

# Chapter 13

## Advance Care Planning

13.1 Advance care planning enables individuals to make plans for their future care. Putting in place such a plan requires discussion with family members, significant others and health care providers about your wishes. It was pointed out to the committee that one of the barriers to making such a plan is the reluctance of some people to discuss death and dying. The chapter considers this reluctance and details suggestions made to address it. It then turns to explaining what advanced care planning is, what is involved, and the issues raised with the committee. It also covers the difference between advance care planning and advance care directives and the national work undertaken on the latter. It considers the potential for electronic records to assist advance care planning.

### **Cultural reluctance to discuss death and dying**

13.2 Talking to family, significant others and health care providers is central to the process of putting in place an advanced care plan. However, witnesses highlighted the reluctance of people to have conversations around death and dying. Professor David Currow explained how this unease has developed:

...we have a very limited view of death and dying, and that is compounded greatly by the increase in life expectancy of the last generation, unprecedented in human history. I have looked after people in my working life who are attending their first funeral of someone close to them that they love, and they are in their fifth or sixth decade. Their grandparents died when they were very young; their parents are still alive and well; their siblings are alive and well; and here they are burying their spouse—and it is the first funeral they have been to of someone that they really love. That for us is a huge challenge. We have lost many of the traditions—and those traditions came about for lots of good reasons—around death and dying. We have lost the language. We have lost the ability, often, to reach out.<sup>1</sup>

13.3 Palliative Care Australia also reflected on the tendency to avoid discussions about death and dying on a personal level:

It is often argued that death has become a taboo subject, detrimentally affecting the level to which death is discussed, including discussion by health professionals who are also situated within the prevailing culture. Details of gruesome traumatic deaths, and those of celebrities are splashed across the media as both news and entertainment. Yet there is apparently little discussion of death on a personal level. It has been argued that this reflects the secularisation of society, the movement of illness and death from the home to the hospital, a simple fear of dying, and the Aussie attitude of hiding or disguising one's true feelings. Whatever the

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1 Professor David Currow, Professor of Palliative and Supportive Services, Flinders University, *Committee Hansard*, 2 July 2012, p. 67.

explanation, we need to ensure greater levels of death literacy. We need to raise awareness of end of life care, and concurrently encourage Australians to complete advance care plans and appoint substitute decision makers in case they lose capacity.<sup>2</sup>

13.4 The use of language and its effects on conversations about death and dying was highlighted by Palliative Care Victoria:

...The fact that we live in a death-denying society compounds the issue for palliative care, because there is still this sense that you must not give up, you failed treatment instead of treatment failing you. There is a language associated with palliative care that we hear all the time—people lose 'battles' with cancer. There is this very combative language around that you have somehow failed if you die.<sup>3</sup>

13.5 Professor Currow emphasised the need for families to engage in such conversations and highlighted the positive response to organ donation, a subject on which conversations can be similarly difficult to have.<sup>4</sup>

### ***Increase public awareness***

13.6 Witnesses emphasised that to facilitate conversations around death and dying there needs to be greater public awareness of the need for and benefits of them. Ms Kim McCartney, a witness who courageously shared her experiences as a brain tumour palliative care recipient, expressed her view of the need to remove the taboo of death and spoke of a public awareness campaign:

Ms McCartney: One of the things when I was diagnosed was that so many people were like: 'Oh, you poor thing.' It occurred to me one day that if someday had walked up to me before I was diagnosed with this and said, 'Hey! Do you reckon you might die one day?' My answer would have to have been: 'I reckon; I'm a good chance, yes.' The only difference between the Kim of then and the Kim of now is that I have had confirmation of what I already knew. I have not changed; I am still no different to anybody else. Don't ask me when; I don't know. I might know how—perhaps. That is the only difference between me and any of you sitting here. I am exactly the same as everybody else. Like I said, it is just that I have had confirmation of what we all know.

CHAIR: You know when you were talking about that awareness campaign? We have a star recruit, I reckon.

Mrs Waanders: Absolutely!

Ms McCartney: I think that if people could understand that, it would take that whole taboo thing about: 'Oh, tumour—poor thing.' I am the same

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2 Palliative Care Australia, *Submission 98*, p. 7.

3 Ms Rachel Bovenizer, Board Member, Palliative Care Victoria; and Chair, Southern Metropolitan Region Palliative Care Consortium; and Chief Executive Officer, Peninsula Home Hospice, *Committee Hansard*, 4 July 2012, p. 43.

4 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 67.

person. In the beginning, when people said, 'Oh,' I used to pat them back and say, 'It's okay; you've got a ticket too. You're on a winner just the same as me.' It is the truth! People look at me as if to say, 'Oh.' You can tell that they have never actually looked at it like that. It is like: 'You're on a winner; it's all good.' But, yes, I think that there does need to be some sort of campaign so that people actually do realise that death is universal—no-one is exempt. If people could get their head around that they might be able to start coping with the thought of palliative care. I remember saying to the hospice one day—they had come around and we were having a chat—I'm putting something out.' They said, 'What's that?' I said, 'I'm on a train; I can't get off. I know where the destination is and until the train stops there I can't get off. But I do have a choice. I can choose to travel third class, on a splintery wooden bench with no back on it and my feet just not quite touching the floor, or I can opt to go first class, with the Jason recliner, a nice cuppa and a magazine—I'll choose first class.' I said to the girl: 'And that's why you're here.' I meant it. I do have a choice on how I can exit this world, and I am going to choose the most comfortable. That is my best explanation of palliative care: choosing to exit first class, not fourth class.<sup>5</sup>

13.7 Palliative Care Victoria also noted the lack of public awareness of palliative care and advocated for a national campaign:

I would reinforce Kim's statement that the awareness of palliative care is very low in the community and that we do need a consistent, large-scale national campaign. You do not bring about education and community awareness through a once-a-year week campaign on a thin budget and have the cut-through, awareness and the understanding that is needed; you need a campaign like beyondblue that really takes it seriously—that says: 'This is a whole of society issue and we are going to address it well. We are going to make sure there is equity of access, which means great awareness for everyone, and clear pathways about where to go. And also a recognition that at a single government level there should be responsibility for a single point of access.' The way they are talking about for aged-care now that needs to happen to ensure that people are not left, as Richard has just explained, trying to navigate a very complex system. It is hard enough for us who are in the system navigating it let alone people who do not know the system.<sup>6</sup>

13.8 Palliative Care Australia emphasised that engaging in such discussions is not the sole responsibility of the health system but is also the responsibility of the community and the individual<sup>7</sup> and also recommended:

That ongoing national campaigns be funded, developed and implemented to increase community awareness of end of life planning options and community capacity to discuss and plan for death and dying.<sup>8</sup>

