

7. Caring for people at the end of life

Key messages

- We face new challenges in providing end of life care. Some of these are related to changes in disease patterns (such as more people with dementia). Other challenges include ensuring that specialist palliative care services are available to all groups who would benefit from such care, and that these services are readily accessible in the community and in people's homes.
- Of the 130,000 people who die each year, many will be able to be supported prior to their death by generalist health professionals – their general practitioner or other primary health care professionals such as community nurses. Some will be managed by other specialists including geriatricians and oncologists.
- The direct support of specialist palliative care services is only needed for a relatively small number of dying people. Specialist palliative care support is sometimes only available at a relatively late stage, and some patients would benefit from earlier access to these services.
- There are some outstanding examples of high quality end of life care being provided by health services across Australia. We also have the benefit of a National Palliative Care Strategy and good outcomes data that can be used by health professionals to improve the experience of supporting people who are dying, together with their families and carers.
- There is good evidence that advance care planning can help people have choice and more control over their dying, with their wishes respected about how and where they die.

Our reform directions

- 7.1 We propose building the capacity and competence of primary health care services, including the Comprehensive Primary Health Care Centres proposed in Chapter 2, to provide generalist palliative care support for their dying patients. This will require greater educational support and improved collaboration and networking with specialist palliative care service providers.
- 7.2 We support strengthening access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on people living in residential aged care facilities.
- 7.3 We propose that additional investment in specialist palliative care services be directed to support more availability of these services to people at home in the community.
- 7.4 We propose that funding be provided for the national implementation of the Respecting Patient Choices program (advance care planning) across all residential aged care services.
- 7.5 We support greater awareness and education among health professionals of the common law right of people to make decisions on their medical treatment, including the right to decline treatment. We note that in some states and territories this is complemented by supporting legislation that relates more specifically to end of life and advance care planning decisions.

A 'good death' is something we all want for ourselves and our loved ones

■ Death comes to all of us. This is a time when we and our families look to our health services, particularly for care and support. A 'good death' is something we all want for ourselves and our loved ones. We heard this view many times. We heard it in our face-to-face meetings with the community and health professionals. We read about these concerns in the hundreds of written submissions sent to us. The many voices and sentiments are captured in the words of one palliative care physician who wrote to us on the value of high quality care at the end of life:

It is very important that our health system provides not only good specialist palliative care services, but a high standard of care for everyone being cared for in the terminal phase of their illness, regardless of whether this is in hospital, residential care or the community. When being admitted to an Australian specialist hospital for a heart transplant, or for coronary artery bypass grafts, a patient can have absolute confidence in the care they will receive during these very complex and technical procedures. Our patients should be able to have the same level of faith and confidence in the care that they will receive when it is their time to die – and the incidence of this condition is one hundred per cent.¹

7.1 Defining and scoping end of life care

End of life care is care provided to people who are living with a condition that will ultimately cause or contribute to their death. For some people, there may be a relatively short and acute period of illness before they die, as occurs with some patients who have cancer or have suffered a severe stroke. Some people may have chronic health problems such as diabetes or kidney disease, or live with other disabling conditions such as multiple sclerosis or dementia for many years. For yet other people, death may be sudden and unexpected, whether arising from injury or violence. And, of course, death can come at any age, so our approach to end of life care needs to be able to respond to the different timings and ways in which people die.

Of the approximately 130,000 deaths each year in Australia, at least 100,000 could be considered to be expected.² While most deaths occur in people aged 65 or above, 25.1 per cent of men and 15.2 per cent of women die in what has traditionally been regarded as their 'working years' – before turning 65.³ The death of children and young people, whether expected or unexpected, represents a heavy burden on families and will usually require support from health services.

We agree with the views of Palliative Care Australia that end of life care can be provided by all health professionals – including general practitioners, other primary health care professionals such as community nurses, and specialists such as geriatricians and oncologists – and is not limited to care provided by palliative care services or specialists.

