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# Dying well

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## Overview

This report is about how, where and with whom we die. The baby boomers are growing old, and in the next 25 years the number of Australians who die each year will double. People want to die comfortably at home, supported by family and friends and effective services.

But dying in Australia is more institutionalised than in the rest of the world. Community and medical attitudes plus a lack of funds for formal community care mean that about half of Australians die in hospital, and about a third in residential care. Often they have impersonal, lingering and lonely deaths; many feel disempowered. Seventy per cent of people want to die at home, yet only about 14 per cent do so. People are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France.

Increasingly people die when they are old. They are also more likely than their forebears to know that they are going to die in the relatively near future. But we are not taking the opportunity to help people plan to die well. In the last year of life, many experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals. Many do not get enough palliative care.

Often, this is because people do not discuss the support they would like as they die. When asked, most people have clear preferences for the care they want at the end of their life. But rarely do we have open, systematic conversations that lead to effective end-of-life care plans.

A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs. This would happen more often with three reforms. First, we need more public discussion about the limits of health care as death approaches, and what we want for the end of life. Second, we need to plan better to ensure that our preferences for the end of life are met. Third, services for those dying of chronic illness need to focus less on institutional care and more on people's wishes to die at home and in homelike settings.

For more people to die at home, investment in community-based support is needed. Doubling the number of people who are able to die at home will cost \$237 million a year, but the same amount could be released from institutional care funding to pay for it.

Despite widespread assumptions about the cost of end-of-life care, only about \$5 billion a year is spent on the last year of life for older people in a health budget of \$100 billion. But only about \$100 million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well.

The voluntary euthanasia debate often clouds this issue. But voluntary euthanasia and assisted suicide are rare, even in jurisdictions that permit them. Instead, this report is about ensuring that when death inevitably comes for each of us, we die comfortably, in surroundings we would choose. We need the courage to promote mature discussions about a topic that many dislike, but that we cannot avoid.

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## 1. Changing patterns of death in Australia

### 1.1 Dying has become institutionalised

Surveys consistently show that between 60 and 70 per cent of Australians would prefer to die at home. Hospitals and residential care – nursing homes – are their least preferred places to die. Yet over the past 100 years home deaths have declined and hospital and residential care deaths have increased.<sup>1</sup> Today only about 14 per cent of people die at home. Fifty-four per cent die in hospitals and 32 per cent in residential care.<sup>2</sup>

Australia’s rate of deaths at home is comparatively low. About 30 per cent of people 65 and over die at home in comparable countries including New Zealand, the United States, Ireland and France - about double the Australian rate.<sup>3</sup>

Death is an increasingly institutionalised and medicalized experience.<sup>4</sup> Hospitalisations have increased significantly for older age groups. In the decade to 2011-12 the hospitalisation rate for those aged over 85 increased by 35 per cent for women and 48 per cent for men.

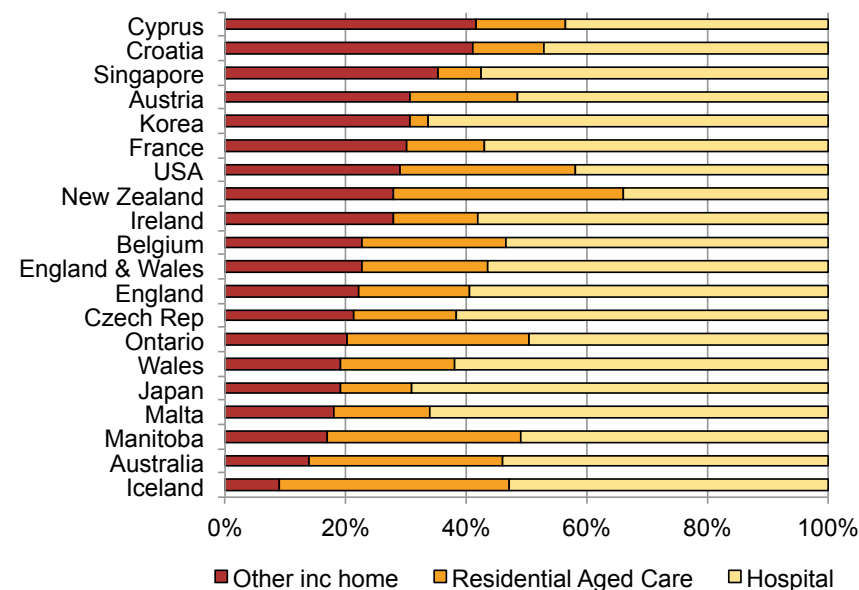
As Horsfall et al<sup>5</sup> point out,

*The concept of a good death has been superseded by the concept of a managed death, one that requires professional*

*support and knowledge ... and takes place in a hospital, or more rarely a hospice, resulting in modern death becoming ‘cellular, private, curtained, individualised and obscured’.*

**Figure 1: Few Australians aged over 65 die at home**

Location of deaths in selected OECD countries; per cent of deaths



Source: (Broad et al., 2013 (2013))

<sup>1</sup> Higginson, et al. (2013)

<sup>2</sup> Broad, et al. (2013)

<sup>3</sup> Ibid.

<sup>4</sup> Kellehear (2007)

<sup>5</sup> Horsfall, et al. (2012)

## 1.2 Causes of death have changed

Dying has changed dramatically over the past century in Australia. The annual death rate per 1000 people has halved. People are much less likely to die young, and far more likely to die in old age of chronic and degenerative disease. Death is less capricious, more predictable and often occurs over a longer period of time. But people are also much more likely to experience an institutionalised death in hospitals and residential care.

In 1900, 25 per cent of the population died before the age of five, largely of infectious disease. Less than five per cent died after the age of 85. By 2011 this pattern was reversed. Less than 1 per cent died before the age of 5 and nearly 40 per cent died after the age of 85, largely of chronic diseases.

Over the past century, average life expectancy at birth has improved by around 30 years through prevention, immunisation and improved treatment.<sup>6</sup> But life expectancy at 85 has changed very little (see figure 2). There is no evidence that maximum life span for humans has changed during this period.<sup>7</sup>

With a relatively fixed maximum life span and an increasing average life expectancy, more people are dying in a relatively small age range in old age. About two-thirds of Australians now die between the ages of 75 and 95.<sup>8</sup>

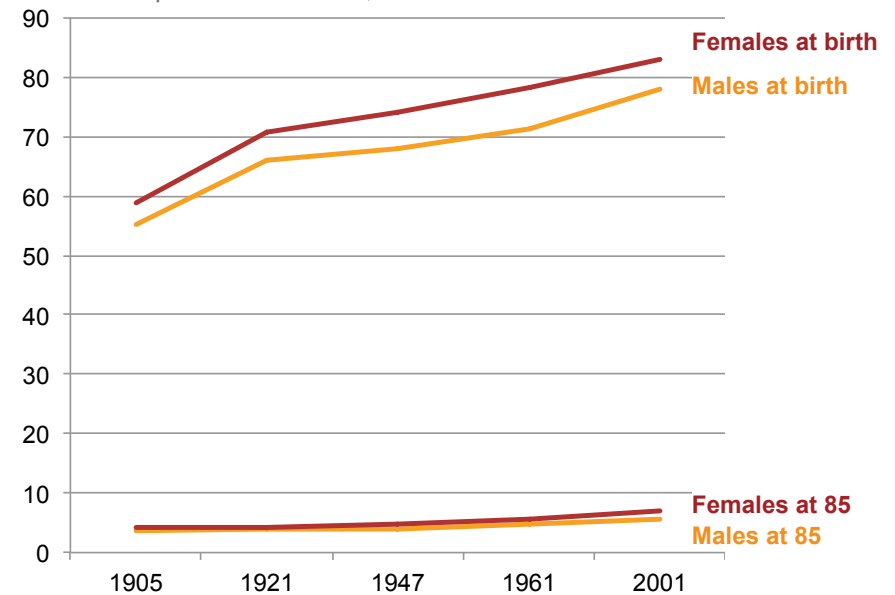
<sup>6</sup> Australian institute for Health and Welfare (2014a)

<sup>7</sup> Holliday (2006)

<sup>8</sup> Australian Bureau of Statistics (2013a)