5 Ms Kym McCartney, *Committee Hansard*, 4 July 2012, pp. 44–45.

6 Mrs Odette Waanders, Chief Executive Officer, Palliative Care Victoria, *Committee Hansard*, 4 July 2012, p. 43.

7 Palliative Care Australia, *Submission 98*, p. 118.

### ***Increase education***

13.9 Similarly, witnesses also highlighted the need for education. However, there are challenges involved in educating around a sensitive or unpopular topic. LifeCircle highlighted their experience of approach raising awareness and overcoming barriers to such conversations with education:

LifeCircle has telephone counsellors, mentors and inaugurated the Life Matters educational event. That was started about two years ago, primarily because we found that people were phoning us pretty late in the game. It meant that a mentor was able to be matched with a carer, but it was in the last few weeks. The Life Matters educational event essentially addresses that issue of death and dying being taboo topics—no-one wants to go there, so no-one wants to think about advanced care planning, because, if you talk about death and dying, you might die. The concept of introducing this was to provide the information so that we could shift the attitudes. It is very interesting. We had a difficult time getting lots of people to the event. You will get between 60 and 80, and at tops 100, for an event that is very well publicised. I think it is precisely because of the topic of death and dying, so we are looking to encourage. It is hard to get the topic going.<sup>9</sup>

13.10 Ms Brynnie Goodwill, Chief Executive Officer, LifeCircle Australia Ltd explained the need for death to be discussed from an early age and the need to include medical professionals:

We need education right through from kids going into all levels of schooling, bringing this conversation into schools, but certainly into universities and medical professions so that it is demystified for doctors. Doctors are trained to see death as a failure and that it means that they got it wrong, so they do not like to talk about death and dying instead of seeing it as a natural part of life and asking, 'How can we help you plan for it and live well right to the end and have the best end you possibly can?'<sup>10</sup>

13.11 The view that doctors are trained to see death as failure means there is a need to include health professionals in awareness and education campaigns. The Victorian Healthcare Association reported that there is a tendency for health professionals to avoid the subject of future care needs at the end of life, particularly when end of life care is complicated by communication and cognitive problems related to old age and combined with the emotions of family members. Recognising there can be a difference in the views of family members and the patient, the Victorian Healthcare Association emphasised there is a need to initiate and promote discussion about end of life care for all people.<sup>11</sup>

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8 Palliative Care Australia, *Submission 98*, p. 21.

9 Ms Brynnie Goodwill, Chief Executive Officer, LifeCircle Australia Ltd, Committee Hansard, 24 April 2012, pp. 50–51.

10 Ms Brynnie Goodwill, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 57.

11 Victorian Healthcare Association, *Submission 57*, p. 7.

13.12 Ms Goodwill, LifeCircle, emphasised the need to engage GPs in awareness and education:

We found that, if you could get GPs engaged early enough, GPs can recommend that their patients and their patients' families to go to a seminar like our Life Matters seminar where they will learn about advanced care planning, tissue and organ donation, enduring guardianship, and the legal issues that you have to face when you are just planning ahead. Typically, you are looking for people in their forties or fifties who bring their parents or come to be informed themselves, as well as people in their sixties, seventies and eighties. The issue is quite complex. It is first about engaging the medical community to feel comfortable about recommending this conversation to their patients and their patients' families and it is about reaching out to people directly within the community.<sup>12</sup>

13.13 Palliative Care Victoria gave anecdotal evidence to the committee of what can happen in situations where there is a failure to discuss end of life wishes in the Australian medical system where not all health professionals who may be involved in the care of a patient have sufficient capacity around death and dying:

I think in our submission I gave a couple of examples of phone calls from members of the public—quite disturbing examples. One particular example was on Saturday morning when I had gone to the office because we had forgotten to switch the fridge back on. So it was just by chance. I had a very disturbing call from a woman who had discharged her parent from a hospital the day before to die at home and things had gone badly pear-shaped. The patient was in not just pain but other things going on that this person could not manage with the care of that person. That was an example of the failure to communicate around preferences for end-of-life care, to get on the same wavelength about where that end-of-life care should occur. So there was a self discharge without support and then all the problems of getting back into the system again; not able to access the GP on a Saturday morning; being told they could not get readmitted back to the ward—they would have to go in through emergency—and the patient was in such a state that that could not occur. There are other examples like that, and not just members of the public. We have had calls from staff in aged-care facilities disclosing that they are very concerned that certain patients are not getting the pain management that they need are too fearful to speak up.

So I think what is happening is that there is failure within the system, with people not knowing and just enduring suffering and not having the support and experiencing a bad death because they do not know where to go and because the system is not geared to provide the levels of support and the communication. There are big gaps. Half the time we do not know who those people are falling through the gaps. I think that is the point and that is the concern, particularly for people from non-English-speaking backgrounds and with low levels of health literacy. It is hard enough, as you have just said, when you have good command of English, are an assertive person and have high health literacy and you know that palliative

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12 Ms Brynnie Goodwill, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 51.

care exist. If you do not have any of those things you really are pretty lost. This is where we need a system that ensures that all health professionals have a capacity around dying and death.

It is a 100 per cent certainty that all of us are going to die. Why is it we have a health system with health professionals who get the inciest amount of training around that and who for the first time might experience a death when they are on placement on a hospice ward and do not know how to deal with it?<sup>13</sup>

13.14 Dr Ron Sinclair, Consumer, Alzheimer's Australia spoke about the experience of his wife:

Despite there being an advanced directive in place at the time which specified no intervention other than for pain management, staff, including RNs in the facility, ignored the directive and continually tried to treat her, either by calling locums when she developed sickness or whatever, and towards the end of her life they tried to force-feed her and to force her to take fluids. On the other hand, in the last few weeks of her life, we had to fight to get pain management managed well because the staff there did not use any pain management scales. I provided the staff with published literature on end-of-life issues, including pain management issues about the provision of artificial nutrition and hydration, use of antibiotics and so on, and they told me that they had never seen or been told about this sort of information. Some of them accepted it with thanks; others would not even read it. The reasons for trying to keep my wife alive centred primarily on what they called 'their duty of care', although there were religious and philosophical views as well. They were also not given a choice by their management on whether they could opt out of looking after my wife and complying with the 'no interventions' in the advance directives.<sup>14</sup>

13.15 The Medical Oncology Group of Australia spoke about the communication skills necessary to have such conversations with patients:

Like many awkward conversations in life, raising with a cancer patient—who you might have known for some years—that this might be a good time to think about making advanced care directives will upset them if they have been still hoping for an extension of life. There comes that day when you start talking about palliative care and talking about advanced directives: 'Not for resuscitation' orders, et cetera. We know that busy oncologists avoid those conversations because it is just easier to give another round of chemotherapy than it is to sit back and say, 'Today's the day we need to think about these things.' Kay helps to manage a lot of training with our trainees in medical oncology about the communication skills that are needed to bridge that very difficult conversation. We know that junior doctors get almost no training and they are sometimes faced with a patient who lobs into hospital unwell, unexpectedly, and their skills are often lacking. It is a very upsetting and difficult conversation.