To put it another way, many of the 130,000 deaths each year will not require direct support from specialist palliative care services. These specialist services involve multi-disciplinary health care teams made up of staff with recognised qualifications or accreditation in palliative care, whose main work is supporting people at the end of life. The Australian and New Zealand Society of Palliative Medicine recognises that it is 'neither feasible nor in fact desirable that all dying patients should be managed by specialist palliative care services'.⁴

1 B Hayes (2008), Submission 235 to the National Health and Hospitals Reform Commission.

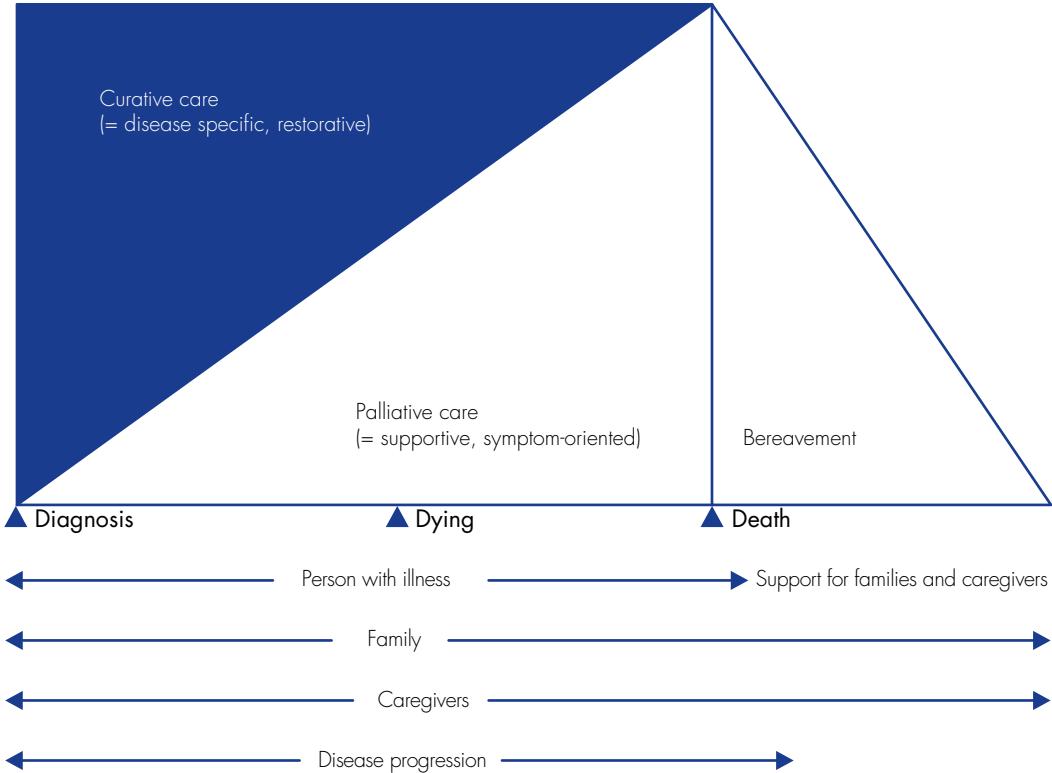
2 Palliative Care Australia (2008), Submission 142 to the National Health and Hospital Reform Commission.

3 Australian Institute of Health and Welfare (2008), Mortality FAQs – Data on age and sex distribution of death in 2006, at: <http://www.aihw.gov.au/mortality/data/faqs.cfm>.

4 Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

For the sub-group of dying people who would benefit from specialist palliative care services, these services can be the sole or dominant source of health and supportive care, or they can act as a back-up and consultation support to other health professionals. Specialist palliative care services may also be provided at the same time as ongoing curative treatment such as radiotherapy for cancer. This changing pattern of end of life care recognises that the actual time of death is unpredictable and that palliative support may be beneficial as a terminal condition progresses (Figure 7.1).

Figure 7.1: Palliative care may start well before dying and extends to support for families and carers after a death



Source: Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

7.2 Building on our strengths

There is much that is positive about the state of play for end of life care in Australia.

A National Palliative Care Strategy has been in place since 2000. Importantly, this strategy is not simply words on paper. It has received some funding support through investment under the National Palliative Care Program, including dedicated funding under the current 2003–2008 Australian Health Care Agreements.

National funding has also been used to drive quality improvement in palliative care. This is vital and ties in well with our principle that health services must be part of a learning system, continuously seeking to improve and innovate through sharing effective practices and measuring improvement through robust data on outcomes. This focus on quality improvement can provide a template for other areas of health service delivery.