**Figure 2: Life expectancy has increased, but maximum life span has not**

Years of expected life at birth, and at 85

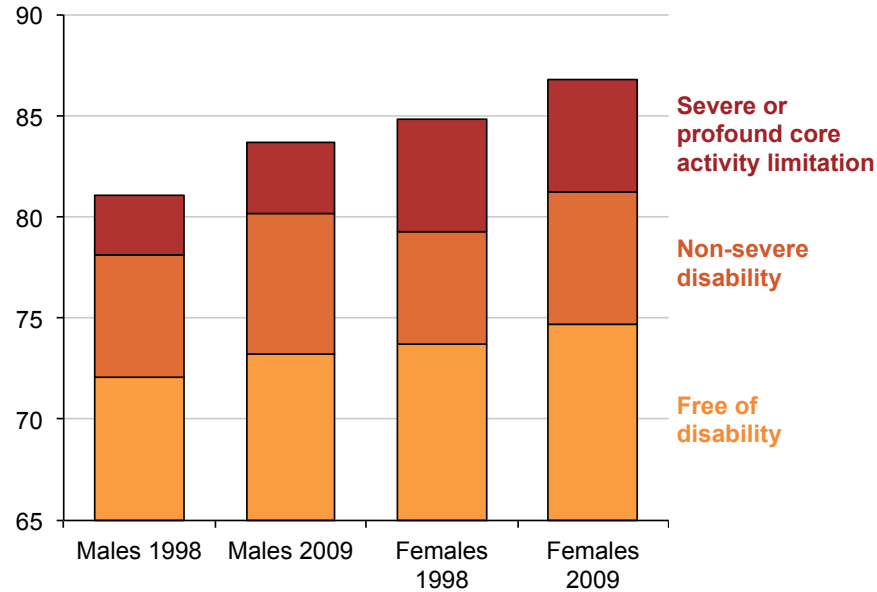


Source: (Australian Bureau of Statistics, 2008)

Death is more predictable and takes longer. About 70 per cent of deaths are expected and many people know when they are likely to die in the relatively near future. Most have chronic diseases and disabilities at the end of their lives. As more people reach older age years of disability have increased. In 2009 those aged 65 could expect more than half their remaining life to be lived with a disability, often severely limiting their quality of life.

**Figure 3: Years of life with disability have increased faster than years of life without**

Expected years of life for a 65-year old by disability status



Source: Australian Institute for Health and Welfare (2012a)

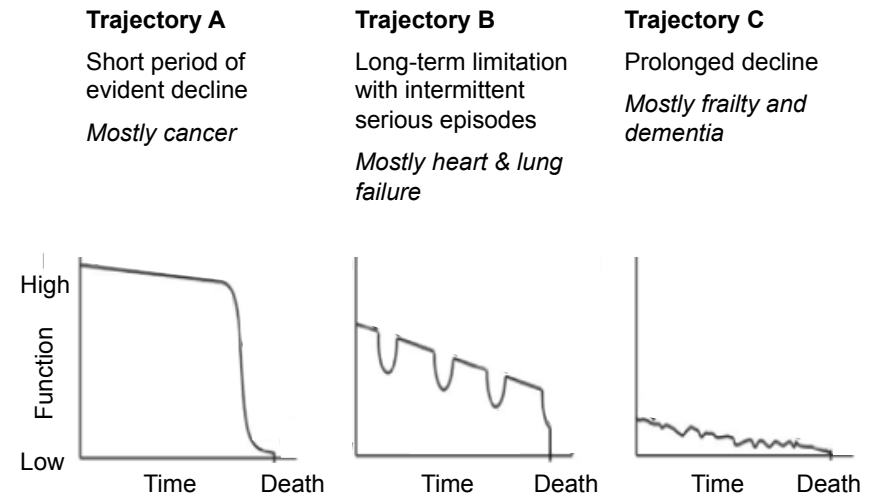
But not all deaths from chronic disease are the same.<sup>9</sup> Those who die of cancer commonly experience a period of relatively high function following their diagnosis, followed by a short sharp decline and then death. Others lose functions more slowly, with intermittent periods of serious illness before death. Those who are frail or have dementia are more likely to have a long period of relatively poor quality of life before death.<sup>10</sup>

<sup>9</sup> Lynne and Adamson (2003)

<sup>10</sup> Ibid.

**Figure 4: Not all deaths are the same**

Functions for typical patterns of illness leading to death



Source: (Lynne and Adamson, 2003)

### 1.3 The boomers are coming, and going

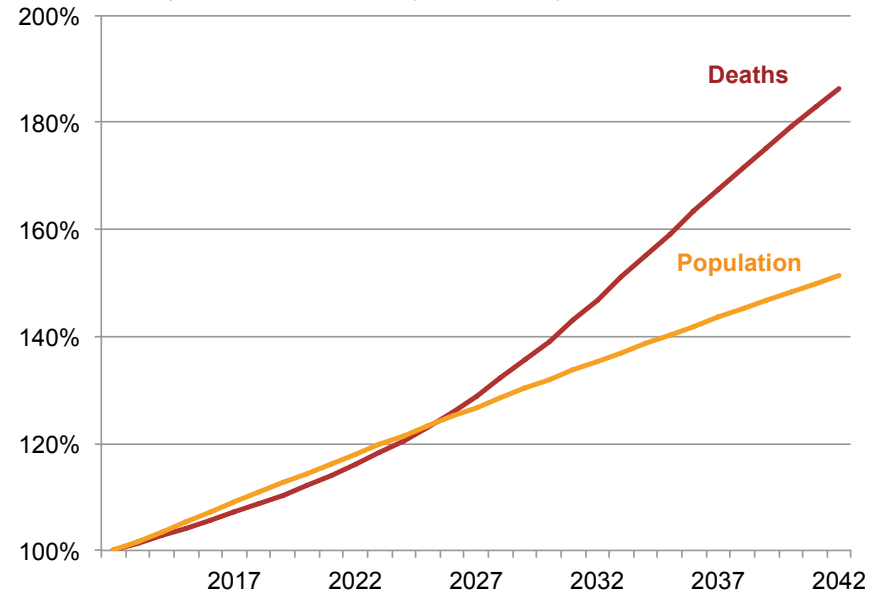
In the near future, increased life expectancy and the transition of the baby boomer generation to older age will see the proportion of older people in the population increase faster than population growth. Those aged over 85 will increase from two to four per cent of the population.<sup>11</sup> As a result the number of people who die each year in Australia will almost double in the next quarter of a

<sup>11</sup> Australian Bureau of Statistics (2013b)

century. As the number of people dying each year increases, pressure to improve the quality of dying is also likely to grow.

**Figure 5: The number of deaths will grow faster than the population in the future**

Growth in Population and deaths (index: 2012)



Source: Australian Bureau of Statistics (2013b)



## 2. What does a good death look like?

### 2.1 What do people want?

Most people prefer to die comfortably at home<sup>12</sup> or in a home-like environment with minimal pain and suffering. They hope to be surrounded by friends and family and the care services they need. A good death meets the individual physical, psychological, social and spiritual needs of the dying person (see box 1).<sup>13</sup>

In a South Australian population survey, Foreman et al<sup>14</sup> found that when people were asked where they would prefer to die if they had a terminal illness, 70 per cent of the population over the age of 15 said they would prefer to die at home, 19 per cent in a hospital, and 10 per cent in a hospice. Less than 1 per cent wanted to die in a nursing home.

Of course, people's preferences may change over time and as death approaches. Some people shift their choices toward inpatient hospice and hospital settings as they near the end of life. Even so, dying at home remains the preference for most.<sup>15</sup>

But the critical issue for people, which will be reinforced as baby boomers age, is choice. At present, often people don't die at home either because support services are inadequate or because they have not had a chance to articulate and implement their choice through proper discussion and planning.

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<sup>12</sup> Higginson, *et al.* (2013); Foreman, *et al.* (2006)

<sup>13</sup> Kellehear (2007)

<sup>14</sup> Foreman, *et al.* (2006)

<sup>15</sup> Higginson, *et al.* (2013)

### Box 1: What is a good death?<sup>16</sup>

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location including home, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives that ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

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<sup>16</sup> Smith (2000)

It is important to be able to choose and control the place, and what support and health care is provided.<sup>17</sup> People want to die with dignity. A good death allows people to determine who is present, to have time to say goodbye, to control the timing of death, and not to have continued medical interventions when quality of life is low and there is little or no hope of improvement.

## 2.2 Good end-of-life care

Good end-of-life care is important in order to die well. End-of-life care can be defined narrowly as the services provided around the immediate time of death, or broadly as the approach adopted once it is clear that a health condition is likely to lead to death in the relatively near future.

As part of end-of-life care, patients with a terminal illness often receive palliative care, particularly if they are facing significant suffering and distress caused by their illness. Palliative care is:

*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>18</sup>*

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<sup>17</sup> Ibid.

