

The Senate

Community Affairs
References Committee

Palliative care in Australia

October 2012

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43rd Parliament

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Abbreviations

AASW	Australian Association of Social Workers
ABF	activity based funding
ACD	advance care directive
ACFI	Aged Care Funding Instrument
ACP	advanced care planning
ACSA	Aged and Community Services Australia
ACSQH	Australian Commission on Safety and Quality in Healthcare
AGPN	Australian General Practice Network
AHMC	Australian Health Ministers Conference
AMA	Australian Medical Association
ANF	Australian Nursing Federation
ANZSPM	Australia New Zealand Society of Palliative Medicine
ATSI	Aboriginal and Torres Strait Islander
BVCHS	Bega Valley Community Health Service
CALD	culturally and linguistically diverse
CHA	Catholic Health Australia
COAG	Council of Australian Governments
COSA	Clinical Oncology Society of Australia
COTA	Council of the Ageing
CVA	Cancer Voices Australia
DoHA	Department of Health and Ageing
DSC	Disability Services Commission (WA)
ED	emergency department
EPA	Enduring Power of Attorney
EPC	Eastern Palliative Care Association
GLBTI	gay, lesbian, bisexual, transgender or intersex
GP	General practitioner
GRAI	GLBTI Retirement Association Incorporated
GSF	Gold Standards Framework
HACC	Home and Community Care program
IHPA	Independent Hospital Pricing Authority

MND	Motor Neurone Disease
MOGA	Medical Oncology Group of Australia
NAHSSS	Nursing and Allied Health Scholarship and Support Scheme
NEHTA	National E-Health Transition Authority
NHMD	National Hospital Morbidity Database
NHMRC	National Health and Medical Research Council
NPCP	National Palliative Care Program
NPY	Ngaanyatjarra Pitjantjatjara Yankunytjatjara
OTA	Occupational Therapy Australia
PaCCSC	Palliative Care Clinical Studies Collaborative
PC	Productivity Commission
PCA	Palliative Care Australia
PCC4U	Palliative Care Curriculum for Undergraduates
PCEHR	Personally Controlled Electronic Health Record
PCNSW	Palliative Care New South Wales
PCOC	Palliative Care Outcomes Collaboration
PCQ	Palliative Care Queensland
PCRAM	Palliative Care Resource Allocation Model
PCV	Palliative Care Victoria
PCWG	Palliative Care Working Group
PEPA	Program of Experience in the Palliative Approach
PPCANZRG	Paediatric Palliative Care Australian and New Zealand Reference Group
RACGP	Royal Australian College of General Practitioners
RACP	Royal Australian College of Physicians
RCNA	Royal College of Nursing Australia
SAAPPCP	South Australia Advanced Practice Palliative Care Pharmacists
SARRAH	Services for Australian Rural and Remote Allied Health
TDHHS	Tasmanian Department of Health and Human Services
TGA	Therapeutic Goods Administration
VHA	Victorian Healthcare Association
WHO	World Health Organisation
YCN	Youth Cancer Networks

LIST OF RECOMMENDATIONS

Recommendation 1

2.39 The committee recommends that the Australian Commission on Safety and Quality in Healthcare (ACSQH) consider the proposal to implement a national standard linked to accreditation, noting that reforms should not result in increased regulatory burden or complexity.

Recommendation 2

3.80 The committee recommends that the Australian government considers extracting palliative care from the sub-acute care category and create a new funding category of 'palliative care'.

3.81 The committee recommends that in determining the appropriate costing for palliative care services the costs of providing care in the community sector also be calculated and allocations made to support the provision of palliative care services by this sector. The committee acknowledges that any allocations of funds to community sector service providers would require rigorous and transparent governance arrangements to be established.

Recommendation 3

3.82 The committee recommends that the creation of a new palliative care funding category should result in the establishment of a palliative care advisory committee by the Independent Hospital Pricing Authority to advise the Authority on appropriate costing for palliative care services consistent with the activity-based funding approach.

Recommendation 4

3.83 The committee recommends that the development and introduction of consistent national data collection specifically provide for the recording and reporting of palliative care data.

Recommendation 5

5.56 The committee recommends that the government, with the assistance of the Council of Australian Governments, take steps to improve the provision and timeliness of information to palliative care patients, their carers and families. Processes should be put in place to ensure that patients, their carers and families are provided with the right amount of information, in the right format, at the right time and that a 'show bag' approach be avoided.

5.57 The committee recommends that this process begin with a review of the CareSearch website.

Recommendation 6

5.58 The committee recommends that all governments work together to fund minimum levels of bereavement service provision for all families and carers of people with a terminal illness.