■ National funding has also been used to drive quality improvement in palliative care

Two of the most significant initiatives are:

- The Palliative Care Outcomes Collaboration (the Collaboration) allows all providers of palliative care services (public and private) to submit data that supports national benchmarking of performance.⁵ The Collaboration is funded by the Commonwealth Government and involves four universities who then link to palliative service providers across Australia. Data collected through the Collaboration measures the health and functioning status of patients receiving palliative care services. Information provided back to palliative care services can be used to support clinicians in treatment decisions. It also allows assessment of how services are tracking against the nationally agreed Standards for *Providing Quality Palliative Care for All Australians*.⁶
- The CareSearch Palliative Care Knowledge Network at Flinders University provides an incredibly rich resource tailored to the needs of patients, families and clinicians seeking evidence-based information related to palliative care.⁷ This one-stop shop covers everything from finding locally accessible palliative care services to systematic reviews of the literature to providing tutorials on how to find and interpret evidence for patients and health professionals. Shared responsibility requires a well-informed community and this resource on palliative care provides one model of an initiative that supports our reform direction of improving health literacy identified in Chapter 1.

Moving from the national to the local level, palliative care providers have developed better ways of organising services that are more people- and family-centred with services available closer to home, as shown in Figures 7.2 and 7.3.

Figure 7.2: Silver Chain is bringing palliative care to West Australians in their homes

Silver Chain is a not-for-profit organisation that has been providing community, residential and health services to the Western Australian community for over 100 years. It is funded by the state government with other funding sources including a mix of community donations, Medicare and Department of Veterans' Affairs payments and direct payments from patients.

In 1982, Silver Chain developed their Metropolitan Hospice Care Service which is one of the largest community-based palliative care services in Australia. It comprises teams of registered nurses, doctors, enrolled nurses, care aides, counsellors, chaplains and trained volunteers, with a case coordinator planning the delivery of care. Patients are also able to access in-home respite services, counselling and bereavement support. Professional support is provided through 24-hour access to telephone-based Nurse Consultancy Services to provide specialist nursing advice, assessment and procedures to meet the needs of individual patients.

This comprehensive palliative care program supports about 550 palliative care patients at any one time in the community. It substitutes for at least half that number of inpatient hospital beds. The extended availability of this service, together with strong clinical governance, has made it the standard model of care for people who prefer to die at home. Silver Chain estimates that this program has contributed to higher rates of people dying at home – about 60 per cent in Perth, compared to about 25 to 30 per cent in the rest of Australia.

Source: Based on communication from C McGowan, CEO of Silver Chain to the NHHRC, May 2008. Further information is available at: <http://www.silverchain.org.au/Services/Palliative-Care>

5 Further information on the Palliative Care Outcomes Collaboration is available at: http://chsd.uow.edu.au/pcoc/about_pcoc.html

6 Palliative Care Australia (2005), Standards for providing quality palliative care for all Australians, at: http://chsd.uow.edu.au/pcoc/documents/standards_palliative_care.pdf

7 Further information on the CareSearch Knowledge Network is available at: <http://www.caresearch.com.au/caresearch/Home/tabid/80/Default.aspx>

Figure 7.3: Link nurses are helping to improve palliative care for Adelaide people living in residential aged care facilities

Commencing in 1999, a Commonwealth and state government funded project provided an education and consultancy service to 49 residential aged care services in Adelaide. 'Link nurses' were nominated to lead the delivery of palliative care in their residential aged care facility, supported through educational workshops and seminars provided by specialist palliative care service providers. A published evaluation revealed that staff were more confident and had better knowledge and skills when caring for dying residents. This initiative has subsequently been implemented in other parts of the country, including the Northern Territory and Queensland.

Link nurses in Adelaide are passionate about the benefits of this approach for their patients.

As our involvement with the Link Nurse Group grew, so did the enthusiasm for 'doing this so much better'. With support from the group we successfully applied for a grant from the Department of Health & Ageing which allowed us to develop a dedicated Palliative Care suite, Reflection room and purchase equipment for home use. We identified gaps not only in our personal knowledge, but also in the systems and processes within the health unit and which were already in place to provide good palliative care for our patients and residents.

In order to address these gaps we have researched and developed a number of palliative care specific tools such as assessment forms, care plans, family charts, and have also adopted the Palliative Care Clinical Pathways and Bereavement Resource Folders, which were developed within the Link Nurse Group, for use within our health unit.