<sup>18</sup> WHO (2014b); Any health care professional working with people who are dying can adopt a palliative care approach. Specialist palliative care for more complex and difficult issues is provided in a range of settings including home, hospice, hospital and residential care.

High quality end-of-life services bring together health services, home care, personal support and support for carers, but always according to the preferences and circumstances of the dying person.<sup>19</sup>

Traditionally, terminal illness and end-of-life care is associated with cancer.<sup>20</sup> Other diagnoses potentially requiring palliative care at the end-of-life are cardiovascular and respiratory diseases, HIV/AIDS, motor neurone disease and multiple sclerosis. In older age, an increasing number of dying people also have dementia.<sup>21</sup>

When it is apparent people are reaching the end of their life it is important to have open discussions about their wishes for treatment, care and assistance. While the predictability of death within a given time period varies, particularly for non-malignant conditions,<sup>22</sup> clinicians are reasonably good at estimating when people are likely to die, although they tend to be overly optimistic.<sup>23</sup> In 60 per cent of cases physicians are accurate in predicting death to within a month. In half to 70 per cent of deaths, death is predictable and expected.<sup>24</sup> Effective procedures for predicting the likelihood of death have been developed for cancer,

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<sup>19</sup> Hales, *et al.* (2008)

<sup>20</sup> Australian Institute for Health and Welfare (2012a)

<sup>21</sup> Palliative Care Australia (2013b)

<sup>22</sup> Coventry, *et al.* (2005)

<sup>23</sup> Glare, *et al.* (2003), Wolf and Wolf (2013)

<sup>24</sup> Commonwealth of Australia (2010); Verne (2011)

<sup>25</sup> and for acute coronary conditions<sup>26</sup> and other non-malignant disease.<sup>27</sup>

End-of-life care often comes late in the progress of disease, usually after exhaustive attempts to cure the patient. When it becomes likely that the person is dying, the choice is between continuing to focus on cure and rehabilitation, or providing relief from symptoms and pain, coupled with assistance with personal, social and spiritual needs – in other words, palliative care.

When good end-of-life services are available, people are much more likely to die at home.<sup>28</sup> They are more satisfied with care, and less likely to be admitted to hospital or visit emergency departments. They also have lower overall healthcare costs,<sup>29</sup> although the difference is not large when the costs of better palliative care services are taken into account (see Chapter 3).

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<sup>25</sup> Stone and Lund (2007)

<sup>26</sup> Eagle, *et al.* (2004)

<sup>27</sup> Coventry, *et al.* (2005)

<sup>28</sup> Jordhøy, *et al.* (2000)

<sup>29</sup> Brumley, *et al.* (2007)

### 3. Death is not discussed

When dying is not discussed and concerns about voluntary euthanasia and assisted dying cloud the debate, the quality of death is poorer.

#### 3.1 Dying is not discussed

Failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying.<sup>30</sup> Having these conversations and making these plans is not easy. When death is near and quality of life is low, it is hard to know how far to pursue treatment, especially when the treatment is stressful, intrusive and likely to further reduce quality of life. Decision-making is even more stressful when treatment preferences have not been previously discussed, and choices are being made in the pressure cooker environment of a hospital. The problems are exacerbated when there has been insufficient discussion with close relatives or when health care staff are anxious about their legal obligations.<sup>31</sup>

As a community, we struggle to talk about death. We prefer euphemisms – “passed on” and “resting in peace” -- to direct speech. We focus more on hopes for the next medical breakthrough<sup>32</sup> than on the limits of health care when death is near. Public discussion of death may even be more cloaked than

it was for earlier generations, when death was more common. Preparation for death has become technical, private and hidden.<sup>33</sup>

As Ashby *et al.*<sup>34</sup> note:

*In personal health care encounters, the idea that cure is improbable or impossible, or that continued life support is inappropriate or unkind, is unacceptable to many families. The wider problem here is that acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in our culture. For many, an almost child-like faith in medicine and science has taken its place.*

The upshot of these attitudes is that most people only get detailed information about end-of-life services when they encounter the system as a patient or as a patient’s relative or friend.<sup>35</sup> Very few people discuss their preferences for end-of-life care with health professionals. Even fewer have made formal plans to ensure their wishes are followed<sup>36</sup> even when it is clear they likely to die in the relatively near future.

In part this is because health professionals are uneasy about discussing death and dying with patients. As a result they can obfuscate about likely treatment outcomes and overestimate the

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<sup>30</sup> Australian Senate (2012b)

<sup>31</sup> Brieva, *et al.* (2009); Curtis, *et al.* (2012); Juce (2002); Sprung (2003)

<sup>32</sup> Schwartz, *et al.* (2002)

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<sup>33</sup> Kellehear (2007)

<sup>34</sup> Ashby, *et al.* (2005)

<sup>35</sup> Only 38 per cent of people in the community could describe palliative care to someone else

<sup>36</sup> <http://dyingmatters.org/page/survey-reveals-our-reluctance-discuss-own-death>

chances of recovery.<sup>37</sup> Often they do not feel they have the required skills to have these hard conversations.<sup>38</sup> They are trained to discuss cure and rehabilitation, not how to make the end of life easier. A patient's condition, cultural background and his or her family's views and perspectives all shape the willingness of health professionals to have frank discussions.<sup>39</sup>

Even when death seems imminent, professionals often feel conflicted between discussing it and the desire to provide hope by focussing on treatment options to prolong life. This is particularly true when the dying person is young. As a result professionals are often overly optimistic about the potential for treatment to succeed, then pursue it for far too long, at significant cost and with little benefit to the patient.<sup>40</sup> The hard discussions about end-of-life care are delayed and sometimes avoided altogether. People and their families then do not have the opportunity to prepare for death. Often treatment that has little benefit is provided and they die in hospital rather than at home.

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<sup>37</sup> Wolf and Wolf (2013)

<sup>38</sup> Silvester (2012) found that only 66 per cent of health professionals had a level of comfort dealing with discussions around Advance Care Plans (ACP). Only 50 per cent perceived that they had skills in dealing with discussions around ACP. Only 24 per cent of staff reported that in the last six months they had discussions about ACP with all/most/some residents. 76 per cent of staff reported having very few or no discussions with residents about ACP in the last six months.

<sup>39</sup> Broom, *et al.* (2014); Australian Senate (2012)

<sup>40</sup> Curtis, *et al.*; Zhang, *et al.* (2009)

### Box 2: Case study of Advance Care Planning<sup>41</sup>

Mrs P is 82 years old, with severe end-stage lung disease. She is on home oxygen 24 hours a day. She has coronary heart disease and has several rib fractures and a fractured arm.

She has become housebound and largely immobile because she is no longer able to exercise and is scared of falling over. She needs to be cared for 24 hours a day by her 48-year-old son.

Through advance care planning, Mrs P expresses her wish to not be admitted to hospital again. She says she only wants to be treated by her own GP in the future and she nominates her son as her substitute decision-maker.

Mrs P's Advance Care Directive gives her son the information he needs to be able to respect her wishes. Because she has indicated her end-of-life wishes, he will be able to legally refuse treatment for her if necessary. Her GP has made a commitment to fulfill this choice if possible.

Mrs P is happy she has given her son clear guidance about her treatment and end-of-life wishes.

Advance Care Plans can provide some of the answer. An Advance Care Plan appoints a substitute decision maker and documents values beliefs and preferences to provide clarity for health professionals who provide treatment and services.<sup>42</sup>

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<sup>41</sup> case study adapted from: <http://advancecareplanning.org.au/advance-care-planning/for-everyone/respecting-patient-choices>

<sup>42</sup> Advance Care Planning Australia (2014)

Usually the Plan sets out preferences for resuscitation, life prolonging treatment and other specific treatments and situations that would be unacceptable as well as the aspects of life that are seen as valuable and important to maintain and protect.

Plans are usually completed in consultation with health professionals and important family members. The process of developing a plan helps people clarify important care and treatment preferences for themselves and others. It formalises their decisions, directives and preferences in the event they are no longer able to express them directly.

Advanced Care Plans are designed (see box 3) to meet patients' wishes for treatment and care and to reduce anxiety for patients and family.<sup>43</sup> Their implementation can also reduce hospitalizations and costly interventions that have little benefit for the patient.<sup>44</sup> Systematic implementation of a plan can significantly improve the quality of end-of-life care and reduce the cost of unwanted interventions.<sup>45</sup>

There is no need to start from scratch. Systems for discussing, documenting, recording and implementing plans are well developed.<sup>46</sup> Clinicians have wide access to validated resources and training to explain them.<sup>47</sup> All Australian jurisdictions have developed regulatory and legislative frameworks to support them.