Recommendation 7

5.68 The committee recommends that Government give careful consideration to the special circumstances of families caring for terminally ill children when considering future changes to the eligibility criteria for the Carer Allowance and/or Child Care Rebate.

Recommendation 8

5.75 The committee recommends that processes be put in place by the Independent Hospital Pricing Authority to ensure that the calculation of activity based funding for the provision of palliative care takes into account its complexities, including the contribution of carers, and the desirability of its provision across a range of different settings.

Recommendation 9

6.66 The committee recommends that medical workforce training include being educated about existing pathways to specialist palliative care, ensuring that this care is applied effectively to best meet patient need.

Recommendation 10

6.67 The committee recommends that the Australian government create an ongoing and dedicated national scholarship fund for postgraduate studies in palliative care nursing.

Recommendation 11

7.32 The committee recommends that service delivery models include a greater emphasis on community-based care, 'dying in place', and a reduction in unnecessary hospital admissions.

Recommendation 12

8.33 The committee recommends that the Council of Australian Governments consider developing and implementing a case management model.

Recommendation 13

8.34 The committee recommends that the Council of Australian Governments develop and implement a uniform national palliative care pathway that clarifies when general palliative care moves into specialist palliative care, and maps the diagnosis and referral process to ensure that a palliative patient's journey involves coordinated access to all necessary services.

Recommendation 14

8.35 The committee recommends that the Council of Australian Governments review the Medicare Locals structure to consider how the provision of palliative care services, both general and specialist, is integrated into primary health care at the local level.

Recommendation 15

9.20 The committee recommends that the Commonwealth government increase its support for paediatric palliative care research.

Recommendation 16

9.46 The committee recommends that Cancer Australia, in reviewing the distribution of research funding, discuss with funding bodies the capacity to ensure that appropriate levels of funding are being provided to palliative care research.

Recommendation 17

9.48 The committee recommends that governments encourage care providers to provide data to the Palliative Care Outcomes Collaboration and consider making the reporting of this data a condition of public funding.

Recommendation 18

9.50 The committee recommends that the Australian government develop a nationally funded framework for palliative care research, as outlined by the Centre for Palliative Care.

Recommendation 19

9.58 The committee recommends that the NHMRC publicly report the results of its work on alternative therapy claims in relation to palliative care.

Recommendation 20

10.35 The committee recommends that the Council of Australian Governments examine the viability of introducing a national equipment library for palliative care patient needs, examining whether such an approach would allow more efficient and timely provision of available equipment and funds.

Recommendation 21

10.36 To prevent the mis-prescribing of equipment, the committee recommends that the Australian government investigate current regulation and consider improving regulation of both private and public palliative care equipment providers.

Recommendation 22

10.37 The committee recommends that the Australian government closely monitor implementation of the recent changes to the Home and Community Care program to ensure that the program is meeting the needs of those over 65, and that palliative care recipients who do not fall into the aged care bracket are receiving adequate support.

Recommendation 23

10.38 The committee recommends that the Australian government consider changing the eligibility to Home and Community Care (HACC) to include palliative care patients or carers of such patients, regardless of their age. The committee notes that as the HACC program is linked to funding and funding agreements, the Australian government consider this recommendation in the context of considering changes to the funding model for palliative care.

Recommendation 24

10.39 The committee recommends that the Australian government analyse and identify potential gaps in the provision of palliative care and palliative care funding for people with disabilities, especially in supported accommodation.

Recommendation 25

11.35 The committee endorses the recommendations of Palliative Care Australia that, in relation to Commonwealth funded programs, it support:

- appropriate training and education about cultural perspectives relating to palliative and end of life care issues, in core curricula for all health workers and health practitioners providing services to Indigenous people; and

- **inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV continuation of PEPA to build on or develop cultural appropriate education for Indigenous health workers.**

Recommendation 26

11.36 The committee recommends that the Australian government increase funding to palliative care programs for Indigenous communities in rural and remote areas, with a particular emphasis on return to country.

Recommendation 27

11.42 The committee recommends that the Australian government give increased attention to the need for improved research, education and services to support the perinatal and neonatal palliative care needs of health professionals, pregnant women and their families and newborn infants.

Recommendation 28

11.66 The committee recommends that, within twelve months, the Australian government review the implementation and evaluation of the recommendations of the Paediatric Palliative Care Service Model Review, and publish the findings of that process.

Recommendation 29

11.67 The committee recommends that there be appropriate formal recognition of the Australian and New Zealand Paediatric Palliative Care Reference Group, and that the Australian government work with the organisation on the development of a paediatric addendum to the National Framework for Advance Care Directives 2011.