The introduction of these tools has created a wider awareness and interest in palliative care among nursing, care and medical staff. This has had a 'ripple' effect which has resulted in a number of our aged care residents now having Advance Directives or a Good Palliative Care Plan in place, the implementation of a Bereavement Support Program, education for all staff around palliative care issues and the commencement of the National Palliative Care Standards Implementation Project which will support and expand the care we currently give to palliative patients and their families.⁴

Source: C Grbich, I Maddocks, D Parker and colleagues (2008), Presentation: Palliative care in aged care facilities for residents with non-cancer diagnoses, at: http://www.pallcare.asn.au/pdf/presentation_pdf/P008.pdf

7.3 Identifying the case for change

We received submissions from the palliative care workforce, service provider and professional associations, and consumer and disability organisations that highlighted some major areas where reform is needed.

7.3.1 Improving access to effective palliative care

Specialist palliative care services largely emerged to meet the needs of one group of dying patients, people with cancer. Many other groups remain less well-served by palliative care services today. For example:

■ The number of patients with dementia is expected to more than triple from 220,000 in 2007 to 730,000 in 2050

- Alzheimer's Australia has identified particular challenges in managing end of life care for people with dementia including communication difficulties, managing adequate nutrition and hydration, and ensuring that pain does not go unrecognised and under-treated.⁸ The number of patients with dementia is expected to more than triple from 220,000 in 2007 to 730,000 in 2050.⁹
- Palliative care services may not be targeted towards younger people with degenerative conditions. There are about 1300 people in Australia with motor neurone disease with an average age of onset of 59 years and an average life expectancy from prognosis of 28 months. Motor Neurone Disease Australia argues that palliative care is relevant from diagnosis onwards 'to provide expert symptom management and psychosocial support for the person with motor neurone disease and their families'.¹⁰
- Generally, non-cancer patients are much less likely to receive access to palliative care services. A recent study in Western Australia of over 25,000 deaths found that two-thirds (68 per cent) of people dying of cancer received specialist palliative care services, but less than one in ten (8 per cent) of people with selected non-cancer conditions were able to access the same services.¹¹
- For Aboriginal and Torres Strait Islander peoples, palliative care services may not be provided in a culturally appropriate way (such as including 'smoking ceremonies' at the time of death). However, the Northern Territory Palliative Care Service has achieved real improvements, with an 85 per cent rate of 'back to home country' visits for dying patients.¹²

7.3.2 Providing more choice in where people die and access to palliative care in all settings

We suggested in *Beyond the Blame Game* that a benchmark might be set to measure the number of emergency department visits and hospital days in the last 30 days of life. Our argument then was that higher rates of use of hospital services may signify a failure in the provision of home-based palliative care.

This concept seemed to be broadly endorsed in many of the submissions we received. The Australian and New Zealand Society of Palliative Medicine (the Society) advised that higher rates of home deaths in Western Australia probably reflect the well established community-based palliative services provided in that state¹³ (see Figure 7.2).

8 Alzheimer's Australia (2006), Palliative care and dementia, at: <http://www.alzheimers.org.au/upload/PalliativeCare.pdf>

9 Access Economics (2005), Dementia estimates and projections: Australian states and territories, Report prepared for Alzheimer's Australia, at: <http://www.alzheimers.org.au/content.cfm?infopageid=1926>

10 Motor Neurone Disease Australia (2008), Submission 114 to the National Health and Hospitals Reform Commission.

11 L Rosenwax and B McNamara (2006), 'Who receives specialist palliative care in Western Australia – and who misses out', *Palliative Medicine*, 20: 439–445.

12 Quality Care at the End of Life Collaborative Stakeholders (2008), Submission 504 to the National Health and Hospitals Reform Commission.

13 Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

The Society cautions against assuming that all deaths should be at home, noting that social and cultural factors make this unrealistic, but that instead the emphasis should be on 'informed choice' for where people die. This is known as 'dying-in-place', a concept that we support and accordingly have included in our amended principle on comprehensiveness.

Some of the barriers that were identified¹⁴ to people receiving end of life care in their home (including people living in a residential aged care service) included:

- workforce shortages that limit access to quality multidisciplinary care at home, with gaps in access to specialist palliative care practitioners in many settings;
- limited access to general practitioners and other primary health care providers to provide pain relief, especially in residential aged care services;
- carer fatigue and lack of access to respite for carers; and
- reluctance by some private health insurers to funding non-hospital based palliative care options, coupled with a lack of access to palliative care services in many private hospitals.