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<sup>43</sup> Detering, *et al.* (2010)

<sup>44</sup> Robinson, *et al.* (2011)

<sup>45</sup> Detering, *et al.* (2010); Molloy, *et al.* (2000); Zhang, *et al.* (2009)

<sup>46</sup> Hammes, *et al.* (2010)

<sup>47</sup> <http://www.rpctraining.com.au/index.php>

While Advance Care Plans can be developed at any point along the journey, they are most needed when death is highly likely in the relatively near future.

The Respecting Patient Choices Program, supported by the Federal and Victorian Governments and trialled at various sites across Australia, focuses on the development of Advance Care Plans, including for new residents at aged care facilities. An evaluation found that an aged care resident who was introduced to the Respecting Patient Choices program was four times more likely than other residents to complete a plan before death.<sup>48</sup>

Yet awareness of Advance Care Plans remains very low.<sup>49</sup> A survey of residential aged care facilities in New South Wales, found that on average only five per cent of residents have documented advance care directives, despite the fact that the average length of stay in these facilities is up to three years and 90 per cent of residents will die in them.<sup>50</sup>

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<sup>48</sup> Austin Health (2006). 89 per cent of patients introduced to program documented their plans in an ACP. 100 per cent of residents who completed a Respecting Patient Choices initiated ACP had their medical treatment wishes respected. The majority (88 per cent) died in their facilities receiving palliative care as requested. 11 per cent died in hospital having been transferred at resident and/or family request for symptom management. Residents had a significantly higher chance of dying in hospital when their wishes were unknown. If a resident had an ACP there was a 257 per cent rise in the likelihood that a patient would receive end-of-life care in the residential aged care facility. Average length of stay in hospital before dying was 15.27 days in patients without an ACP versus 6.86 days for those with (p=0.035).

<sup>49</sup> Australian Senate (2012a)

<sup>50</sup> Bezzina (2009)

**Box 3: Best practice advance care planning<sup>51</sup>**

- Facilities have readily accessible, written policies and procedures about advance care planning that establish it as a routine component of care.
- Regular education is provided to aged care service staff, residents and relatives, and GPs.
- Residents and families are given information about Advance Care Plans before or at admissions.
- A plan is offered to residents within 28 days of admission.
- It is completed by an appropriately skilled health professional during an in-depth discussion with the patient and/or their family.
- The conversation focuses on reasonable outcomes and living well. It raises the issues of life-prolonging treatment generally but does not focus on any specific treatment.
- GPs are involved in the discussion.
- Completed plans are regularly reviewed.
- Plan documents clearly specify at a minimum: a nominated substitute decision maker where applicable; current state of health; values and beliefs; future unacceptable health conditions; level of preferred future medical treatment indicated; specific wanted/unwanted treatments; goals for end-of-life care; appropriate signatures; evidence of GP review.
- Facilities have effective information transfer systems to enable residents to gain information about Advance Care Plans.

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<sup>51</sup> Silvester (2012)

In another analysis, Taylor et al<sup>52</sup> found that only eight per cent of emergency patients had an Advance Care Plan. There are no national standards or guidelines for advance care planning<sup>53</sup> and the different legal position of plans in each state makes consistent national implementation difficult.<sup>54</sup>

### 3.2 Concerns about hastening death

When people's preferences are not clear, it is harder to shift from a focus on a cure to a focus on palliative care, which often involves withdrawing treatments that have little or no benefit and can include pain relieving treatment that hastens death.

Not surprisingly, some dying people want to be able to actively manage the time and circumstances of their death through voluntary euthanasia or assisted dying. Although not the focus of this report, the issue is frequently raised in discussions of death and dying.

Voluntary euthanasia means "ending another person's life at his or her own request".<sup>55</sup> Assisted dying means "providing someone with the means to end his or her own life."<sup>56</sup>

Assisted dying is legal in Switzerland and in the US in the states of Oregon, Vermont and Washington. Voluntary euthanasia is legal in Belgium, The Netherlands and Luxembourg. In Australia,

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<sup>52</sup> Talyor, *et al.* (2003)

<sup>53</sup> Palliative Care Australia (2013a)

<sup>54</sup> *Ibid.*

<sup>55</sup> Demos (2011)

<sup>56</sup> *Ibid.*

it was briefly legal in the Northern Territory between 1996 and 1997 and it is being considered in Canada.<sup>57</sup>

The conditions under which people make requests to die vary. People with a terminal illness may ask to be helped to die to end or avoid unbearable suffering. In some cases, even high quality palliative care cannot relieve significant pain and suffering.<sup>58</sup> Others are distressed by the prospect of a lingering death incapacitated by the loss of cognitive and physical functions.

Yet experience over more than six decades indicates that across jurisdictions where it is permitted, the rates of assisted deaths are low. They vary from about 0.2 per cent of all deaths in the US States of Oregon, Vermont and Washington to three per cent in the Netherlands.<sup>59</sup>

There is pressure for this issue to be considered more thoroughly through law reform commission bodies.<sup>60</sup> Debate and further proposals to legalise voluntary euthanasia and assisted dying are likely to increase in future.

This report is about a different issue. It focuses on the importance of good preparation and planning for treatment and care when people are dying. This is important because medical practitioners often face choices about whether to discontinue treatment, or to

provide additional pain relief. They know that in these circumstances, death will probably occur earlier. However, provided that they do not deliberately intervene to accelerate death, it is legal under Australian law. Medical practitioners commonly provide treatment that both alleviates symptoms and may lead to an earlier death.<sup>61</sup> Even where euthanasia is illegal, it is estimated that in about a third of deaths an explicit medical decision to increase pain relief or not prolong life is made.<sup>62</sup> A significant proportion of those with a terminal illness desire a hastened death through either withdrawing treatment or additional pain relief.<sup>63</sup>

It is common to withdraw treatment for people with a terminal or incurable disease. Up to 80 per cent of patients who die in intensive care units have treatment withheld or withdrawn when further interventions are useless and death is imminent.<sup>64</sup> Treatments that are withdrawn include mechanical ventilation, vasopressors, inotropes, oxygen supplementation, intravenous fluids, nutritional supplementation and renal dialysis.

Concerns about voluntary euthanasia and assisted dying often clouds discussion about end of life care. This makes it more difficult to address much more common situations of withdrawing treatment and increasing pain relief. Preparation to anticipate these choices and planning for how we want to die is critical for dying well.

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<sup>57</sup> <http://healthydebate.ca/2014/08/topic/euthanasia-assisted-death>

<sup>58</sup> PCOC (2013)

<sup>59</sup> (<http://www.care.org.uk/advocacy/end-of-life/euthanasia-country-comparison>, [http://healthvermont.gov/family/end\\_of\\_life\\_care/patient\\_choice.aspx](http://healthvermont.gov/family/end_of_life_care/patient_choice.aspx), Dees et al (2009)

<sup>60</sup> <http://www.theage.com.au/comment/the-age-editorial/euthanasia-the-debate-must-start-now-20140429-37fsk.html>

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<sup>61</sup> Seale (2006) found in a survey of UK medical practitioners that 32.8% had alleviated symptoms with possibly life shortening effect.

<sup>62</sup> van der heide, *et al.* (2003); Kuhse, *et al.* (1997)

<sup>63</sup> Guy and Stern (2006)

<sup>64</sup> Brieva, *et al.* (2009)



## 4. Services could be better

In Australia people often do not have the opportunity to choose and control the manner of their death, we do not provide enough support for carers, end-of-life services are fragmented, and sufficient palliative care is often not available,

### 4.1 Dying at home puts pressure on informal care

Despite wanting to die at home most people end up in institutions. Usually this happens when they become so dependent that informal carers cannot cope or are unavailable and, regardless of the person's wishes, there is insufficient formal home and community care for the person to stay at home.<sup>65</sup> People dying at home have to be supported. The main support is informal care by spouses, children, parents and friends.<sup>66</sup>

In 2010, informal carers provided 1.3 billion hours of home care.<sup>67</sup> If paid carers were to do this work it would be worth an estimated \$40.9 billion.<sup>68</sup>

<sup>65</sup> Higginson, *et al.* (2013)