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13 Mrs Odette Waanders, Palliative Care Victoria, *Committee Hansard*, 4 July 2012, p. 42.

14 Dr Ron Sinclair, Consumer, Alzheimer's Australia, *Committee Hansard*, 24 April 2012, p. 1.

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We did some research recently to prove that you can train people to do that and I have brought copies of that paper for you. It has just been published. But it is a resourcing issue. Yes, we know how to train people. Show us the money and we can do it!<sup>15</sup>

13.16 Palliative Care Australia noted evidence from clinical research studies which found that advance care planning discussion between patients and their care team is generally poor and there is a substantial gap between what the patient wants to discuss and what is actually discussed.<sup>16</sup> Palliative Care Australia recommended:

That a national training program on how to engage in end of life discussions and advance care planning be supported, and that it is incorporated into end of life care education for primary and specialist health care providers.<sup>17</sup>

### ***Committee view***

13.17 The committee recognises the value in encouraging people to have conversations around death and dying to ensure that those around them are aware of their wishes. The recognition of individual preferences allows people to have control over the level of health care they receive at the end of life. Not only can this give an individual peace of mind but it can remove the burden of treatment decisions from the family and assist care givers. Advance care planning is a vehicle for everyone to consider issues around end of life, and not something to be contemplated when confronted by a terminal illness.

13.18 The 'DonateLife' campaign<sup>18</sup> is an example of raising awareness around the issue of organ and tissue donation. It highlights the importance of having discussions with family and others. The committee believes that a national campaign run along similar lines covering advance care planning and advance care directives could address the reluctance to engage in conversations about death and dying, promote the benefits of advance care planning and explain the process which may contribute to a greater uptake. While processes currently differ across jurisdictions, and this is discussed in greater detail below, the committee considers that a national campaign to raise awareness and encourage conversations around future care would be of benefit. This would need to be followed up by campaigns in each jurisdiction to ensure clarity around processes in each jurisdiction of how to put plans and directives in place.

### **Advance Care Planning**

13.19 Being able to engage in conversations about future health care that include death and dying is an important aspect of putting in place advance care planning.

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15 Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 43.

16 Palliative Care Australia, *Submission 98*, p. 118.

17 Palliative Care Australia, *Submission 98*, p. 21.

18 See Australian government, DonateLife, <http://www.donatelife.gov.au/home> (accessed 31 August 2012)

***What is it?***

13.20 Advance Care Planning (ACP) enables a patient to express wishes about their future health care in the event that they become incapable of participating in treatment decisions.<sup>19</sup> As noted by the Australian General Practice Network:

Advance care plans detail ideas and processes developed by a patient and their informal and formal care team about how care will be provided in likely future circumstances.<sup>20</sup>

13.21 An advance care plan may include:

- an Advanced (Health or Care) Directive (or other similar instrument);
- an Enduring Power of Attorney (EPA) (or similar instrument);
- a letter to the person who will be responsible for this decision-making;
- an entry in the patient medical record;
- a spoken instruction or other communication which clearly enunciates a patient's view; or
- any combination of the above.<sup>21</sup>

***How does it occur?***

13.22 Dr Leslie Bolitho, President, Royal Australasian College of Physicians explained how advance care planning occurs:

Advanced care planning allows patients with a terminal illness to set out their preferences regarding their end of life care and other affairs. The process is led by the patient, ideally in consultation with the family and their treating health professionals. Advanced care plans record the medical treatment the patient wishes to receive, the location of that treatment as well as the legal and spiritual wishes. An advanced care plan applied with the right advice in the right circumstances can significantly improve the patient's experience in the last phase of their life as well as assisting in the grieving process for family and loved ones...However, it must be recognised that a patient's preferences may change, which can be complicated further if the patient has significant cognitive impairment...<sup>22</sup>

***Advantages***

13.23 Advantages of ACP include:

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19 For some other definitions see Australian Medical Association, *Submission 65*, p. 3; Respecting Patient Choices program, *Submission 102*, p. 1; Palliative Care Australia, *Submission 98*, p. 12; Australian General Practice Network, *Submission 107*, p. 19.

20 Australian General Practice Network, *Submission 107*, p. 20.

21 Department of Health and Ageing, *Submission 96*, p. 25.

22 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 10.

- It supports people to take control over the circumstances in which they live the last stages of their life, and in which they die;<sup>23</sup>
- it takes the burden of decision making from third parties, most of whom find it very stressful to make decisions that reflect the person's wishes;<sup>24</sup>
- family members are often unable to agree on decisions;<sup>25</sup>
- increasing numbers of people have no family to make decisions as they die;<sup>26</sup> and
- in the absence of a clear statement of the wishes of a patient, doctors usually initiate aggressive treatment that the patient may not want.<sup>27</sup>

13.24 ACP can assist in addressing patient's loss of capacity, and ensure their dignity. Medical successes mean that many more people die having lost decision-making capacity.<sup>28</sup> Advance care planning addresses people's fear of being unable to make their preferences known when crucial health decisions are required after they have lost decision making capacity.<sup>29</sup> It also helps address the concern that 'many Australians are kept alive under circumstances that are not dignified and this causes unnecessary suffering'.<sup>30</sup>

13.25 As patient care preferences and future scenarios can change over time, organisations such as Palliative Care Australia stressed the need for advance care planning to be a continuing process that:

begins as early as possible in a patient's illness trajectory; is embedded in clinical routines and professional practice; and is preceded by a screening process that assesses the capacity of people.<sup>31</sup>

13.26 To address the fact that a plan can be a static document and a patient's needs may change, Professor Frances Boyle, Medical Oncology Group of Australia reported that:

...if they are written carefully they can allow a certain amount of clinical judgment. Most sensibly written plans will say: 'If I have a life-limiting illness like cancer and there comes a time when specific anti-cancer therapy

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23 Australian General Practice Network, *Submission 107*, p. 19.