The lack of access to palliative care across all settings means that people may be transferred from their home to hospital when they are dying. For people and their families, the unfamiliar environment, the lack of continuity and the need to navigate and work with a new set of health care professionals compounds what is already an incredibly difficult situation. The Australian and New Zealand Society of Palliative Medicine argues that the need to provide seamless integrated care is perhaps 'the single most important reform required to improve end of life care for all Australians'.¹⁵ We believe that poor communication and integration should be tackled throughout our health system, and especially for vulnerable groups such as dying patients and their families.

7.3.3 Supporting consumer control through better use of advance care planning

One effective approach to tackling problems in communication and continuity for dying patients is the use of advance care planning. These plans are about helping to ensure that people's wishes about how and where they die are respected, not about helping people to die earlier. There is compelling evidence that the use of advance care plans can help people to die in the setting of their choice and to exert greater control over the types of care they receive when they are dying.

■ There is compelling evidence that the use of advance care plans can help people to die in the setting of their choice

14 Quality Care at the End of Life Collaborative Stakeholders (2008), Submission 504 to the National Health and Hospitals Reform Commission.

15 Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

Figure 7.4: Patients and health professionals support the use of advance care plans

Clinicians involved in implementing the Respecting Patient Choices program in different settings (residential aged care facilities, hospitals and general practice) contributed case studies to us on the positive impact of using advance care plans. Two of these stories follow:

Mr Jones suffered from chronic obstructive pulmonary disease, epilepsy and dementia. As he was unable to articulate his own concerns, his family clearly stated their preference should his symptoms warrant urgent attention: 'He's absolutely terrified of hospital. We'd hate him to be sent off alone by ambulance in the middle of the night.' A family conference was arranged in consultation with the local medical officer and advice was received from the regional palliative consultant, who had particular expertise in managing respiratory crises. A step-by-step plan was formulated and shown to the family. The plan proved effective on several occasions when Mr Jones suffered distressing symptoms of dyspnoea [shortness of breath]. An appropriate plan was also developed for his epilepsy. When he suffered a major seizure, the crisis was managed in the aged care facility. Both the family and the aged care team expressed satisfaction that his symptom control could be managed well by the nurses, that he had a well-formulated care plan, and that he was spared a distressing and disorienting hospitalisation.

Thank you so much for your excellent documentation which accompanied Mrs A last night. We agreed with her 'directive' that all possible measures be taken to exclude any reversible cause of her health crisis and that, if nothing further could be done, then her preference would be to return to the nursing home to be cared for by her 'second family'. She has suffered a massive brain stem stroke and we recommend she be returned to your care and given the benefit of palliative care. Your clear documentation helped us resolve a difficult ethical decision.

Source: W Silvester and colleagues (2008), Submission 18 to the National Health and Hospitals Reform Commission.

Up to 50 per cent of people will not be in a position to make their own decisions as they near the time of their death¹⁶, with some people having significant cognitive impairment due to conditions such as dementia or a stroke and other people having major physical impairments. The evaluation of the Respecting Patient Choices Program (a model of advance care planning initially implemented across 17 residential aged care services and two palliative care services) found that advance care plans were important in promoting 'dying in place'. It found that 85 per cent of people with an advance care plan received end of life care in their residential aged care facility, while 67 per cent of people without an advance care plan were transferred from their residential aged care facility and died in hospital.¹⁷ Research has also shown that most people expect health professionals to initiate discussions on advance care plans, while only 2.3 per cent of residents in aged care facilities approached about advance care plans wanted no further discussion on the issue.¹⁸

However, we heard through both our submissions and our listening tour that advance care plans are not widely used. Some of the barriers to greater use of advance care plans include the lack of national leadership, confusion about differences in the legislative framework across states and territories, and the lack of support for workforce training on the use of advance care plans.

16 Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

17 Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

18 Australian and New Zealand Society of Palliative Medicine (2008), Submission 430 to the National Health and Hospitals Reform Commission.

7.4 Creating a better future

We believe that there is a need to improve access to palliative care services. We see this issue having several dimensions.

First, we want to emphasise the vital role of primary health care services in providing a palliative approach in the care of dying patients. Clearly, 'end of life care is everyone's affair'¹⁹, not just the job of specialist palliative care services. We believe that this will require greater educational support for general practitioners and other primary health care professionals in how to better manage dying patients. We also expect that this will require improved integration between specialist and primary health care services involved in supporting dying patients. Other specialists, such as geriatricians, often have a very important role in caring for dying patients and their families. Specialist health care teams involved in the long-term care of some patients (such as those with cystic fibrosis) also need to focus on the early, appropriate introduction of a palliative approach.