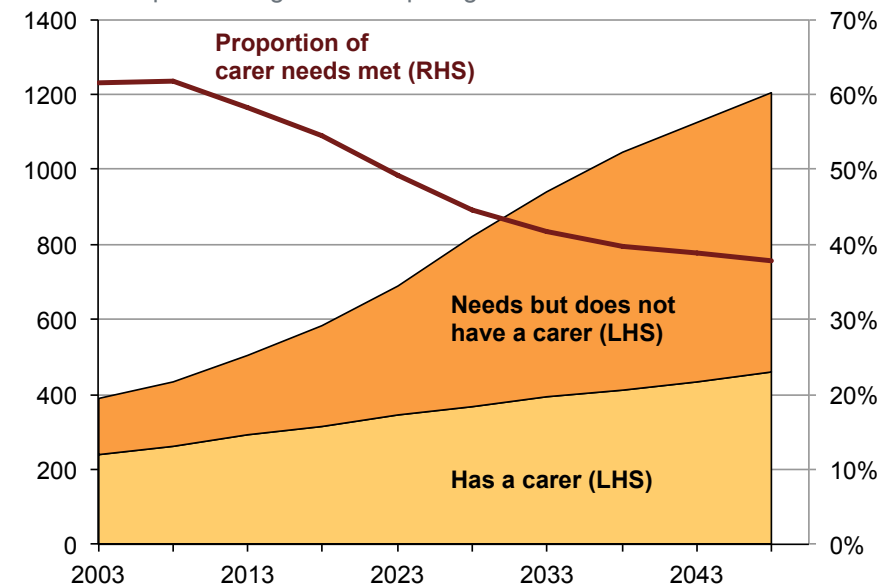
<sup>66</sup> Jeannette Moody, CEO of the Eastern Palliative Care Association, cited in Australian Senate (2012)

<sup>67</sup> Access Economics (2010). But carer hours are unevenly spread. Primary carers provide 54 per cent of care despite making up only 19 per cent of the informal care workforce.

<sup>68</sup> *Ibid.*

**Figure 6: Carer demand and supply is becoming challenging**

Number of persons aged 65+ requiring a carer



*Note: includes supply and demand for informal carers of all types, not only for people who are dying*

*Source: Access Economics (2010)*

In the next three decades more dying people will require care than ever before. Most will want to die at home. But informal care is under pressure. It carries financial, emotional and time costs.

Often carers face considerable waiting periods to get support through carer packages and home-based care.<sup>69</sup>

Most importantly, without the development of new support for informal care, it is unlikely to be available to meet additional demand.<sup>70</sup> With social change and increased population ageing, the carer ratio – the number of people who need a carer to the number of people who have one – is falling. Already, a significant proportion of dying people do not have a carer.<sup>71</sup>

## 4.2 Care is fragmented

More coordinated end-of-life care is needed to support people to die in the way they want to, including at home and in homelike environments. While Australia's end of life system ranks well by international standards,<sup>72</sup> we put less emphasis on holistic, end-of-life care and 'dying in place' than do New Zealand, the United Kingdom, Canada and Europe.<sup>73</sup>

Providing a good patient journey is difficult. The service system is fragmented. Patients, carers, and even health professionals find it hard to navigate the system. Dying people are often admitted and discharged from hospital into community care, creating an end-of-life journey that is disjointed and confusing for patients and their

family.<sup>74</sup> In hospital, they are often cared for in non-palliative care beds, where staff may lack the specialised skills to care for a dying patient and support their family.<sup>75</sup>

Governments and non-government organisations in Australia and overseas have produced a range of end-of-life care strategies to improve care.<sup>76</sup> But there is no consistent national strategy to give dying people the confidence their choices will be respected and that they will get the care and support they need.

Several major Australian reviews have considered end-of-life care. The National Health and Hospitals Reform Commission noted in its final report in 2009:

*The current experience of end-of-life care in Australia is disparate and inconsistent and we cannot in good faith promise patients at the end of their life access to care that is customised to preferences and reliably delivers good symptom control. Our health system can do better.<sup>77</sup>*

The Commission recommended strengthening the primary care system to combat the lack of palliative care services outside of hospitals. It proposed additional investment in generalist palliative

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<sup>69</sup> Australian Senate (2012)

<sup>70</sup> The National Carer Strategy identifies six priority areas to strengthen the position of carers: recognition and respect; information and access; economic security; services for carers; education and training; and health and well being

<sup>71</sup> The Eastern Palliative Care Association reports that 26 per cent of their patients have no carer.

<sup>72</sup> WHO (2014a)

<sup>73</sup> Australian Senate (2012); Broad, *et al.* (2013)

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<sup>74</sup> The number of people who have multiple visits to metropolitan public hospital emergency departments or multiple public hospital admissions in their last year of life is increasing, Health Performance Council of South Australia (2013).

<sup>75</sup> Palliative Care Queensland (2012)

<sup>76</sup> Commonwealth of Australia ; Department of Social Services (2013); Department of Health (Vic) (2011); Department of Health (NSW) (2012); Department of Health (WA) (2012); Canadian Hospice Palliative Care Association (2012)

<sup>77</sup> National Health and Hospitals Reform Commission (2009)

care services and in specialist care services for home, community and residential care settings. It focused on the need to bring care to the patient, rather than bringing the patient to care.

Better co-ordination of end-of-life services is critical, because even when Advance Care Plans are in place and people's wishes for treatment, support and care are clear, plans are often not implemented. Effective co-ordination would ensure that every patient has his or her needs assessed and has access to the right services.<sup>78</sup> More work must be done on a regional and service governance model that gives people a better end to life.<sup>79</sup>

### 4.3 There is not enough palliative care

An estimated 69 to 82 per cent of people who die in high-income countries need palliative care.<sup>80</sup> Palliative Care Australia has estimated that 90 per cent of cancer patients and half of non-cancer patients could benefit from palliative care services.<sup>81</sup> If these estimates are right, at least 100,000 people who die each year in Australia need palliative care.

In 2010-11, nearly 20,000 people died in hospital while receiving palliative care.<sup>82</sup> Nationally consistent data on community-based palliative care services is not available.<sup>83</sup> From the data we have

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<sup>78</sup> Department of Health (WA) (2008)

<sup>79</sup> Australian Senate (2012)

<sup>80</sup> Murtagh, *et al.* (2014)

<sup>81</sup> Palliative Care Australia (2003)

<sup>82</sup> from the National Hospital Morbidity Database. This was 26% of all hospital deaths.

<sup>83</sup> Australian Institute for Health and Welfare (2012b); Analysis of data provided by Palliative Care Victoria indicates that 28% of people who died in Victoria in

we know that while community-based palliative care services exist in Australia, they are limited, and sometimes only available for people with certain prognoses. In Queensland, for example, packages to support care at home are only available for those with fewer than three months to live.<sup>84</sup> Some palliative care programs are tied to specific diagnoses – cancer, in particular.<sup>85</sup>

The Senate Community Affairs Committee has conducted an extended review of palliative care services.<sup>86</sup> It recommended extending the scope and quality of palliative care through a greater emphasis on training, research and capacity building, and providing more information for the public and patients on end-of-life choices and options. It also proposes a new funding category for palliative care services, national accreditation of these services, and more emphasis on case management and service coordination.

### 4.4 Learning from overseas

A number of approaches have been developed overseas. Britain's Gold Standards Framework, one of the best, sets out clear tasks that health professionals must do to implement patient choices.<sup>87</sup> Similarly, an NHS trust in England and the Marie Curie Cancer

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2012/13 received community based palliative care. Of those who received community based palliative care, 24% died at home; 56% died in hospital.

<sup>84</sup> Palliative Care Queensland (2012)

<sup>85</sup> *Ibid.*

<sup>86</sup> Senate Community Affairs Committee (2012)

<sup>87</sup> Communication, coordination, control of symptoms, continuity of care, continued learning, carer support, care in the dying phase.

Care charity have developed a care framework that can be tailored to patients near the end of life.

