-life. And doctors, whether it's in the hospital system or out in general practice, simply don't have the time to do that, they're struggling to have enough time to provide all the healthcare they need to provide. And we've shown both in the hospital and where we're running Respecting Patient Choices, for example, down in Geelong that training up nursing staff to be able to have these discussions, they are excellent at it, they identify well with the patients, patients identify well with them, and they can assist in having the main part of that discussion and then have the doctor sign-off on the Advanced Care Plan. But to do this right across Australia would be a substantial investment. It would actually be cheaper than having an MBS item number or using the 75+ health assessment to have the doctor trying to do it. We know the doctors don't have time. What are your thoughts about having nurse practitioners or practice nurses doing this in a systematised way across Australia in primary care, before patients end up in hospital?

JAN MCLUCAS: I'll preface this by saying I'm not the Shadow Health Minister and I'm not presenting you Labor Party policy by any stretch. But it's been my view that we've got to make sure that we have the best use of our health professionals and that we should be ensuring that people are deployed to the most appropriate and most effective service delivery. So that's really interesting information that you're getting great results from and stands to reason really that a nurse will have the time to spend the time to talk through the circumstances of that patient. Without making policy on the run, I think it's a very valuable and potentially very useful observation that you've made.

HAL SWERISSEN: I think you're right, that it takes time and the process for the over 75's health assessment could easily I think be adapted around that and that's a key trigger point where people might have the conversation. Now, the reality is not everybody will want to have a full-scale conversation at that point, but what's important is that it's opened up as a possibility so the people who do want to have the conversation can pursue it. There are other points as well which are in the recommendations, exiting from hospital etc. The important point is that nurses I think are an excellent group of people to be part of that conversation, it doesn't always have to be a GP or a specialist, and it's really a question of setting up some systems.

The Respecting Patient Choices, which you've developed, is a terrific model and we should build on what's already there to make these things happen. The resources are already available, it should be adapted in policy, but what now needs to happen is it needs to be put into policy in a systematic way. It isn't there at the moment and it won't be there unless we create incentives for that to happen.

AUDIENCE: Thank you very much. Hal, I really am glad to hear the recommendations that you've made, particularly the drive to support more people to die at home, and you've focused on the importance of care support and Advanced Care Plans and you alluded to the importance of education, particularly around communication. But if we are going to move a lot of people who are dying in hospital into community environments, I'd really be interested in hearing how you envisage the health system reorienting itself to provide healthcare, not cure, but healthcare support to people in the community given that we have found it very difficult to engage with GPs in particular around the space? Thank you.

HAL SWERISSEN: I think the evidence is that when you do bring to bear a more coordinated approach – and there are some agencies now that are developing in Australia to do home-based end-of-life care – that once you do that you start to see a much greater number of people, a greater proportion of people who are getting services actually have the option of staying at home at the end-of-life. When I started working on this report I was a bit anxious about these sorts of numbers and so I spent some time talking to some of the big palliative care agencies about that, and the research does suggest that you can significantly increase the number of people who can die at home because they want to die at home, provided you provide those services.

I understand the point you're making which is that it puts pressure on carers, so I don't think everybody's going to die at home and it's not a prescriptive approach. It's about giving people the option and what's the problem at the moment is that there aren't enough services to provide informal carers with support and they're not integrated enough into the system and they don't have sufficient capacity at the moment to do that. So the critical thing is to increase that capacity and to do that in a systemic way. We've done that in aged care. In 1983 we reformed aged care for the community and we brought in the HACC program. We need something like that for end-of-life care.

AUDIENCE: Thank you Hal and Stephen for the presentation. I have a question but also just a statement before that, and I think it follows on from that comment in terms of an assumption that we make that everybody does want to die at home. And in Victoria we do collect information not just about the percentage of people who nominate their choice to die at home, but also the percentage of people who nominate to be cared for before dying. And that gives us a really nice indication of understanding not just how we are contributing to the productive sustainability of the health system, but also recognising that for many people the choice is to be cared for for as long as possible at home, but not necessarily to die at home. And I think that that's an important distinction to make in terms of thinking about how we measure our success in palliative care.