Recommendation 30

11.68 The committee recommends that the Commonwealth, state and territory governments consult with palliative care organisations, and existing children's palliative care support services Bear Cottage and Very Special Kids, about the feasibility of, and funding required for, establishing similar facilities in other jurisdictions.

Recommendation 31

12.40 The committee recommends that the federal government initiate a full review of the medications available on the pharmaceutical benefits scheme for palliative care, particularly schedule 8 drugs.

Recommendation 32

12.41 The committee recommends that through the Council of Australian Governments the federal government expedite the introduction of uniform regulations for the supply of schedule 8 drugs.

Recommendation 33

12.42 The committee recommends that the federal government review the role of nurse practitioners and registered allied health professionals in prescribing palliative care medications to remove barriers to accessing such medications in settings of care where these professionals have a central role in care.

Recommendation 34

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

Recommendation 35

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

Recommendation 36

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

Recommendation 37

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

Recommendation 38

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

Chapter 1

Introduction

The referral

1.1 On 23 November 2011, the Senate resolved to refer the matter of the provision of palliative care in Australia to the Senate Community Affairs References Committee for inquiry and report by 12 September 2012.¹ The Senate subsequently extended the time for reporting to 19 September 2012 and then again to 10 October 2012.²

1.2 In referring the matter for inquiry, the Senate agreed to the following terms of reference:

The provision of palliative care in Australia, including:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

- (i) people living in rural and regional areas,
- (ii) Indigenous people,
- (iii) people from culturally and linguistically diverse backgrounds,
- (iv) people with disabilities, and
- (v) children and adolescents;

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

(c) the efficient use of palliative, health and aged care resources;

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

(e) the composition of the palliative care workforce, including:

- (i) its ability to meet the needs of the ageing population, and
- (ii) the adequacy of workforce education and training arrangements;

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians;

(g) advance care planning, including:

- (i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,
- (ii) national consistency in law and policy supporting advance care plans, and

1 *Journals of the Senate*, no 70 – 23 November 2011, p. 1910.

2 *Journals of the Senate*, no 108 – 11 September 2012, p. 2934.

(iii) scope for including advance care plans in personal electronic health records; and

(h) the availability and funding of research, information and data about palliative care needs in Australia.³

Conduct of the inquiry

1.3 Information about the committee's terms of reference was advertised in the national press and on the committee's website. The committee also wrote to a large number of stakeholders to notify them of the inquiry and invite submissions. Submissions were called for by 23 March 2012. However, submissions have been accepted by the committee throughout the term of the inquiry. The committee received 138 submissions. In referring the matter of palliative care to the committee for inquiry and report the Senate did not ask the committee to consider the complex matter of euthanasia. The committee agreed that material received in relation to euthanasia would be returned to its author. A list of the individuals and organisations that made submissions is provided at Appendix 1.

1.4 Public hearings were held in Canberra on 24 April and 13 August, Sydney on 2 July, Melbourne on 4 July, Adelaide on 5 July and Alice Springs on 25 July. A list of stakeholders who gave evidence to the committee at these public hearings is provided at Appendix 2.

Acknowledgements

1.5 The committee wishes to express its sincere gratitude and acknowledge the courage of the many witnesses and submitters who shared their experiences with the committee throughout its inquiry. The committee thanks all submitters and witnesses who participated in the inquiry process. The evidence provided was extremely valuable and has informed the committee's report and recommendations.

Other inquiries

1.6 The committee notes that Queensland Parliamentary Health and Community Services Committee is currently conducting an inquiry into palliative care in that state.

What is palliative care?

1.7 The World Health Organisation (WHO) has defined palliative care as:

[A]n 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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;

3 *Journals of the Senate*, no 70 – 23 November 2011, pp. 1910–1911.

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁴

1.8 The Australian government and most organisations, including the Palliative Care Working Group (PCWG), the body responsible for the implementation of the national strategy on palliative care recognise this definition as being appropriate.⁵

1.9 Traditionally palliative care has been associated with caring for cancer patients, however as the population ages and life expectancy increases, so too do life limiting illness such as dementia, cardiovascular, and respiratory diseases.⁶ These chronic, and generally incurable, illnesses often have a longer disease trajectory than cancer yet similarly require the provision of palliative care services. In recent years the broadening of patient groups accessing palliative care has begun to be recognised and in the future will increase the demand for quality and effective palliative care services. The committee also heard that the majority of people would prefer to die at home rather than in a hospital based setting.