24 Ms Bernadette Tobin, *Submission 103*, p. 4; Australian Medical Association, *Submission 65*, p. 3.

25 Ms Bernadette Tobin, *Submission 103*, p. 4.

26 Ms Bernadette Tobin, *Submission 103*, p. 4.

27 Respecting Patient Choices, *Submission 102*, p. 3.

28 Ms Bernadette Tobin, *Submission 103*, p. 4.

29 Palliative Care Australia, *Submission 98*, p. 117.

30 Respecting Patient Choices, *Submission 102*, p. 3.

31 Palliative Care Australia, *Submission 98*, p. 119.

is no longer useful to me and measures to extend life...' rather than saying something like, 'If I get cancer, just let me die.'<sup>32</sup>

### ***What is an advance care directive?***

13.27 There is a difference between advance care plans and advance care directives. An advance care directive (ACD) has a legal status. It is a formal recording of an advance care plan recognised by common law or authorised by legislation.<sup>33</sup>

13.28 While the Australian Medical Association supported advance care planning through the use of advance care directives,<sup>34</sup> Palliative Care Australia believed that advance care planning should not be reduced to a singular focus on ACDs.<sup>35</sup> However, Palliative Care Australia recognised that:

Formalised ACDs can form an integral part of the advance care planning process for those who wish to develop one, serving as a vehicle for decisions about the type and level of medical intervention people wish to have.<sup>36</sup>

### **The need for national consistency**

13.29 The lack of consistency between jurisdictions was raised with the committee as a key issue requiring attention. State and territory legislation governs advance care planning and directives.<sup>37</sup> Currently there are jurisdictional differences governing advance care directives (ACD) which results in it having different meanings across jurisdictions.<sup>38</sup> The level of variability makes it difficult for one jurisdiction to legally recognise an ACD from another jurisdiction.<sup>39</sup> Palliative Care Australia also pointed out that the legal differences between jurisdictions governing advance care planning affects the uptake of advance care planning.<sup>40</sup>

13.30 Mr Glenn Rees, Chief Executive Officer, Alzheimer's Australia drew attention to this lack of consistency and its effects:

I suppose we would like the unachievable, which is universal national laws that use the same terminology that consumers can understand and where they do not find a barrier to moving from one state to another. We understood that there was some mutual harmonisation going on. I honestly

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32 Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 43.

33 Palliative Care Australia, *Submission 98*, p. 117.

34 Australian Medical Association, *Submission 65*, p. 3.

35 Palliative Care Australia, *Submission 98*, p. 21.

36 Palliative Care Australia, *Submission 98*, p. 118.

37 Department of Health and Ageing, *Submission 96*, p. 25.

38 Palliative Care Australia, *Submission 98*, p. 119

39 Australian Health Ministers' Advisory Council, *Advance Care Directives Framework*, September 2011, p. 1.

40 Palliative Care Australia, *Submission 98*, p. 119.

do not know how extensive that has been. I do not think the issue is just legal; the issue is obviously cultural and attitudinal, because people do not actually do those things early enough. I suppose one of the things that we would really want to face up to in developing guidelines is truth telling and starting the journey at the appropriate time, because that is really what we should be doing more of when we are counselling people about their diagnosis and what their journey will involve. There are some quite good documents around about truth telling and how you approach people in terms of facing up to the realities without being cruel. I think we need to look a lot more at those cultural and attitudinal things as well as the legal things, but the legal things certainly do not help.<sup>41</sup>

13.31 Officers from Alzheimer's Australia expressed the view that a standardised approach across Australia would be very helpful. Mr Glenn Rees, Chief Executive Officer added:

We have been advocating for that for probably six or seven years and based very much on consumer views. They just did not know what the terminology was and, in some cases, moving from state to state was becoming very difficult in terms of barriers.<sup>42</sup>

13.32 Professor David Currow echoed the call for national consistent process for advance care directives:

We are asking people to redo whole documents as they shift between states, because we say that they do not carry through. We have hospitals that say that they cannot take a decision made in one admission and assume that it would be the same in this admission. If that is underpinned by an independent advanced care directive that was not made during that admission, I worry that we are unreasonably burdening people in the community—and patients particularly—with those process. We need a simple and nationally consistent process that allows people to make these decisions and talk about to their families and loved ones.<sup>43</sup>

13.33 Ms Robyn Coulthard, member, Australian Nursing Federation added that although there has been a lot of training for nursing and care staff at all levels about advanced care directives the jurisdictional differences commonly cause problems:

The setting in which nurses work makes a huge difference to the way that they manage advanced care directives. In aged care there has been a lot of training for nursing and care staff at all levels about advanced care directives. The problem is that advanced care directives have no legal standing in many states and are often contrary to the wishes of the enduring guardian or the enduring power of attorney for medical treatment, so issues erupt daily, not every day, but they are common...

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41 Mr Glenn Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 24 April 2012, p. 4.

42 Alzheimer's Australia, *Committee Hansard*, 24 April 2012, p. 6.

43 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 69.

They commonly erupt and there are issues then culturally and I do not mean in Aboriginal culture I mean in other cultures with head of family and who makes the decisions...

It can be in aged care it can be quite a treacherous path for the staff and for the nurse. In the end it is often managed by negotiation and mediation rather than a legal document. The biggest issue in residential aged care is the advanced nature of dementia. People are often not able to say what they want themselves.<sup>44</sup>

13.34 Ms Brynnie Goodwill, Chief Executive Officer, LifeCircle Australia Ltd also spoke about the lack of a national standard and spoke about the situation in the UK:

The lack of having a national advanced care directive that would be recognised is a problem. The fact that state to state—I know that New South Wales health now has one up on its website—there are myriad forms. We just had Dr Julian Abel out from the UK, who is involved with the National End of Life Care strategy. The UK has an advanced care directive, and it is registered in the hospitals. So if an ambulance gets called, the ambulance driver will first check into the hospital and see what the wishes are. They will still go to someone's house but they will actually know what the wishes are and if they say 'no resus', they will just stay there and will not resuscitate. So it is about that clarity—

Senator MOORE: And to feel the strength to do that.

Ms Goodwill: and that interface from having one simple document. I heard the people who were testifying before mention a three-page document, as well as nursing homes having their own document, which are 18-page forms, and then there are 34-page forms. So there is a great deal of confusion. Imagine what it is like for a simple person who is looking to figure out what to do.

The first thing to do is to have the difficult conversation, because no-one likes to talk about these issues. Some people do like to talk about these issues, and that is why we are here today. There are traditions whereby people absolutely feel that death is a natural part of life and that if you remove that fear of death you have a lot more space for life. That is exactly why we are here. We are looking to present that message so that this whole area can be opened up and we can get onto documentation like advanced care directives. One simple, straightforward standard that is respected in all the jurisdictions and then uniformly applied throughout aged-care centres, nursing homes and hospitals and then through legal representation would be a big asset.<sup>45</sup>

13.35 Ms Jo Root, National Policy Manager, COTA spoke about the difficulties people face in putting in place an advance care directive. She noted that while they begin with problems of language and national consistency, they do not end there:

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44 Ms Robyn Coulthard, Member, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, pp. 40–41.

45 Ms Brynnie Goodwill, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 51.

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The fact that we use different language in different jurisdictions is just a starting point. I think the distinction between advance care planning, which you might do in residential care and which is done jointly with the facility about what you are going to do, and consumer directed advance health directives is part of the problem. People raise with us the difficulties of putting in place an advance care directive and how you go about it. As we put in our submission, we get a number of calls each week asking, 'How do I do it in the ACT?' In the ACT we are lucky; we can refer people to the Respecting Patient Choices facilitator. We have had feedback that that has been a satisfactory process.