End-of-life registers or records enable patients, carers and health professionals to access the patient's condition and wishes. About 90 per cent of GPs in England have a register of patients nearing the end of life, according to the King's Fund.<sup>88</sup> The register helps to ensure consistent support for a patient's preferences.<sup>89</sup>

Home helplines can assist both patients and carers.<sup>90</sup> They advise on how to make patients comfortable and help patients and carers feel that someone is there for them, even if they are at home.<sup>91</sup> By connecting patients and carers to hospitals by phone when problems emerge, they can often avoid emergency department visits.<sup>92</sup>

Marie Curie Cancer Care in the UK has established a program of rapid response teams that can provide immediate support to patients at home or in hospices. The introduction of these teams has led to a statistically significant increase in the number of patients with illnesses other than cancer who die at home.<sup>93</sup> For

patients with cancer there is an increase for patients outside the program, but it is not statistically significant.<sup>94</sup>

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<sup>88</sup> Addicott (2010)

<sup>89</sup> NICE (2004)

<sup>90</sup> Ibid.; Kidd, *et al.* (2010)

<sup>91</sup> NICE (2004) ; Campbell, *et al.* (2006) found that Hospice nurses provide effective, compassionate telephone advice in stressful situations; 64% of calls are from carers

<sup>92</sup> NICE (2004)

<sup>93</sup> In the two years previously, 14.5 per cent and 15.8 per cent of patients died at home. In the year of the RRT intervention, 20.3 per cent of patients died at home; 34.9 per cent of patients who were in the program died at home. Addicott and Dewar (2008)

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<sup>94</sup> In the two years previously, 24.8 per cent and 27.7 per cent of patients died at home. In the year of the RRT intervention, 30.3 per cent of patients died at home; 44.5 per cent of patients who were in the program died at home. Ibid.

## 5. Will a better death cost more?

Most Australians say they want to die at home but end up dying in hospitals or nursing homes. Not only does this not meet people's wishes, it would not cost more to die at home. However, spending is not well targeted to support the way people want to die.

### 5.1 Dying is a modest part of Australian health budgets

The cost of dying, while significant, is modest as a proportion of Australia's health budget of over \$100 billion.<sup>95</sup> This is because although the cost per person of dying is high, less than one per cent of the Australian population dies each year.

Most of these costs are for older people, although the cost per person is higher for younger people.<sup>96</sup> An Australian estimate suggests that hospital care for the last year of life for those aged 65 years and over is about nine per cent of all inpatient costs.<sup>97</sup> Each year \$2.4 billion is spent on acute inpatient care for people who are dying, according to this estimate.<sup>98</sup>

International estimates of the cost of dying vary. The measures that exist are underdeveloped and make comparisons between countries difficult. While comprehensive information is also not readily available in Australia, the overall costs of health and aged

care for people aged 65 and over in the last year of life are estimated at about five per cent of the total health budget (see Table 1).

To date increased life expectancy and population ageing have not significantly pushed up health care costs in Australia. Inflation, population growth and the move toward more tests, treatments and use of pharmaceuticals have been more important than ageing. This is in part because costs associated with dying, which occur largely in the last year of life, are deferred to later in life as people live longer.

**Table 1: Place and costs of death for older people**

Place of death	No. deaths	% deaths	Costs (\$M)	% costs
Acute inpatient	51,759	35%	2,440	48%
Sub acute	21,470	15%	221	4%
Residential care	50,866	35%	2,330	46%
Community care	4,655	3%	77	2%
Other	18,182	12%	-	-
Total	146,932 <sup>99</sup>	100%	5,066	100%

However, the demographic transition of the baby boomers into old age over the next 25 years will see the population rate of dying –

<sup>95</sup> Australian Institute for Health and Welfare (2014b)

<sup>96</sup> Moorin and Holman (2008)

<sup>97</sup> Kardamanidis, *et al.* (2007)

<sup>98</sup> In 2012-13 Activity based funding for public acute inpatient funding was \$26 billion see

<http://www.publichospitalfunding.gov.au/reports/national?month=jun2013#table3>

<sup>99</sup> for 2011 Australian Bureau of Statistics (2012)

the crude death rate – increase sharply. The real costs of dying will increase accordingly. If the current costs of dying remain constant, aggregate health and social care costs associated with dying are likely to double to more than \$10 billion a year in 2013-14 dollars. It is important to get the policies right, as the costs of dying are likely to increase dramatically in the near future as more people die each year.

### 5.2 Spending in institutions is comparatively high

People want to die at home, but most spending in the last year of life is in hospital and residential care. Each year over \$2 billion is spent on older people who die in hospital. Costs are highest for those who die as acute in-patients. They comprise 48 per cent of identified hospital and aged care costs. Sub-acute care in hospital is far less costly, comprising just 4 per cent of costs. About a third of all people who die in hospital have only one admission – the one in which they die. The average cost of that admission for those aged 50 and over is about \$19,000.

The cost of deaths in residential aged care is about half the cost of dying for all deaths.<sup>100</sup> In 2010-11, 50,866 people died in residential aged care – 35 per cent of all deaths.<sup>101</sup> More than 90 per cent of permanent residents of aged care facilities died there.

Costs are comparatively high for residential aged care. In 2010-11 the average annual subsidy per residential place was \$45,798.<sup>102</sup>

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<sup>100</sup> based on the last 12 months of life .

<sup>101</sup> <http://www.aihw.gov.au/publication-detail?id=10737422821>

<sup>102</sup> [http://www.pc.gov.au/\\_\\_data/assets/pdf\\_file/0006/114963/47-government-services-2012-chapter13.pdf](http://www.pc.gov.au/__data/assets/pdf_file/0006/114963/47-government-services-2012-chapter13.pdf)

The estimated total cost of residential care in the last year of life for those who died in residential aged care is \$2.3 billion.

### 5.3 Spending on community care is comparatively low

Much less is spent on community aged care for dying people than for those in hospital and residential care. In 2010-11, 4655 people died while receiving an aged care package<sup>103</sup> – just 3 per cent of all deaths and 2 per cent of identified costs. The estimated Commonwealth cost of packages for those who die at home is \$77 million.<sup>104</sup> The states also provided funding for palliative care, but consistent data on the distribution of this funding is unavailable.

The total estimated cost of public hospital, residential aged care and community-based aged care services for the last 12 months of life for older people is at least \$5 billion, as Table 2 shows. Only two per cent of identified expenditure is spent on community care packages. We estimate that the average cost of community based care for the last three months of life for community aged care packages is about \$6000.<sup>105</sup> The costs of supporting individuals to die at home are therefore lower than hospital and residential care, but to achieve overall savings hospital and residential care would have to be replaced by community based services.

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<sup>103</sup> Home care packages provide a coordinated set of services including personal care, clinical services, home modification, cleaning and maintenance, and social and community support for transport, shopping and social activities.

<sup>104</sup> Adjusting for the length of time people were in receipt of a package and 2013/14 dollars;

<sup>105</sup> Based on averaged costs for people who died while receiving community aged care packages and validated against community palliative care costs.

## 6. Better dying

Australians can and should have better deaths. To meet our desire for better deaths we need to:

- be informed about the limits of health care and the importance of discussing our preferences for end-of-life care;
- ensure that greater incentives and encouragement exist for the development and implementation of Advance Care Plans;
- increase the availability of community- and home-based support for people who are dying, particularly for older people with chronic conditions

### 6.1 Encouraging public discussion

Public debate tends to avoid discussions of the limits of health care and how we can better manage the end of life. As a result the public is ill-informed and overly optimistic about the effectiveness of health care. A program of public education about the end of life is needed to combat misperceptions and to encourage people to realistically discuss their preferences for end-of-life care and to put in place plans to ensure they are met.

Health education programs are a well-established way to inform the public and facilitate change.<sup>106</sup> They have been important in

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<sup>106</sup> Successful public education campaigns have been conducted on range of health issues including smoking, motor vehicle safety and work injuries as part of

prevention campaigns, in winning support for blood and organ donation, and in promoting the rights of older people and people with disabilities.

Public education would encourage people to consider and discuss their end-of-life preferences with their families and health care professionals and document them in Advance Care Plans.<sup>107</sup>

A national public education campaign would focus on encouraging people to discuss their preferences and choices for end-of-life care with health professionals, including GPs.

For this report we commissioned an indicative plan of costs and strategies for a national public education campaign. A 12- to 18-month campaign, encompassing mass and digital media, public relations, direct marketing and education is estimated to cost \$10 million.<sup>108</sup> A sample television script treatment is presented in box 4.

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overall strategies to improve health outcomes Aaron and Harris (2004); Nutbeam (2000)

<sup>107</sup> In the United States, each year a number of States have April 16th as National Health Care Decision Day – a day when people are encouraged to consider completing advance care plans. Australia has Dying to Know Day <http://www.dyingtoknowday.org/> and Palliative Care Week <http://www.palliativecare.org.au/nationalpalliativecareweek.asp> <http://www.cdc.gov/features/advancedcareplanning/index.html>

<sup>108</sup> A detailed plan is available on the Grattan website <http://grattan.edu.au/home/health/>

**Box 4: Indicative TV script treatment (developed by Stokes Studio)<sup>109</sup>**

DYING: IT'S A LIVING THING

WOMAN TO CAMERA: Well I certainly don't want to be medicated to the point of not being conscious...