1.10 Indeed many witnesses spoke of the desire of people to die at home, surrounded by their family and friends in a familiar environment. Ms Kim McCartney, who has a brain tumour, appeared before the committee and explained the reasons for her preference to die at home:

We were talking about this one day and a nurse said to me, 'If you had a choice, would you prefer to die at home or would you prefer to die in hospital?' I said, 'If I had a choice, I would prefer to die at home.' She said, 'Why is that?' I said that my mother ended up in Gandarra. I said, 'I would love to know that I could still just get wheeled outside and sat at the back door if I wanted to get some fresh air.' Or I could have a cup of coffee at four o'clock in the morning if that is what I wanted to do. I remember

4 Australian Health Ministers Conference, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, 2010, p. 4.

5 The PCWG was previously named the Palliative Care Intergovernmental Forum – it is the body responsible for the implementation of the national strategy and falls under the AHMAC committee structure. Source: Department of Health and Ageing, *Submission 96*, p. 2.

6 Department of Health and Ageing, *Submission 96*, p. 3.

visiting my mum and her saying, 'Just open up a window,' and telling her, 'I can't, Mum.' She would say, 'I'm so hot. It's so stuffy in here.' I could not stand that. That is when they said, 'If we know that's what you want, we can do our best to make sure that's what you get. We will keep you at home for as long as we possibly can.' That gave me great comfort. I said, 'That would be lovely. Even if I have to sleep in the kitchen because it's closer to the door, I don't care. At least I can be at home, where my family are and my friends know where I am. I know where I am and I'm not reliant on the buzzer.'⁷

1.11 Kim poignantly explained to the committee the resistance she and her partner Gary had faced getting practitioners to accept her incurable status and provide her with the palliative care she wants and needs:

Gary and I are so grateful for the palliative care in Ballarat because it gives you options that normally you would not even be told about. Like I said, on the second time around at the Royal Melbourne they were sending us home and I said to the surgeon, 'This is incurable, isn't it?' He said, 'Yes.' I said, 'All right. So why am I going home to have treatment?' He looked at me and said, 'What do you mean?' I said, 'You're not going to cure me, are you?' He said, 'We can't cure you.' I said, 'I know that, so why am I going home to go through all these loops? Get me in touch with palliative care.' He said, 'Oh, you don't have to be macabre! There's no need for that. Go home. Have the treatment. Don't mention that 'p' word here. We haven't given up the fight.'

As I said to another oncologist in Ballarat, 'The problem is that what I've got in my head is your enemy. The tumour in my head is your enemy and that is what you're trying to fight; it just happens to be in my body. I'm the battlefield and your enemy is living in here.' That is scary. I know it is their job to try to cure people. That is what they are there for. Sometimes they are very, very good at it and sometimes they are not—they are shithouse at it. In the meantime, do not forget where this battle is taking place.'⁸

1.12 Ms Cherie Waight explained the resistance and lack of cultural understanding she encountered when she fought to take her husband home to die:

My late husband used to always say to me, 'The last thing I want to do is to be put into somewhere where I am just going to die.' So I would often say to them, 'No, I need to bring him home.' The choice was taken out of my hands. I would say, 'No, as Aboriginal people we take care of our own.' That is all I know. We did that with my grandfather when I did not even know what a palliative approach was... There were cultural differences. I went home to the in-laws and explained to them I want him to come home. What you call palliative care was called hospice care at the time. I challenged the situation and they said, 'He must stay here. You cannot take care of him.' I said, 'How do you know I cannot take care of him? I have been washing and cleaning him, feeding him, dressing him and getting him

7 Ms Kim McCartney, *Committee Hansard*, 4 July 2012, p. 40.

8 Ms Kim McCartney, *Committee Hansard*, 4 July 2012, p. 40.

to his parents, who were also totally incapacitated and unable to assist in things because they had no transport and were a low-income family. The father had very serious chronic illnesses too. I wanted to talk to them about some cultural issues, which went in one ear and out the other. They did not want to know about it.⁹

1.13 The committee consistently heard of a need for greater awareness of the palliative care needs of groups other than the ageing and those with malignant diseases (cancer). In fact, BlueCare Queensland informed the committee that approximately one in four deaths that require palliative care services in aged care facilities are associated with non-cancerous diseases.¹⁰

1.14 Throughout its inquiry the committee heard from many submitters and witnesses that the concept of palliative care is often misunderstood and is generally seen as end-of-life care:

It [palliative care] is for older people, it is for those with cancer, it is for the end of life, it is giving up and it is handholding—all those sorts of things—without necessarily understanding it as a rigorous evidence based active approach to achieving a good life in the face of a difficult [disease].¹¹

1.15 Palliative Care Australia (PCA) explained to the committee that palliative care is really about life and that it needs to be an integral part of the health system:

In whatever way we perceive palliative care to be, the bottom line is that it is about life - about the proper care of someone who is alive, someone who still has days, months or years remaining to their life. It is about maintaining and improving on a quality of life that you and I would deem reasonable for ourselves and others that ensures comfort, dignity and freedom from preventable pain. This is not an impossible ask. In fact it is imperative that we, as a civilised nation, ensure our end days are filled with good experiences and memories of meaningful and worthwhile relationships.¹²

1.16 Professor Jane Phillips explained that palliative care does not always have to be at the end of life and that in some circumstances a patient may move in and out of palliative care following treatment for symptom management. Professor Phillips explained the key to properly understanding the WHO definition is noting that palliative care is an 'approach' to care:

There are a few key words in the WHO definition which I am sure others will have pointed out to you. The key one is that it says that palliative care is an approach; it is not necessarily saying that it is just for specialist

9 Ms Cherie Waight, Victorian Aboriginal Care Project Coordinator, Victorian Aboriginal Community Controlled Health Organisation, *Committee Hansard*, 4 July 2012, p. 47.

10 Mrs Marie Robinson, Community Care Adviser, BlueCare, *Committee Hansard*, 2 July 2012, p. 1.

11 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, pp. 29–30.

12 Palliative Care Australia, *Submission 98*, p. 9.

services but rather saying that it is an approach to care. There is probably the definition of palliative care and there is a definition about what constitutes specialist palliative care and a better understanding of what a palliative approach is.¹³

1.17 Although the committee heard that the WHO definition is widely accepted, some submitters and witnesses consider that it is not broad enough and is still being misunderstood in the community. The Royal Australasian College of Physicians (RACP) explained their thoughts on changing the term to ensure palliative care is disassociated with end-of-life care:

I strongly recommend that...palliative care is not terminal, end-of-life care, and convincing people that it is not end-of-life care and that we are not assigning them to the exit strategy. Can we change? We have looked at it for years to change the term 'palliative care' to a better term so that people understand.¹⁴

1.18 It was suggested however that this misunderstanding could be the result of a cultural reluctance to consider the issue of mortality and that regardless if how palliative care is defined or referred to, people will eventually associate it with death:

About five years ago we talked about whether we should change our name, but I thought, 'What are we going to call ourselves? Orange Care or Rhinoceros Care, or something like that.' Eventually people associate whatever the word is with end of life, dying. That is just a reflection on us as a society, where we are at with their comfort zone about our inevitable mortality. It is not something that we entertain on a daily basis and we seek not to entertain it unless we really have to do.¹⁵

1.19 Despite discussion around the appropriateness of the definition, Palliative Care New South Wales (PCNSW) explained that the evidence shows that 'good, specialist palliative care processes improve the quality of life for people even early in their treatment regime.'¹⁶

1.20 Resthaven Inc. nurse practitioner candidate Mr Peter Jenkin explained the importance of disassociating palliative care with end of life care given the benefits of early diagnosis, intervention and treatment:

...the first and most important thing is we need to be clear about what palliative care is. If we ask the first person out in the street what palliative care is, they would generally give you a definition that talks about the last days and hours of life. That is a problem, because if we only focus on that then we do not put the plans in place to provide the care at that stage...

13 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, Sydney, *Committee Hansard*, 2 July 2012, p. 62.

14 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 12.

15 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, p. 56.

16 Mr Peter Cleasby, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, p. 56.

1.21 Fundamentally however, the committee was advised that palliative care is:

...in its truest sense...just good care...it is holistic care, it is meeting all the needs of someone, which is what we should always be doing anyway. That differs from specialist palliative care. I guess that is why we call that a palliative approach. We try and distinguish it because palliative care to many health professionals is the specialist care—the people like myself or someone from a specialist palliative care service coming in to deal with symptoms that are burdensome or out of control or significant, psychosocial sort of distress, whereas a palliative approach, or palliative care, if you want to call it that, is something that every healthcare provider, from a care worker to a family member up to a physician, needs to be able to do and do really well.¹⁷

Current government policy framework

1.22 The Australian government commenced development of its palliative care strategy in 1998 which was endorsed by all of the state and territory health ministers in 2000 through the Australian Health Ministers Conference (AHMC).¹⁸ That strategy was updated in 2010 and the updated *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life* (the strategy) was released in 2011.¹⁹

1.23 Although the strategy identifies goals for palliative care, it also articulates that responsibility for the provision of these services ultimately rests with the states and territories:

Whilst there is a National Palliative Care Program that supports national approaches, most palliative care service provision occurs within the remit of the State and Territory health systems. Each State and Territory has an articulated approach to palliative care in their jurisdiction. This Strategy aims then to enhance and build on the work occurring at the jurisdictional level, not duplicate or contradict it.²⁰

1.24 The Australian government supports the states and territories through the provision of funding.

Structure of the report

1.25 This report is comprised of 13 chapters:

- Chapter 2 of the report discusses the current guidelines and standards that guide the provision of palliative care services.