People need more assistance in taking out advance care directives, but their big fear is they are not respected, that clinicians know best and overrule what people have said or try to talk them through it. I think that is changing, but many people's understanding of what happens is perhaps not what actually happens. There is a bit of a distance. They know one person whose advance care directive was not followed—<sup>46</sup>

13.36 Ms Root added that their main concern is that residential aged care needs to have advance care directives built into the accreditation standards to ensure these discussions are undertaken. In addition there should be active promotion of advance care directives by residential care facilities.<sup>47</sup>

13.37 The issues of community awareness and national consistency were similarly identified by Ms Julianne Bryce, Senior Federal Professional Officer, Australian Nursing Federation:

There is quite a variance in what is available and it varies considerably from state to state. There are some programs that are quite well understood and taken up in certain states—Respecting Patients Choices obviously has quite a large profile nationally but particularly in Victoria. There are a range of advanced care directives. It is not a nationally coordinated process. It is a really important conversation that needs to happen. What we are emphasising in our submission is the importance of the coordination of that with the legal issues around guardianship and power of attorney so that you have a really good understanding of what that person would actually like to happen in their care. It is important to have that conversation as early as possible so that you know what is going to happen into the future and can deal with things before you get to that stage where it is incredibly difficult to make those kinds of decisions on someone else's behalf even where they are able to contribute to that discussion. It is quite varied and it is important to have national consistency and a better understanding. More and more we are seeing it incorporated into undergraduate curricula. It is part and parcel of postgraduate curricula...it is a varied model across the states and territories. It is not well coordinated nationally.<sup>48</sup>

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46 Ms Jo Root, COTA, *Committee Hansard*, 10 July 2012, pp. 21–22.

47 Ms Jo Root, COTA, *Committee Hansard*, 10 July 2012, pp. 21–22.

48 Ms Julianne Bryce, Senior Federal Professional Officer, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 40.

13.38 Ms Bryce noted the importance of the palliative care workforce in ensuring that effective conversations take place around future care:

What is really important about advanced care directives is that the person makes the decision about who they want to talk to. To some extent we need to have a workforce that is prepared to have that conversation so to be able to direct people where it is not the scope of practice or to be competent in that area of practice. It is a broad education that we all need to have around being able to work with people to set up an advanced care directive and then to build on that with some specialist expertise for people who are quite wholly and solely devoted to that role in helping people to have those difficult conversations.<sup>49</sup>

### **A national framework for advance care**

13.39 In 2008, the Australian Health Minister's Conference (AHMC) commissioned work to progress the development of nationally consistent guidelines for advance care directives and related issues. This framework consists of a code for ethical practice and best practice standards for advance care directives which are underpinned by nationally agreed terminology. The National Framework for Advance Care Directives was published in September 2011.<sup>50</sup> An objective was the mutual recognition of ACD across jurisdictions to be facilitated through harmonisation of formats and terminology.<sup>51</sup>

13.40 This work was supported by the Australian Medical Association (AMA) which added that it should guide development of nationally consistent legislation. In order to facilitate greater acceptance the AMA stated that medical practitioners and other health care providers need to have: quick access to legal certainty; and protection from criminal and civil liability and from disciplinary proceedings.<sup>52</sup>

13.41 However, the committee heard that the work to date does not yet go far enough. Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia explained:

I think it is fantastic that there has been the group which has looked at harmonisation of the legislation. It does not go far enough. We absolutely need single legislation across the country. Even though this is something that sits within the states and territories, in thinking about it, there is not really any reason why we cannot use the same model that we use for achieving national registration and accreditation of health professionals,

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49 Ms Julianne Bryce, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, pp. 40–41

50 Department of Health and Ageing, *Submission 96*, p. 25. See also A National Framework for Advance Care Directives, available from: [http://www.ahmac.gov.au/cms\\_documents/AdvanceCareDirectives2011.pdf](http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf) (accessed 28 August 2012).

51 Australian Health Ministers' Advisory Council, *Advance Care Directives Framework*, September 2011, p. 1.

52 Australian Medical Association, *Submission 65*, p. 3.

where we had model legislation that was adopted in each of the states and territories with only minor variation. We have ended up with basically national legislation. I cannot see any reason why we cannot do that with advance care planning as well.<sup>53</sup>

13.42 While the work on a national framework outlined above is a welcome start it is currently up to the states to progress it further in legislation. Mr David Butt, Deputy Secretary, Department of Health and Ageing explained:

In fact, it was considered by the Australian health ministers and a national framework was endorsed by health ministers late last year and so has been released. That sets out a range of principles that should be followed. Legislation is very much a state and territory issue so this was about trying to get standardisation across the country. I notice today that South Australian health minister John Hill has announced that they are reviewing their legislation to simplify it, which I understand is in accordance with what the framework suggests...

Minister Hill also said in his announcement that once the legislation is through they will embarking on a publicity campaign with GPs, senior citizens groups and residential aged-care facilities to get them to understand the new arrangements and how they will apply in those services.<sup>54</sup>

13.43 Ms Alice Creelman, First Assistant Secretary, Department of Health and Ageing added that the national framework has been referred to the Standing Committee of Attorneys-General for consideration.<sup>55</sup>

### **Respecting Patient Choices and other support programs**

13.44 The Respecting Patient Choices project aims to set a national standard for advance care planning. It is currently trialling approaches to advanced care planning for people with dementia and other special needs groups.<sup>56</sup>

13.45 The program is funded jointly by the Department of Health and Ageing and by the Victorian Department of Health, and it is based at the Austin Hospital in Melbourne.<sup>57</sup> The committee spoke with Associate Professor William Silvester, Director, Respecting Patient Choices, Austin Health:

We have successfully demonstrated that we could pilot this program in every jurisdiction in Australia without requiring legislated documents. We

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53 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 22.

54 Mr David Butt, Deputy Secretary, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 10.

55 Ms Alice Creelman, First Assistant Secretary, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 10.

56 Ms Alice Creelman, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 10.

57 Associate Professor William Silvester, Director, Respecting Patient Choices, Austin Health, *Committee Hansard*, 13 August, 2012, p. 6.

have developed an advanced care plan which is two pages long and which works under common law. The legal advice we have had is that the two-page advance care plan we have developed has evidentiary weight under common law and, because it is recognised by doctors as a document that is witnessed by the patient or witnessed by the family of behalf of a non-competent patient and also witnessed by a doctor, it holds sufficient weight that they would be ill-advised to ignore it. We always get questions about the legalities in the documents but I have to emphasise that the most important thing is the discussion. When find that a patient has had a chance to reflect, discuss with their family and say what they do and do not want, you can almost tear up the paper that has been used as a tool to generate that discussion. What actually happens at the coalface, and I am talking about in the emergency department, up on the ward or in the ICU, what do the doctors do? They always turn to the family. They always say, 'Look, this is what has happened with your mum. This is what we think is going on. This is what we recommend. What are your thoughts?'<sup>58</sup>