Dying is a part of life. Our primary health care services, particularly general practitioners, already provide most care to dying patients. This may include coordinating the provision of clinical support services such as community nurses and other personal support services (such as help with showering) for people at home. We have stressed throughout this report that primary health care must be the foundation of our future health care system. This means that specialist palliative care services need to integrate more closely with primary health care professionals and provide more outreach so that the capacity of primary health care services to support dying patients is expanded.

■ Dying is a part of life. Our primary health care services, particularly general practitioners, already provide most care to dying patients

Reform direction 7.1

We propose building the capacity and competence of primary health care services, including the Comprehensive Primary Health Care Centres, to provide generalist palliative care support for their dying patients. This will require greater educational support and improved collaboration and networking with specialist palliative care service providers.

Second, we understand that there is likely to be a shortfall in the overall provision of specialist palliative care services. Palliative Care Australia has proposed that the recommended referral rate to palliative care services should be 262 people per 100,000 population, while the current referral rate is somewhere between 111 and 198 per 100,000 population.²⁰ However, we note that these are high-level national estimates and there is a lack of data about shortfalls in palliative care services at a state or local level and what are the precise service and workforce gaps. We would welcome any advice and further data that can be used to assess the size of the unmet need for access to specialist palliative care services more systematically at a national and local level.

Third, we are strongly of the view that access to specialist palliative care services should be made easier across all settings. Most specialist palliative care services are based in public hospitals and funded directly by state governments (with funding sourced from both the state and Commonwealth governments). We are very aware that under existing governance and funding arrangements these services may be viewed as being 'owned by' or 'owed to' public hospital patients. Where it exists, this view must change. We must unshackle 'services' from their existing institutional homes, or indeed their self-made prisons! It is patently nonsensical that specialist palliative care services are not readily available to people living in residential aged care facilities, on the basis that these services and facilities are funded by different levels of government. The same holds true for patients in other settings including private hospitals.

19 Palliative Care Australia (2008), Submission 142 to the National Health and Hospital Reform Commission.

20 Palliative Care Australia (2003), Palliative care service provision in Australia: A planning guide, at: <http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceProvision.pdf>

Reform direction 7.2

We support strengthening access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on people living in residential aged care facilities.

The achievement of this reform direction requires that once we have better data on the current distribution and gaps in access to specialist palliative care services, we begin setting benchmarks for access to these services, including in residential aged care services. We note that the Commonwealth Government has previously released guidelines on implementing a palliative care approach in residential aged care facilities and that Palliative Care Australia is developing training resources to support staff in these facilities.²¹