17 Mr Peter Jenkin, nurse practitioner candidate, Resthaven Inc., *Committee Hansard*, 5 July 2012, pp. 8–9.

18 Australian Health Ministers Conference, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, 2010, p. 6.

19 Department of Health and Ageing, *Submission 96*, p. 2.

20 Australian Health Ministers Conference, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, 2010, p. 5.

- Chapter 3 examines the current federal funding arrangement for palliative care.
- Chapter 4 examines state and territory arrangements for palliative care. The chapter identifies the demarcations between state/territory and federal responsibilities for the provision of care and considers aspects of how states and territories are delivering palliative care services.
- Chapter 5 discusses the important role of carers in the provision of palliative care.
- Chapter 6 examines the composition of the palliative care workforce, including its ability to meet the needs of the ageing population and the adequacy of education and training programs.
- Chapter 7 identifies some models of service delivery and examines how those models overcome systemic problems to provide coordinated and quality palliative care.
- Chapter 8 investigates the role of case management in the provision of palliative care.
- Chapter 9 identifies the role of research and data in the provision of quality palliative care and looks at what is being done to ensure sufficient resources are being dedicated to this area.
- Chapter 10 considers the important role of medical equipment and aids in assisting palliative care recipients to remain in the community for longer. It examines the different programs in place that support the provision of equipment.
- Chapter 11 examines the unique challenges to ensuring quality and appropriate palliative care is provided to Aboriginal and Torres Strait Islander Australians, children and adolescents, culturally and linguistically diverse (CALD) communities, and people identifying as gay, lesbian, bisexual, transgender or intersex (GLBTI).
- Chapter 12 seeks to address a number of specific other matters which were raised with the committee throughout its inquiry.
- Chapter 13 examines and discusses advance care planning and the role e-health may play in supporting national consistency.

Chapter 2

Guidelines and Standards

Introduction

2.1 The provision of palliative care in Australia is governed by guidelines - *Palliative Approach for Aged Care in the Community Setting – Best practice guidelines for the Australian context* (the guidelines). These guidelines were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 26 November 2010. The NHMRC's approval of the guidelines is valid for five years although the guidelines are expected to be reviewed 'no less than once every five years.'¹

2.2 The 2010 guidelines are a companion to the 2006 *Guidelines for a Palliative Approach in Residential Aged Care*. They are intended for use by 'healthcare professionals providing care for older Australians in the community' and while they are best practice guidelines, they are not prescriptive.²

2.3 In addition to the guidelines provided by the federal government, in 2005 Palliative Care Australia (PCA) released its fourth edition of *Standards for Providing Quality Palliative Care for all Australians*. PCA developed these standards in collaboration with the Department of Health and Ageing (DoHA/the department).³ They are intended to be used alongside other standards and guidelines for health service provision and outline the level of expectations for all services involved in the provision of care to people with life limiting illnesses.⁴ A list of the 13 standards developed by PCA can be found in Appendix 3.

2.4 Throughout this inquiry stakeholders consistently raised concerns around the jurisdictional differences in the standard of palliative care being provided. This chapter examines the palliative care arrangements for the delivery of palliative care services, the effectiveness of those arrangements and the adequacy of the guidelines and standards that apply to ensure a consistent level of care.

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- 1 Australian Government Department of Health and Ageing, *Guidelines for a Palliative Approach for Aged Care in the Community Setting – Best practice guidelines for the Australian context*, 2011, p. 2.
 - 2 Australian Government Department of Health and Ageing, *Guidelines for a Palliative Approach for Aged Care in the Community Setting – Best practice guidelines for the Australian context*, 2011, p. 2.
 - 3 Palliative Care Australia, *Standards for Providing Quality Palliative Care for all Australians*, 2005, pp. 8–9.
 - 4 Palliative Care Australia, *Standards for Providing Quality Palliative Care for all Australians*, 2005, p. 2.

2.5 Although it is difficult to forecast the number of people who will require palliative care services at the end of their life, DoHA suggest that the figure could be anywhere between 36,000 and 72,000 people annually, of the total average number of annual deaths – 143,500.⁵

The national guidelines and PCA's standards

2.6 Representatives of the Population Health Division at DoHA explained the difference between the guidelines and standards to the committee noting that neither were mandatory:

There is the differentiation between guidelines and standards and no national standards that are endorsed by all governments for palliative care. However, the PCA standards, that are a voluntary approach that most palliative care specialist services use and assess themselves against—I think it is around 80 per cent of current services.