MAN TO CAMERA: As long as there's breath, there's hope...

MAN 2 TO CAMERA: I just don't see the point in distressing everyone...

VOICE OVER: While we prepare practically for death by making wills and funeral plans we never prepare ourselves emotionally about what happens before death.

And making sure you, your loved ones and your carers have an understanding of what your thoughts and feelings are, is as simple as beginning a conversation.

It's not about dying, but how you want to live.

SUPER IMPOSED: Dying: It's A Living Thing

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<sup>109</sup> The full communications strategy is available at <http://grattan.edu.au/home/health/>

## 6.2 End of life discussions and planning

There are now well-developed and effective approaches for how to discuss end-of-life treatment and care and develop an Advance Care Plan. Yet much greater encouragement and incentives are required to ensure that plans are more widely implemented.

Palliative Care Australia argues that:

*All Australians should be supported to consider and provided the opportunity to specify the type of care they would like to receive at the end of life. Continual reassessment of current circumstances and likely future scenarios are part of this consideration.*<sup>110</sup>

Views about death and choices about dying vary across the community. They also change over time for individuals. Therefore discussions with health professionals about end-of-life care and the plans that emerge from them need to be seen as an ongoing process that is refined over time.

The Italian writer, Umberto Eco, said it was “necessary to meditate early, and often, on the art of dying to succeed later in doing it properly just once.”<sup>111</sup> Yet most people don't follow this advice. Even health professionals, whose direct experience of death and dying puts them in a much better position than the rest of us to initiate end-of-life discussions, too often find this difficult.<sup>112</sup> It is therefore important that formal prompts and

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<sup>110</sup> Palliative Care Australia (2013)

<sup>111</sup> Eco (1994)

<sup>112</sup> Broom, *et al.* (2014); Keon-Cohen (2013)



incentives are put in place to encourage health professionals to discuss and plan for end of life with their patients when the time is right.

End-of-life plans should set out the range of interventions a person wants – from aggressive intervention through to palliative care. In particular, the following trigger points for mandatory discussions are recommended:

- Health professionals should initiate discussions on end-of-life preferences during over-75 health assessments
- Advance Care Plans should be discussed and developed for all residents of aged care facilities and for high-needs recipients of home care packages as part of assessment and care planning
- Plans should be discussed and developed for all hospital in-patients who are likely to die in the next 12 months.

#### Discuss dying in over 75 health checks

All Australians aged 75 and over are eligible for an annual health assessment to identify health problems that are potentially preventable or amenable to intervention.<sup>113</sup> Health Assessments are comprehensive and provide a structured opportunity to discuss a range of health and social issues.

They also provide an excellent opportunity to discuss preferences for end-of-life care and to develop Advance Care Plans and

Directives. Good conversations will take time. Practice nurses may initiate conversations, then general practitioners confirm any decisions as part of health assessments. Requiring the initiation of a conversation doesn't mean a plan must be finalised the same day. People taking part in assessments need to make that decision themselves. Yet unless conversations are initiated no plan will be completed.

Guidelines, reporting and monitoring procedures for health assessments of those aged 75 and over, should be amended to include a normal expectation that end-of-life options and Advance Care Plans are formally discussed.

#### Encourage discussion as part of chronic disease management

About 100,000 Australians die from chronic diseases each year. In many cases health professionals know when a person is highly likely to die in a year or less.

The Commonwealth Medical Benefits Schedule includes a series of items to enable general medical practitioners to plan and coordinate care for people with chronic diseases and terminal conditions.<sup>114</sup> When appropriate, the discussion, development and implementation of Advance Care Plans should be included as a required part of the management chronic disease under the Schedule.

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<sup>113</sup> Department of Health (2014c)

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<sup>114</sup> Department of Health (2014a)

### Plan for dying in age care services

Governments fund aged care for people who are no longer able to live at home due to health, disability or social circumstances. Nearly a third of Australians die in residential care and 90 per cent of permanent residents die there. Yet very few residents have Advance Care Plans.

When a person seeks entry into a residential aged care facility, a discussion of end-of-life options and the development of a plan should be a normal expectation as part of the initial aged care assessment and planning process.<sup>115</sup>

Similarly, a preliminary discussion and the development of a plan should be a normal expectation when people with high-level needs are assessed for eligibility for a home care package. These packages are increasingly used as substitutes for residential aged care. They fund a range of services including: personal care, nursing services, home modifications, specialist equipment, transport, social support and respite care.

### Plans for people who are in hospital and likely to die

End-of-life discussions, including the development of plans, should be initiated with all hospital in-patients who are likely to die of a chronic condition in the next year. This should be part of discharge planning.

The Respecting Patient Choices program provides a good basis to support the development of plans at appropriate moments in

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<sup>115</sup> *ibid*

health care.<sup>116</sup> The program provides information for patients and appropriate training for health professionals. It should be extended to require the development of plans at key points in patient care.

The proposals outlined above would require health professionals to initiate conversations about how, where and with whom people want to die. These conversations are often difficult for both health professionals and patients, and trigger points and incentives are needed to ensure they occur. Through their undergraduate and postgraduate training, and on the job, health professionals will need to be educated and supported to have these conversations. Fortunately, guidance, advice and resources are available.<sup>117</sup>

### 6.3 Ensuring Advance Care Plans are implemented

Plans are important but they are not enough to ensure that the wishes of dying people are met.<sup>118</sup> Further measures are needed to ensure that plans are implemented as part of systematic and patient-centred care.

There is little point in having Advance Care Plans and Directives if there is uncertainty that they will be followed. States are responsible for legislating on end-of-life decision-making. They should either ensure that National Guidelines for Advance Care Plans and Directives, such as those developed by the Australian

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<sup>116</sup> <http://advancecareplanning.org.au>

<sup>117</sup> Training resources for health professionals in initiating conversations and developing ACPs are widely available online (e.g.

<http://www.health.vic.gov.au/acp/training.htm>)

<sup>118</sup> Predegast (2001)

Health Ministers Advisory Council, are followed,<sup>119</sup> or they should work with the Commonwealth to develop nationally consistent legislation to underpin the plans, as the Senate inquiry into palliative care has recommended.<sup>120</sup>

Good care at the end of life should be coordinated across different health professionals. Yet this is difficult in Australia's largely siloed health system. As well, people receiving palliative care are often transferred from home to general practice to specialist medical practice to hospital to residential care.

Greater coordination of end-of-life care is essential, as hard as that is to do in a fragmented system.<sup>121</sup> Effective strategies include the management and coordination of care on behalf of those who are dying,<sup>122</sup> case conferencing and team discussion.<sup>123</sup> Dying people often need a well qualified and authoritative health professional to advocate for them and help them to get the care they need.

Legislative frameworks and guidelines for Advance Care Plans (see above) should include mechanisms to assign specific responsibility to health care professionals to coordinate and implement plans when people enter end-of-life care.

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<sup>119</sup> Australian Health Ministers Advisory Council (2011)

<sup>120</sup> Australian Senate (2012)

<sup>121</sup> De Vlemminck, *et al.* (2014); NICE (2004); *ibid.* A specialist nurse co-ordinator key link led to improved quality of life in carers.

<sup>122</sup> NICE (2004); *ibid.* A specialist nurse co-ordinator key link led to improved quality of life in carers.

<sup>123</sup> *Ibid.*; Jordhøy, *et al.* (2000) found that more patients who had multidisciplinary coordinated care died at home than those in the control group ( $p < 0.05$ ).

## 6.4 Support people to die at home

End-of-life care will have to change to meet the wishes of most Australians to die at home or to be cared for at home during their last months of life.

The burden on carers can be reduced by providing more coordinated home care services for dying people. Such services will become increasingly important as the number of informal carers declines. Support for people dying at home should include nursing and personal care, specialist medical services when required, carer support and respite. A range of agencies provide these services including not-for-profit community agencies, public hospitals and community nursing agencies. Referrals come from GPs, specialists, hospitals and other health services. Good care services already exist, as Box 5 on the Silver Chain home-based palliative care service in Western Australia demonstrates.

Community-based palliative care can significantly increase the proportion of people who are able to die at home.<sup>124</sup> At present while 70 per cent of people say they want to die at home, only about 14 per cent do so.

A reasonable goal would be to reach the levels of home deaths achieved in comparable countries. The number of people dying at home in Australia would have to double to reach 30 per cent of all deaths -- a level comparable to Korea, Singapore, Ireland, France, Austria, Croatia, USA, Cyprus and New Zealand.