My question to you, Hal, was about workforce and whether or not in your research, particularly overseas, have there been any significant findings that you've made about the skills of the workforce and where those workforce resources are located in order to improve home-based services?

HAL SWERISSEN: The workforce is very important obviously and, as you know, there are essentially two parts to that. One is the specialist palliative care services which deal with complex issues and the difficulties of dying, and then what's called the "palliative care approach" which is a much more generalist set of skills which virtually every healthcare professional should really have when they're dealing with people generally at the end-of-life. So it's a complex and long discussion about what's happened. There are about a hundred palliative care specialists in the country at the moment roughly speaking, so they're not going to deal with the 150,000 people who die. So we really need a much more broadly-based approach to that. Is the workforce well-trained? Well, it's conflicted about dying.

People are not well-trained in their initial training, so we now need to have that as a post-initial training set of issues. As I said earlier, here are now well-developed resources to help people to do that, but we need to create more incentives for those conversations and for those services to exist. That's the challenge at the moment in Australia.

AUDIENCE: I want to follow-on from a previous question and the last question that was asked, and I'm thinking back to the 1980s when the gay community in particular developed models of enabling people to die at home which generally involved a specialist, a GP, a domiciliary nursing service and, in a lot of cases, a 24-hour care team, sometimes totally made up of volunteers, sometimes volunteers integrated with family. Now that I'm working in the palliative care sector and I ask the question "Why isn't that available?" the answer that I get is that there are a range of regulatory things that would prevent that service being put in place that have to do with Occupational Health & Safety with safety of volunteers – there's a whole range of impediments that are being discussed that would prevent that kind of model.

In policy terms, have you given some thought to how that might happen and the extent to which perhaps palliative care services can provide support to informal groupings who wouldn't be part of the palliative care service with all those restrictions, but do need some support if a group of family and friends and neighbours was going to get together and try and look after someone who wanted to die at home?

HAL SWERISSON: That's a good question. There are a range of models that have developed to deal with these issues in the community. At a broad policy level I think the critical issue is to create a funding stream and a set of policy objectives and an overall program which supports the availability of what people call "packages" or effectively places or service bundles which are available to people who are dying at home. And then I think the sort of innovation that you are talking about becomes much more possible, once it becomes a much more broadly-based program than what it currently is.

AUDIENCE: You've mentioned a couple of times introducing requirements or incentives for having the conversation as part of the structure, which is obviously a fantastic idea, but have you addressed or can you talk to how you might make that happen to be actual real discussions, rather than just tick-box exercises that don't achieve anything other than a signed piece of paper that doesn't mean anything?

HAL SWERISSEN: All policy is plagued by the problem that once you put in systems there are always going to be people who do it well and people who do it not so well. The answer to that is obviously training and support and all of the usual quality assurance measures that you want to see happen. The critical thing at the moment though I think is to start to put in place a broadly-based set of incentives and requirements to see some of these things happen. The paradox is that we all only die once, but the healthcare professionals are dealing with people who die over and over again, so they are the people that you need to put the responsibility on to have the conversations, to initiate the conversations. Otherwise you're asking people to figure it out for themselves in their one moment in time when they desperately need some support and help.

So we need to create policy incentives to get the healthcare system to respond to these needs, rather than asking individuals to drive that. Now, some of it is going to involve some regulatory arrangements which could be corrupted to become tick and flick sorts of things, but that needs to be dealt with in the normal way that these things are dealt with to avoid that.