In terms of the guidelines, there are the APRAC guidelines which are the Guidelines for a palliative approach in residential aged care. They are currently being updated through an NHMRC process, but also there is a series of pieces of work that are currently underway to translate those into online versions and the like and to provide more information for users of those guidelines. There will be a public consultation, I understand, around the revised draft of those in the next calendar year, and then there are the compact guidelines, which are the Guidelines for a palliative approach for aged care in the community setting as well. Those are the two key documents that are used.⁶

2.7 The Ageing and Aged Care Division at DoHA went on to further explain that in respect of aged care specifically, there are aged care standards with which aged care providers are required to comply. These aged care standards are different to the guidelines which the government released in 2006 and 2010 for palliative care and the PCA's standards.

2.8 Although the government aged care standards (which are linked to funding) are mandatory, they do not provide specific detail in respect of palliative care. In contrast, the more specific palliative care guidelines which the department has developed are, unlike the aged care standards, not mandatory.⁷

DoHA's national guidelines

2.9 Mr David Butt, Deputy Secretary of DoHA, informed the committee that there are a number of ways in which guidelines are developed. He further explained that in the past 12 months, a new commission has been established, the Australian Commission on Safety and Quality in Healthcare (ACSQH), which has been given the

5 Department of Health and Ageing, *Submission 96*, p. 3.

6 Mr Nathan Smyth, First Assistant Secretary, Population Health Division, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, p. 39.

7 Ms Rachel Balmanno, Acting First Assistant Secretary, Ageing and Aged Care Division, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, p. 39.

task of developing a new set of government standards which will particularly focus on accreditation standards for healthcare. Mr Butt told the committee that in Australia's diverse health system 'where we have Commonwealth, state and territory arrangements' it will be the new accreditation standards which the ACSQH is developing that will need to be adopted by the states if they are to be effective:

...we really are dependent on the states to adopt, to agree to and then to require of their hospital systems or their local hospital networks.⁸

2.10 Mr Butt detailed the complexities associated with achieving consistency in service provision even through the adoption of standards given the federated system in place in Australia:

The issue of standards, for example, in relation to palliative care is something that would need to be done in association with the states and territories, so you would have to actually get buy-in from the states and territories to agree to the application of standards. You also then have the issue of clinical pathways...and they will vary across the country, again because of our diverse system. Also, a lot of clinical pathways are developed by clinicians from the ground up, and they are demonstrations of best practice and benchmarking across clinical groups.

One of the issues that we do have which impacts not just on palliative care but more broadly on the health system is that with clinical pathways you tend to have patients who are in the primary healthcare sector going into the acute sector, coming out into subacute services, going back into the primary healthcare system or indeed dying. You then have different funding arrangements which cut across those pathways, so in many ways pathways are ways of ensuring that primary health care works with the acute sector and the subacute sector to ensure that people go through the system in an uninterrupted way and do not run into barriers of care. We know that that does not work very consistently across the country.⁹

2.11 Given that a number of guidelines and standards have been developed for application in the provision of health care, aged care and palliative care more specifically, the committee sought to understand who is responsible for ensuring the guidelines and standards developed specifically for palliative care are reviewed and remain relevant.

2.12 The department explained to the committee that the government guidelines developed for palliative care 'generally last about five years' and that:

It is usually a standard thing that after five years the NHMRC rescinds the guidelines and requires them to be updated if they are produced through that process with the NHMRC. You would then have organisations,

8 Mr David Butt, Deputy Secretary, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, pp. 38–39.

9 Mr David Butt, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, pp. 38–39.

academic institutions and professional bodies applying for funding to update those guidelines to maintain their currency.¹⁰

2.13 The department explained that:

...there are between 30 and 40 guidelines endorsed by the NHMRC that were funded by the department. There are hundreds of others that were not. Many were funded by states, others by colleges and others by particular interest groups on particular disease patterns, for example. So it varies. But in relation to the NHMRC guidelines on palliative care, they are ones that we actually funded.¹¹

Views on the guidelines

2.14 Among other submitters, Alzheimer's Australia were critical of the government issued guidelines and suggested they were in need of review:

Both the community and residential palliative care guidelines fall short of the mark with respect to dementia, particularly in the difficult areas of force feeding, terminal dehydration, and patient's wanting to die. In part, this is because the recommendations contained in the guidelines require a relatively high level of scientific evidence for endorsement by the NHMRC, and in many of these difficult areas, despite lots of practical knowledge and anecdotal evidence, the more rigorous research has simply not been undertaken.