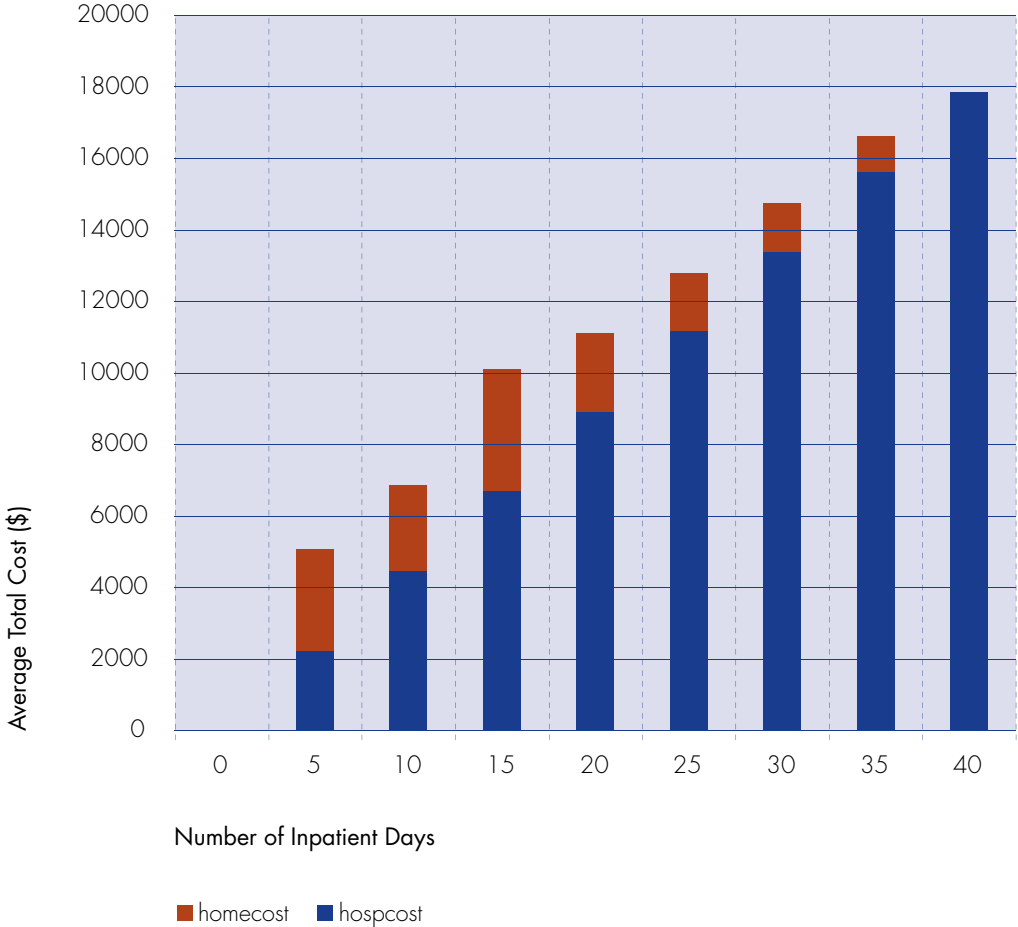
We endorse the collaborative models of outreach and support that have been developed between some hospitals and residential aged care facilities. While local cooperation is laudable, we are conscious that it is all too easy at a systemic level for governments and agencies to revert to the 'blame game', and claim that they are 'not responsible' for ensuring access to appropriate palliative care for aged care residents as they are not 'funded' for this service. We are pleased to note that changes to the Aged Care Funding Instrument being phased in from 2008 to 2011 will result in higher payments for people with complex health needs (including potentially palliative care for dying patients) living in residential aged care facilities. In our next report, we will consider if other systemic changes (including funding levers, benchmarks etc.) are necessary to give effect to the reform direction of strengthening access to palliative care for this population group.

Fourth, we believe that palliative care services need to be more accessible on an ambulatory basis (that is, for patients who are not admitted to a hospital) and provided to people in their homes in the community. Silver Chain provided data to us²² on their success in operating a community-based palliative care service. We find these data compelling (see Figure 7.5). Of about 3000 patients under the care of Silver Chain in the three year period from January 2005 to December 2007, 961 patients (32 per cent) were able to be cared for solely at home during the last 40 days of their life. This is a wonderful example of a people- and family-centred health service. While this is our overriding objective, this approach also helps meet our principle of a health system that is focused on 'value for money'. The average cost of community-only care for a dying patient over the last 40 days of their life was \$4600. This compares with an average cost of just under \$18,000 for people who spent the last 40 days of their life in a hospital. If this experience was translated to a national level, the potential savings from smarter investment are substantial.

21 The Guidelines for a Palliative Approach in Residential Aged Care, at: <http://www.agedcare.palliativecare.org.au>

22 Information provided by C McGowan, CEO of Silver Chain, October 2008: Hospice Care Service Model.

Figure 7.5: Community-based palliative care is more cost-effective than only providing palliative care in hospitals



Source: Information provided by C McGowan, CEO of Silver Chain, October 2008: Hospice Care Service Model

Note: The chart shows the costs of providing palliative care to patients who differ according to how much of their care is provided in the home or in a hospital. The left-hand side of the graph presents the costs for patients who receive the last 40 days of their care at home. The right-hand side of the graph presents the costs for patients who receive the last 40 days of their care in a hospital.

Reform direction 7.3

We propose that additional investment in specialist palliative care services be directed to support more availability of these services to people at home in the community.

We turn now to the issue of advance care planning.

Once again, we find that the evidence²³ in support of action on advance care planning, and more specifically the Respecting Patient Choices model, is strong and cannot be ignored:

■ The evidence in support of action on advance care planning, and more specifically the Respecting Patient Choices model, is strong

23 Austin Health (2008) Submission 534 to the National Health and Hospitals Reform Commission

- Residents in aged care facilities who had been 'introduced' to the Respecting Patient Choices program had an 18 per cent chance of hospital admission, with an average length of stay of 6.9 days; but
- residents in aged care facilities who were not introduced to the Respecting Patient Choices program had a 46 per cent chance of hospital admission with an average length of stay of 15.3 days prior to dying.