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<sup>124</sup> Jordhøy, *et al.* (2000); In Western Australia, 66% of Silver Chain clients receiving home based palliative care died at home in 2013/14

To reach this number will require a major increase in the availability of community-based palliative care. In principle, dying people should be able to choose a community-based palliative care package that supports them to die in place, particularly if they want to die at home. In practice, while community-based palliative care has expanded recently in some states, comparatively few people have access to it.<sup>125</sup>

The Commonwealth provides Home and Community Care (HACC) funding so that older people are able to continue to live at home when they become ill, frail or disabled.<sup>126</sup> In 2010-11, 4655 people who died were supported by a Commonwealth funded home and community care package. The Senate Community Affairs References Committee has recommended changes to HACC funding to include palliative patients and their carers regardless of their age.<sup>127</sup>

In line with this proposal, we recommend that HACC funding be extended to provide community-based palliative care packages to support people of any age who want to die at home. In particular, support should focus on the last three months of life. In practice, the majority of these people will be over the age of 65.

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<sup>125</sup> Senator Fiona Nash (2014); Silver Chain (2014)

<sup>126</sup> Department of Health (2014b)

<sup>127</sup> Australian Senate (2012)

**Box 5: Silver Chain home based palliative care service (Perth, Western Australia)**

Silver Chain provides services for people with a terminal condition who are living at home.

People are referred to Silver Chain by GPs, hospitals and other services.

The service includes personal care and practical support, symptom management for pain and nausea, psychological support, bereavement counselling, advice, respite, spiritual support and service coordination and consultancy.

In 2013/14 Silver Chain supported 1788 people to die. On average these people were aged 72 years and received services for 3 months. Most had terminal cancer.

Two thirds died at home, as they wished.

National data on the quality of services provided indicate that for most people using the service, pain, distress and symptoms were managed successfully at home in a timely fashion.

A range of agencies that provide community based palliative care already exist. Well-established guidelines and procedures for the allocation of home and community care funding are in place through the HACC program.<sup>128</sup> These should be modified to support people dying at home with community-based palliative care packages.

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<sup>128</sup> Department of Health and Ageing (2012)

We estimate that about \$6000 would be enough on average to provide comprehensive, home-based palliative care during the last three months of life.<sup>129</sup> (see Appendix). Extending the availability of community packages to enable 30 per cent of deaths to occur at home would require additional total investment of \$237 million.

At the same time, increased home and community care for those who are dying is likely to reduce demand on hospital and residential aged care services<sup>130</sup> The evidence suggests that about 70 per cent of people who receive good quality community palliative care can die at home rather than in hospital or residential care.<sup>131</sup>

If about 70 per cent of those who receive community based palliative care, reductions in costs for people who would otherwise enter residential were estimated at \$33 million. Similarly reductions in hospital costs of \$200 million were estimated. Together a total of \$233 million would be available to offset the costs of increased community based palliative care services for a net loss of \$4 million – effectively cost neutral.

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<sup>129</sup> Based on the average cost of 3 months home and community care packages support for those who are dying in 2013/14 dollars

<sup>130</sup> Brumley, *et al.* (2007); McCaffrey, *et al.* (2013)

<sup>131</sup> An analysis of Silver Chain community based care in Perth indicates that 66% of clients receiving services die at home during 2013/14

## 7. Conclusions

Over the next 25 years the number of people who die each year in Australia will double. Australians want to die a better death. They want to choose where and with whom they die. Most want to die comfortably at home supported by family and friends if they can. Yet more than three quarters die in hospital or residential aged care, at a cost of more than \$5 billion a year. Only a tiny proportion of health spending is on community- and home-based end-of-life care and support.

In Australia we tend to avoid discussion of and preparation for death, hoping that the health system can put off its inevitability. At the same time, our health system struggles to shift its focus from cure and rehabilitation to care and support for people who are dying.

Both the community and health professionals need to discuss more openly the limits of health care and people's wishes to die at home. Without systematic policy change, it is unlikely that such discussions will occur or that services will be reoriented to meet people's preferences for dying.

As Table 2 outlines, we recommend a national public education campaign to promote more informed discussions about options for end-of-life care, along with more incentives and obligations to ensure that such discussions occur.

Clear points of coordination are needed to ensure that end-of-life preferences and plans are put in place. Enabling people to die at home and in home-like environments will require significant

additional investment in community-based palliative care; but these costs can be offset by reducing institutional care costs.

**Table 2: Key recommendations**

Implement a national Public education campaign on end-of-life	National public education campaign on the limits of health care and end of life decision making (\$10m)
Ensure end of life discussions and plans occur	Funding incentives and service requirements to: <ul style="list-style-type: none"> <li>• trigger conversations about end of life preferences for 75+ health assessments and Medicare funded chronic illness management plans</li> <li>• require the development of ACPs on entry to residential care &amp; allocation of high needs home care package</li> <li>• encourage GPs to initiate conversations on end-of-life care and discharge plans for those likely to die within 12 months</li> </ul>
Better coordination and implementation of end-of-life plans	Nationally consistent regulatory and legislative base for ACPs to ensure they are authoritative and enforceable Assignment of clear coordination responsibility to health professionals for the implementation of ACPs
Provide home based support for carers to support people to die at home	Provide additional 39,000 palliative care services to support people who choose to die at home (overall cost neutral)

## 8. Appendix: Costing methodology

Costing calculations for the introduction of community based palliative care packages are summarised here.

The distribution of deaths was estimated from ABS, NHCDC, NHMD, AIHW and Home and Community Care data sets for 2010-11. All costs were adjusted to 2013/14 dollars. Deaths for various circumstances (home etc) are presented in Table A1 below for people aged 20 and over.

Cost of death for community palliative care packages was derived from data on separations for CAC, EACH and EACHD packages and the average cost of packages for each type for those who died in receipt of a package. Average (mean) package costs were calculated from total costs and the number of packages funded. The number of deaths that required community support was set as 30% of total deaths less deaths supported by Home and Community Care packages already provided.

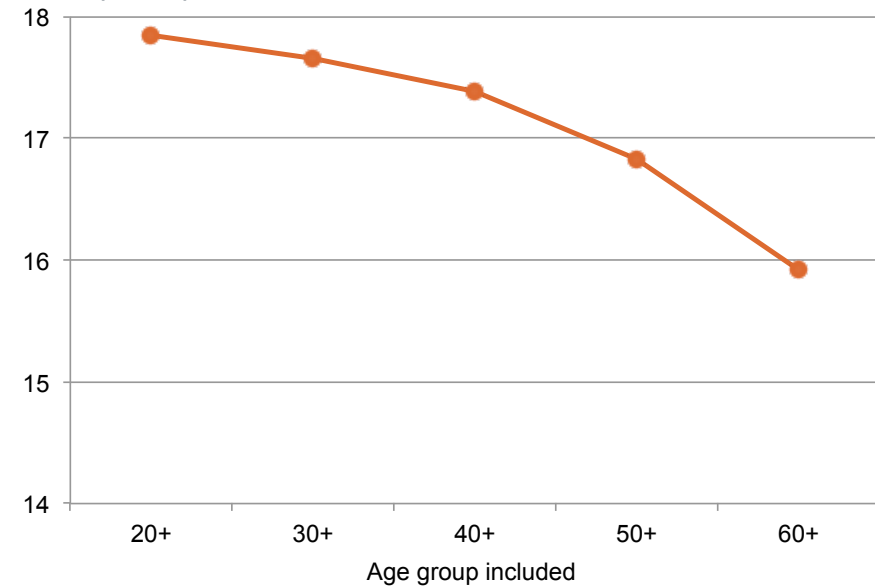
The cost of death for residential care was derived from data on residential care in Australia for permanent residents of residential care facilities and the average cost of places. Average (mean) residential care cost for those who died in residential care was calculated from total Commonwealth funding for residential care (excluding residents contributions) and the number of places allocated. Average costs were adjusted for a 3 month length of stay.

Savings were estimated assuming community based palliative

care would reduce permanent admissions to residential care for those with a three month or less stay by 66%.<sup>132</sup>

**Figure A1: Average cost of death in hospital decreases with age**

\$'000 per separation



<sup>132</sup> Data from Silver Chain Hospice Care (Perth) show 66% of recipients of comprehensive community care die at home.

Cost of death for public acute inpatient care and subacute care was calculated for the episode (separation) in which death occurred, excluding trauma. We excluded acute admissions where the main diagnosis was for trauma (including accident, injury, other external causes and self-harm). To be conservative, we only included admissions for people aged 50 and over, despite the packages being available to younger people if they choose. We assumed that 66% of those receiving community care would die at home.



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