AUDIENCE: Thank you for your presentations. As an older person, I'm here to learn about how to get an Advanced Care Plan, but I've got oodles of friends who do not want to talk about death. And my view is at the moment most people die where they happen to be and I'm not sure there are choices people are making about where they die and how they die. So I'm asking from the community point of view how we try to engage people into having that conversation – and we're talking about professionals here mostly – how do we engage Mrs Ordinary and Mr Ordinary and at what stage? We're talking about 75+ and, as an aside, the nurses do come and do the 75+ medical exam in some areas, so that could be a starting point if they're well-trained in that and getting people to talk about dying and death, which is a taboo subject for so many people.

JAN MCLUCAS: I think it's partly community education and the Health Report recommends that there needs to be a public discussion around end-of-life in the community, and I would think that's a good starting place. I think we've just all got to become far more literate as health consumers. And there's a role for government there, there's a role for the medical profession there, but there's a role for us as health consumers as well to become engaged with our health and all the elements of it, including what the end of our life might be like. But I think the answer is to start with a community education program.

HAL SWERISSEN: We've gone out and asked a marketing company to actually give us the campaign for how to talk about death. So I think we've done that in a number of other sensitive and difficult areas and we need to start to think about this systematically, otherwise what we have is the sort of conversations that we're currently having. We need to see this as a public policy objective to get people to have conversations about dying.

AUDIENCE: I'm a consultant physician who's worked in teaching hospitals and private hospitals for over 30 years. I have some concerns really about the implied disparity between the costs of dying at home versus dying in the hospital. I'm pleased to see that you think that I can predict when people are going to die, but the fact of the matter is my colleagues and I are very poor at doing that, especially in a small timeframe. And so I believe that the costs of an acute hospital admission are really mostly in the first 24 hours, that's when all the investigations and interventions are done, whereas the cost of dying at home for people who are barely conscious are really rather major in terms of personal care that's required, and if that's going to go on for several weeks that can be a major cost. So although I agree with most of your perspectives and thank you for the opportunity to listen, I have major concerns about any presumed cost disparity.

HAL SWERISSEN: I was anxious about it too and so I've spent a bit of time having a look at the costs that specific palliative care providers have in providing care at home, and I'm reasonably confident that the disparities are managed. What effectively happens of course is that some people end up being in hospital even in a home-based palliative care service, probably a proportion of them will end up in the hospital to die, but effectively a number of people who otherwise end up in hospital to die when they didn't need to be end up in a home-based service. So it breaks both ways. You end up with people who shouldn't be in hospital but they end up there because there was no other alternative, but when there's a palliative care service they don't. But that doesn't mean to say that everybody who's in a home-based palliative care service ends up dying at home, a proportion don't. There'd be a long discussion here tonight to go through all of that, but essentially what home-based palliative care does is it provides a better set of options to get it right as to who should be where.

AUDIENCE: Thanks for your presentation. My father was living on an isolated rural property when he was diagnosed with cancer a year ago. There are a few observations; one is that a big part of the quality of the end of his life - he died two weeks ago – was the central role of the GP in making sure he had informed consent, rather than unnecessary intervention. We did manage to get home-based care for him, starting mainly two months ago because two-and-a-half months ago his GP said, “Look, your life expectancy is about two months” so he was quite accurate. Two weeks before he died we tried to get his homecare package upgraded and the assessor said, “Well, that will take about two weeks to process”. So if it wasn’t so tragic it would be funny. In the end, he was living in his own house up until the day before he died, went into a hospital for observation and he died in hospital just 24 hours after going in. So the statistic will record that as a death in hospital, but really he was dying for a year before that. So the statistics, as you say, don’t tell the whole story. I’ll leave it at that, thanks.

JAN MCLUCAS: It’s very similar to the experience that my mother had four years ago in a rural community in Far North Queensland.

STEPHEN DUCKETT: So thank you again to Hal and Jan for stimulating this discussion. Thank you very much to this audience, especially the people who have been kind enough to ask questions to challenge Hal and Jan on what they’d said and to give us some additional ideas. So, thank you very much. Thank you to the Library for providing the venue and join with me in thanking Hal and Jan again.

END OF RECORDING