13.46 Health Consumers Association of Australia supported the Respecting Patient Choices program:

The Respecting Patient Choices program started off in the Austen Hospital in Melbourne. We would like to see a system nationally. Particularly in the ACT we care about this because [of] being a small jurisdiction... We would really support that, but I must say it has not been easy to implement in the ACT. It was started at least five years ago. Calvary and the public hospital system started together. It was agreed that it would operate no matter which hospital you would go to. Since then, Calvary have kind of dropped out of it. What happens in the ACT if you do a Respecting Patient Choices directive is that it goes on your electronic health record in the ACT government system. Then if you come in, say, to the emergency department at the Canberra Hospital, an alert comes up at the top saying that you have a Respecting Patient Choices order. That informs the emergency staff. That is really helpful.<sup>59</sup>

13.47 Professor David Currow also spoke of the Respecting Patient Choices program. Professor Currow highlighted the importance of the 'values' conversation in the advance care planning process:

Prof. Currow: I think that the Commonwealth has invested in Respecting Patient Choices as a national program. The thing that I would draw to the committee's attention from that is the values conversation, so what are the values that underpin this advanced care directive and hence the advanced care planning? I have been faced clinically with people coming in with incredibly long and complex advanced care directives and I could challenge them in about 30 seconds, unfortunately, with a scenario that either does not

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58 Associate Professor William Silvester, Respecting Patient Choices, Austin Health, *Committee Hansard*, 13 August, 2012, p. 12.

59 Dr Adele Stevens, President, Health Care Consumers Association ACT, *Committee Hansard*, 24 April 2012, p. 46.

cover it or has an unexpected consequence for what they have put down there in very specific terms.

Senator MOORE: Professor, could you give us an example of that?

Prof. Currow: It is very easy to give an example.

Senator MOORE: It would be just to make that clear.

Prof. Currow: Yes. I was asked by a urologist colleague to see a patient of his who was very keen to do the right thing and have an advanced care directive so that the family was in no doubt as to what was happening. He had early-stage metastatic prostate cancer, so his life expectancy was measured in years at that time. He was in good health. He had a level of function equal to any of us in this room. So he put together an advanced care directive which said, 'If at any time I am unconscious I want nothing done, including intravenous fluids, intravenous antibiotics or blood transfusion.' It was very clear. It was quite explicit. I said, 'So this afternoon you go out of here and you are knocked over by a bus.' He said, 'Oh, that's not what I intended. This is only if I am unwell.' 'Okay, so how unwell would you need to be?' Then you have got a huge issue which is well documented and is well outside palliative care in lots of other areas of health care where people shift the goalposts even then: 'If ever I become paraplegic I will shoot myself.' The person becomes paraplegic and, in fact, a year later they rate their quality of life as better than it has ever been. So that is why Respecting Patient Choices is so powerful, because it has been about the values: what are the values that underpin the sorts of decisions so that we can reflect those if we are called on to do so? That is rather than a long list of highly codified directives. You may want antibiotics to relieve the symptoms of a urinary tract infection without it in any way affecting your prognosis. That can make you comfortable almost instantly in a way that almost no other therapy can. So to say, 'I never want antibiotics again,' may not actually reflect that person's genuine underlying values. Let us look at values. Let us have that broader community conversation. Let us make sure that we tell the people around us who are likely to be asked 'What would David want in this circumstance?' what our values are so that they can articulate those values that would be the foundation of the decisions that I would make were I able to do so.<sup>60</sup>

13.48 Published research about the program shows that its use results in improved end of life care and patient and family satisfaction, as well as reducing the stress, anxiety or depression experienced by surviving relatives.<sup>61</sup>

13.49 Catholic Health Australia, while supportive of the objectives of Respecting Patient Choices, had some reservations about what it perceived as a limited role for a representative of the person. It also commented on the respecting patient choices program and the need to incorporate changing needs:

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60 Professor David Currow, *Committee Hansard*, 2 July 2012, pp. 68–69.

61 KM Detering, AD Hancock, MC Reade, W Silvester, 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *BMJ*, vol. 340, 2010, p. 1345.

We are very much in favour of having the very practical discussions, which are had with individuals and families, with palliative care specialists about what their options are. We take a slightly different approach to that which the Commonwealth has taken. We see that the planning discussions should give the individuals the opportunity to appoint a person to be part of the decision making for them in the event of changed circumstances. Respecting patient choices, a tool promoted by the Commonwealth, places an emphasis on a contractual-type obligation, a signature by the individual which states 'these are my wishes'. We respect that way or that framework.

We think a more suitable alternative is where the individual expresses their intentions, health professionals are aware of and are respectful of those intentions, but there is also an individual appointed by the person to act on their behalf. It is that person to act on their behalf, who is perhaps not central to respecting patient choices, that we say is an important part of how care planning should be undertaken. Involve a family member or a trusted person in addition to the expression of your own intentions to ensure that healthcare professionals are able to deal with some of those challenges that very often present themselves during these times in a person's life.<sup>62</sup>

13.50 Carers are involved under the Respecting Patient Choices program: for example, 'Choosing someone to speak for you' is one of the key steps in their advance care planning process,<sup>63</sup> and in this regard there appears no difference between Respecting Patient Choices and Catholic Health Australia's view. It is important to ensure that discussions take place and that patient wishes are clear, because it is well known that patient wishes and those of their families often diverge.<sup>64</sup>

13.51 Amaranth Foundation is a not-for-profit organisation 'to provide support and assistance to people living in rural communities, who are living with serious and advanced life limiting diseases'.<sup>65</sup> It works with social workers to deliver care and support, including for people with mental health care needs. The Foundation has a partnership with the Respecting Patient Choices program for delivering advance care planning information. Mrs Julianne Whyte, Chief Executive Officer, Amaranth explained how their advance care planning program works:

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62 Mr Martin Laverty, Chief Executive Officer, Catholic Health Australia, *Committee Hansard*, 2 July 2012, pp. 36–37.

63 Respecting Patient Choices, Advance care planning for everyone, [http://www.respectingpatientchoices.org.au/index.php?option=com\\_content&view=article&id=1:advance-care-planning-for-everyone&catid=5&Itemid=2](http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=1:advance-care-planning-for-everyone&catid=5&Itemid=2) (accessed 3 October 2012)

64 See, eg, PH Ditto, JH Danks, WD Smucker, J Bookwala, KM Coppola, R Dresser, A Fagerlin, RM Gready, RM Houts, LK Lockhart and S Zyzanski, 'Advance directives as acts of communication: A randomized controlled trial', *Arch Intern Med*, vol. 161, 2001, pp. 421–430; PM Abadir, TE Finucane and MK McNabney, 'When Doctors and Daughters Disagree: Twenty-Two Days and Two Blinks of an Eye', *Journal of the American Geriatrics Society*, vol. 59, 2011, pp. 2337–2340; RA Pruchno, EP Lemay, L Field and NG Levinsky, 'Spouse as health care proxy for dialysis patients: Whose preferences matter?', *Gerontologist*, vol. 45, pp. 812–819.