On the basis that there are about 41,000 deaths each year of people living in residential aged care services, the national implementation of Respecting Patient Choices in all aged care facilities could result in 237,800 fewer hospital bed days used each year. In round terms, this is equivalent to a saving of about \$250 million annually.

The decision by the Commonwealth Government to fund the piloting and evaluation of the Respecting Patient Choices program in Australia has laid the groundwork for our proposals on these issues. (As a general comment, health professionals across Australia told us they wanted a health system that moved beyond the dreaded disease of 'pilotitis' – endless cycles of pilot projects – to investing in systemic reforms. In Chapter 13, we present some views on how to promote smarter investment.)

Reform direction 7.4

We propose that funding be provided for the national implementation of the Respecting Patient Choices program (advance care planning) across all residential aged care services.

We understand that national implementation of this program across all aged care facilities would generate a strongly positive return on investment, compared to the \$250 million annual costs of hospital admissions avoided for this group. However, we also note that there may need to be a shift in the provision of palliative care resourcing from hospitals to residential aged care services to accommodate the higher needs of more people dying in these facilities.

Ultimately, the implementation of advance care planning is about honouring the wishes of patients and their families. The guiding principle of the Respecting Patient Choices program is:

If your choices for future health care are known, they can be respected.²⁴

We noted in Figure 7.1 that a palliative approach to care can co-exist with curative treatment for some patients. In line with this situation, we believe it is important that people have early access to information on advance care planning. People need good information about the likely course of their illness, as early as possible, so that they can plan and make decisions about their future use of health care services.

National implementation of advance care planning requires national leadership. We believe that there will be a need to establish a national peak body²⁵ to promote the development and implementation of advance care planning. Among other functions, this agency should:

- lead a national social marketing and communication strategy to promote awareness about the use of advance care plans. Effective communication and information is vital for many groups – the general community, people who are dying and their families and carers, and health professionals.

24 Austin Health (2008) Submission 534 to the National Health and Hospitals Reform Commission.

25 Further information on Respecting Patient Choices is available at: <http://www.respectingpatientchoices.org.au>

- ensure that advance care planning is systemically embedded in accreditation and benchmarking processes. We note, for example, that Austin Health (as the current home of the Respecting Patient Choices program) has been collaborating with the Aged Care Standards and Accreditation Agency to develop guidelines on how advance care plans can assist in meeting accreditation criteria.
- work with other organisations – including government, private providers and funders, professional bodies, consumer and carer groups – to promote the adoption of advance care planning across all settings. This would include general practice, public and private hospitals, and residential aged care services. For example, we understand that the Royal Australian College of General Practitioners, with the support of the Respecting Patient Choices program, will shortly roll out an online general practitioner education module on advance care planning.
- collaborate with universities and professional associations to promote the inclusion of advance care planning in all undergraduate programs.

A final issue relates to the differences across states and territories in the legislation relating to end of life decisions and advance care planning.²⁶ Some states have no supporting legislation. In states which have legislated on this issue, there are differences in the approach used on issues such as whether a witness is required; whether substitute decision-makers can be used; and whether advance care plans can only be made for patients with a terminal illness. We understand that some health professionals are concerned that these interstate differences may impede continuity and appropriate implementation of advance care plans for people who receive care outside their home state. We have been advised that Attorneys-General across Australia are undertaking work on harmonising relevant aspects of existing state legislation on end of life decisions and advance care planning.

Reform direction 7.5

We support greater awareness and education among health professionals of the common law right of people to make decisions on their medical treatment, including the right to decline treatment. We note that in some states and territories, this is complemented by supporting legislation that relates more specifically to end of life and advance care planning decisions.

In forming this view, we are cognisant of the fact that legislation is neither necessary nor sufficient to change the cultural practice and adoption of advance care planning. The successful implementation of the Respecting Patient Choices program was driven not by legislation, but by a strong focus on training to equip health professionals to work with patients and their families, and attention to organisational and cultural change. Accordingly, we support working with health care professionals to promote better understanding of the existing common law right on medical decision-making.

²⁶ W Silvester and colleagues (2008), Submission 18 to the National Health and Hospitals Reform Commission.