65 Amaranth Foundation, <http://www.amaranth.org.au/> (accessed 3 October 2012).

With this protocol the advance care directive is done very, very early in the piece. I can explain later how we do that. I think we have got a really good model. I do not think our model is expensive at all. We can do the advance care plan and the ambulance protocol really early with the person, while they still have competence and capacity, in a family meeting environment with the GP, signed off by the GP. It is actually an agreement between the patient and the GP with the ambulance working as collaborators with us to facilitate it. Yes, they sign it. But it is actually on their electronic care planning database as well. So the ambulance will get a call from, say, Greg Santamaria to say that I need an ambulance. It will come up on this screen: 'Greg Santamaria, terminal care, cancer of the lung' or whatever. 'These are his medications, these are his treatments and this is his treating doctor.' It comes on the computer screen before they have left the station.

Then when they arrive, we organise a little folder for them—something like that—which they can put on the fridge, which is their advance care plan, documentation, who their care workers are and the medication and protocols that have already been signed off and agreed to by the GP. Then the ambulance can come. They are advance care paramedics. They actually come to the patient's house and sit there with them. They are funded for an hour, so they can stay with that family for an hour.

One paramedic said to me last month, when we did another one for a lady with dementia, that the hardest thing for him was to do nothing but he knew the greatest thing he was doing was saying to the family, 'What you are doing is good palliative care; this is beautiful.' The woman died at five or six o'clock in the morning and they were called at two o'clock, because they thought, 'We should be doing something; she sounds as though she's dying.' They came and said, 'What she is doing is dying. This is okay.' They sat there for an hour with this family. When I came later and said to the family, 'How was that experience?' they said, 'It was just amazing to have these competent, big, tall guys in the ambulance who would sit there with them, have a cup of tea and say, 'This is really cool—no, we don't need to do hydration and, yes, the pain relief is okay. Let's check—everything is fine,' and actually sit with the family for an hour.'<sup>66</sup>

13.52 Amaranth explained how they had trained with Associate Professor Bill Silvester of the Respecting Patient Choices Program at Austin Hospital and the success of the program when they had run it:

Mrs Whyte: There would have been a 70 to 80 per cent take-up of advance care plans, and of those more than 50 per cent were done in family conferences. The outcomes of that research were phenomenal. I have the final report of that research, which was presented to DoHA. It is now on KeySearch. We have that report with us here...

Senator MOORE: Does it say why the other 20 did not?

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66 Mrs Julianne Whyte, Chief Executive Officer, Amaranth, *Committee Hansard*, 10 July 2012, p. 28.

Mrs Whyte: Lack of time. Either I did not get to them in time or they lost competence.

Senator MOORE: So there was no-one who had a philosophical objection to it?

Mrs Whyte: Nobody. I am not exaggerating here. It was something that we kept taking back to our board, the steering committee. What surprised us was that no-one had an objection to it. They knew why we were coming. They knew why we were having the conversations. Often I would go with the nurse. They would be joint visits. This is the model that I always try to use: joint visits with the nurse. The nurse can worry about the clinical symptoms and I or one of the social workers that we employ can sit there and listen to the stories that underpin it. Take the carer away, if there is a carer; but if there is no carer then we work with the community group around that person, or, because of the social nature of our work, we create a care environment for them.

At one stage we were trying to look at bringing the Home Hospice program down to the region but there were some issues with the area health service in doing that. But I think if we had that it would be a wonderful thing. It would help people who are self-carers.<sup>67</sup>

### *Committee view*

13.53 The committee heard that not having their wishes respected or being overruled by others is a great fear for patients and the committee is disturbed to hear of instances where this has occurred. While it appears this situation is changing gradually, it is clear that the jurisdictional differences and complexities which remain around advance care planning, and particularly advance care directives, work against greater take-up. The committee is pleased to hear of the work undertaken to develop a national framework. While this work is seen as a useful start, jurisdictions need to follow up with changes to legislation. Putting in place a form of nationally consistent legislation to provide certainty and remove the potential for additional stress at a difficult time should be a matter of urgency for jurisdictions.

13.54 While the committee can understand why legal certainty is an important issue for physicians and others and agrees it needs to be pursued on a national basis as outlined above, the committee also recognises that there should not be an exclusive focus on legal processes. Facilitating communication on death and dying through advance care planning has an important role to play. The committee heard that disputes over care and treatment are often resolved not by legal means but by negotiation and mediation. If all parties have had a discussion and are clear about a patient's wishes then legal avenues become a last resort. The committee acknowledges programs such as Respecting Patient Choices which aims to set a national standard for advance care planning.

13.55 Generating discussion is important to assist people to form or reflect on their views and feelings about their care. It is also the key to patients feeling secure that

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67 Mrs Julianne Whyte, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 30.

their wishes will be respected, for family to be able to carry out their wishes if necessary, and to assist those providing care. Discussion should start early but will often need to be ongoing as the committee acknowledges that advance care plans and directives may need to change as unanticipated circumstances arise.

13.56 A national public awareness campaign as recommended above should not only encourage conversations but jurisdictions should take the next step of promoting appropriate jurisdictional information so that individuals can easily take the next step of putting in place an advance care plan or directive. This recognises that work is underway to standardise processes around advance care directives but that it will take some time. The committee recognises that jurisdictional information on advance care planning and directives is already available on the Respecting Patient Choices website.<sup>68</sup>

13.57 The committee noted the strong track record, documented clinical outcomes, and stakeholder support for the Respecting Patient Choices program. It is being implemented across many Victorian health services, as well as in other states, and in aged care facilities.<sup>69</sup> Work is also being undertaken with Aboriginal and Torres Strait Islander communities in the Northern Territory, Queensland and South Australia.<sup>70</sup>

13.58 The Victorian Government is a funding partner in Respecting Patient Choices, and has clearly committed to its adoption in Victorian area health services. The Commonwealth is supporting its implementation in aged care settings. Given its strong track record and demonstrated outcomes, the committee believes more widespread adoption would contribute to greater capacity for people to ensure a high quality of their lives at end of life, including ensuring appropriate palliative care. More extensive adoption nationally does not need to await consistent national legislation.

13.59 The committee understands that an important limiting factor is the funding available to 'train the trainer'. Respecting Patient Choices program leader Associate Professor Bill Silvester noted that what is needed is 'to fund the staff who are trained and required to provide the education. The model we have recommended is that training organisations dealing with nursing staff, particularly from aged care, be identified and contracted to provide this'.<sup>71</sup>

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68 Respecting Patient Choices®, ACP Documents, [http://www.respectingpatientchoices.org.au/index.php?option=com\\_content&view=article&id=46&Itemid=45](http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=46&Itemid=45) (accessed 4 September 2012)

69 Palliative Care Queensland, *Submission 130*, pp. 8–9; Respecting Patient Choices® Victorian and Interstate Programs [http://www.respectingpatientchoices.org.au/index.php?option=com\\_content&view=article&id=49&Itemid=52](http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=49&Itemid=52) (accessed 3 October 2012)

70 Associate Professor William Silvester, Respecting Patient Choices, Austin Health, *Committee Hansard*, 13 August, 2012, p. 7.

71 Associate Professor William Silvester, Respecting Patient Choices, Austin Health, *Committee Hansard*, 13 August, 2012, p. 9.

**Recommendation 34**

**13.60** The committee recommends that in the next review of aged care accreditations standards, the Australian government consider requiring some form of advanced care training as a component of the standards.

**Recommendation 35**

**13.61** The committee recommends the Australian government increase the level of funding for the Respecting Patient Choices program, to support development of training providers in several jurisdictions, significantly expanding the reach of the program in the aged care sector.

**Recommendation 36**

**13.62** The committee recommends that national model legislation for advanced care planning be developed, and that all governments pursue harmonisation of legislation as a high priority.

**Recommendation 37**

**13.63** The committee recommends that the Australian government fund a national public awareness campaign around advance care planning and directives, starting immediately, and expanding once a process of national harmonisation of advance care planning regulation has been undertaken.

**Potential for the PCEHR and technology in the provision of healthcare**

13.64 The committee explored whether the Personally Controlled Electronic Health Record (PCEHR) system could be a vehicle to address the issues raised about jurisdictional differences. PCEHR is a secure, electronic record of a patient's medical history, stored and shared in a network of connected systems. Information will be able to be accessed by the patient and their authorised healthcare providers. Over time patients will be able to contribute to their own information and add to the recorded information stored in their PCEHR.<sup>72</sup> The establishment of PCEHR was examined by the Community Affairs Legislation Committee which tabled a report on the relevant provisions in March 2012.<sup>73</sup>

13.65 Currently, there are significant issues with the accessibility of advance care plans or documents. The Medical Oncology Group of Australia explained the difficulties associated with accessing records by the right people at the right time:

...[F]rom the point of view of the practicalities, different states have different approaches to this. If you say to a patient—if you want an advanced care directive, different hospitals have different approaches. Then, when you have gone to the trouble of writing your directive and it sits in the oncologist's file, in the rooms, but you are admitted to the local

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72 Information available from: <http://www.nehta.gov.au/ehealth-implementation/what-is-a-pcher> (accessed 30 August 2012)

73 Community Affairs Legislation Committee, Personally Controlled Electronic Health Records Bill 2011 [provisions] and the Personally Controlled Electronic Health Records Bill 2011 (Consequential Amendments) Bill 2011 [provisions], March 2012.

emergency department there is no way of carrying that piece of information. The intern or resident faced with giving that patient antibiotics, resuscitating them or putting them on a drip or ventilator does not have access, even in the best-laid plans. This factors into the whole idea of patient-held record. E-health issues will need to include a section on advanced care plans.

We have also done some research looking at, once again, education of patients and carers, to try to encourage them to take up doing those things. But even if they have gone to that trouble, not all the necessary people need to find those documents at a time when the rubber hits the road.<sup>74</sup>

13.66 Participants in this inquiry, while recognising that there are issues that will need to be addressed, were positive about the capacity of the PCEHR to assist with advance care planning. The Victorian Healthcare Association spoke of the potential role of the PCEHR in the provision of palliative care:

I want to touch quickly on the electronic health record. It does have some capacity to and is an example of a development in the provision of palliative care that could provide a benefit. The electronic health record is best suited to those who have multiple chronic care conditions or to those who are in constant care. Somebody who is in receipt of palliative care who is able to understand the access and the way in which the electronic health record works could receive a benefit, in our view. We acknowledge that that is a step forward and to the extent possible some guidelines and some information sheets, however they are created, should be created specifically for people in palliative care to demonstrate to them what benefit could be drawn from participation in the Personally Controlled Electronic Health Records system.<sup>75</sup>

13.67 Dr Alan Rouse of the Tasmanian Health Organisation expressed his organisation's hope in the potential of e-health records:

Basically, this process then has been tied to an e-health initiative and a shared medical record, so the process we have is one where we use this cultural change to do person-centred care but we have this fantastic computerised system that works very well with this culture change. The GPs have access to this in their surgeries.

When you come into the hospitals, we are hoping that the hospital has access to the resident's wishes, access to what the GP thinks these wishes are, and to these clinical action plans so that, instead of admitting them to intensive care or admitting them to the hospital, we might be able to get on top of their symptoms so that they may be able to go back to their place of care.<sup>76</sup>

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74 Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 43.

75 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 12.

76 Dr Alan Rouse, Tasmanian Health Organisation – North West, *Committee Hansard*, 5 July 2012, p. 4.

13.68 The committee discussed the inclusion of advance care directives in PCEHRs with DoHA. Ms Sharon McCarter, Assistant Secretary, eHealth Division responded:

It is actively being considered in the context of the fact that we have now had a pilot with Cradle Coast and the learnings coming out of that will allow us to be able to create specifications and make policy decisions around how the advance care plan can work in the PCEHR. At the moment, as you know, in the personal health summary section for our consumer in the PCEHR, you can put the location of your advance care directive and the custodian. That is the first step. Obviously, the work we have done in Cradle Coast allowed us to be able to progress that and enabled us to incorporate the advance care record over time in the PCEHR.<sup>77</sup>

13.69 Ms McCarter added that pilot evaluation results will be available in December. Mr Nathan Smyth, First Assistant Secretary, Population Health Division advised that the Respecting Patient Choices Program is working with National E-Health Transition Authority (NEHTA) and looking at the requirements for the PCEHR and how to include an advanced care directive. He added that there is a separate program underway in Tasmania also working with NEHTA to find the optimal model. Mr Smyth advised that they are investigating different models as each advance care directive will differ and need to be tailored to the circumstances of the individual and their care providers so there does not have to be a one-size-fits-all solution. However, he stressed that the overall aim is for anyone who has a PCEHR to be able to put their advance care plan on it if they wish.<sup>78</sup>

#### *Committee view*

13.70 The committee can see the potential and benefits of using technology to facilitate access to advance care plans. The committee is pleased to hear that work is underway for anyone who has a PCEHR to be able to include advance care plans on it if they wish.

#### **Recommendation 38**

**13.71 The committee recommends that the Australian government ensure that personally controlled electronic health records have the capacity to include palliative care information, including advanced care plans.**

**Senator Rachel Siewert**

**Chair**

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77 Department of Health and Ageing, *Committee Hansard*, 10 July 2012, pp. 42–43.

78 Department of Health and Ageing, *Committee Hansard*, 10 July 2012, pp. 42–43.