The more recent community palliative care guidelines are better than the older guidelines for a palliative approach in residential care, particularly when considered alongside the associated practice guides for care workers and for family carers. The residential care guidelines are in urgent need of review, with attention to the specific needs of people with dementia.¹²

2.15 Alzheimer's Australia also raised the point that the nature of life-limiting illnesses and the different disease trajectories of malignant and non-malignant diseases means that palliative care is often provided by general health or aged care workers rather than specialists and this needs to be accounted for when specific palliative care guidelines are developed:

Most of the end-of-life care delivered to people with dementia is provided by general health or aged care workers, with assistance and support from palliative care professionals only as needed. As palliative care guidelines are unlikely to be used or adopted by generalists, there is a need to develop a more general set of guidelines for the care of people with dementia that deal with the same end-of-life issues in a way that is more appropriate for non-specialist health and aged care professionals. These guidelines should reference the palliative care guidelines (both residential and community

10 Mr Nathan Smyth, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, p. 40.

11 Mr David Butt, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, p. 40.

12 Alzheimer's Australia, *Supplementary Submission 44*, p. 4.

care), and emphasise the need for consultation with palliative care specialists from the point of diagnosis on.¹³

2.16 When the question of whether a review of the guidelines was being considered, representatives from the department explained that, of the guidelines issued by the department, only those that were released in 2006 were due for review:

There are actually two sets of guidelines. One relates to residential aged care and the other one to community care. The community care guidelines were released last year. Both sets of guidelines are NHMRC endorsed, so they go through quite a rigorous process in terms of levels of evidence and expertise. The residential aged-care guidelines are now due for review.

...We are currently in the process of putting out a request for quotation to members of a panel that the department has to review and update the guidelines. That is currently in process.¹⁴

Committee comment

2.17 The committee is of the view that the residential care guidelines are overdue for review.

Views on PCA's standards

2.18 Stakeholders also commented on the PCA-developed (collaboratively with DoHA) *Standards for Providing Quality Palliative Care for all Australians*. The Victorian Healthcare Association (VHA) suggested that the problem with the standards is the fact that participation in the standards process is voluntary and therefore will not always result in consistency:

There are 13 standards for providing quality palliative care at the moment which have been set by Palliative Care Australia. However, participation in that process is voluntary. The VHA is a strong believer in the capacity to develop industry benchmarks which can withstand the scrutiny of the external research and analysis. Unfortunately, a voluntary system does not always lead to that capacity. We would have a preference towards some tightening up of that. Whether that ends up being compulsory—I am not sure I would want to use that word—at the moment I am not sure we are capturing the data we really would like to see available for external analysis through the voluntary process.¹⁵

2.19 Catholic Health Australia (CHA) was of the same view as the VHA. They too suggested that the lack of consistent national standards was the reason for inconsistency in care and suggested that a minimum standard linked to accreditation needed to be introduced. They highlighted the fact that the current arrangements in

13 Alzheimer's Australia, *Supplementary Submission 44*, p. 4.

14 Mr David Butt, Deputy Secretary; Mr Andy Paras, Director, Cancer and Palliative Care Branch, Population Health Division, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 8.

15 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

relation to standards do not support consistency in the provision of palliative care as the provision of palliative care, unlike the provision of aged care, is not linked to any sort of accreditation:

...palliative care is not part of the accreditation framework of aged-care services. While ever you do not have accountabilities, you are not necessarily going to have the funding decisions made and then, in turn, the staffing decisions made to live up to that standard.¹⁶

2.20 CHA explained that it their view 'a minimum national healthcare standard' should be developed by the recently established ACSQH:¹⁷

Australia needs to articulate a standard that all should be able to access when they seek palliative services at whatever point in their life cycle is necessary. To be very specific, we are proposing that a minimum national healthcare standard be developed by the Australian Commission on Safety and Quality in Healthcare to determine a consistent level right across Australia of the type of care services that you are able to access regardless of the setting, be it hospital, residential aged care or in community.¹⁸

2.21 CHA explained how they consider standards linked to accreditation would work:

...if the area health service, or the hospital in Narrabri, [for example] had its accreditation linked to meeting a new national standard on palliative care that addressed consistent care planning for all consumers of palliative services, that ensured that all consumers receive the same type of assessment options and that they all had access to these types of specialist services as part of the health services accreditation, you then have the funders—who are state governments, the Commonwealth to some extent, private providers and others—needing to live up to those accreditation standards.¹⁹

2.22 CHA took the view that the development of a single national consistent standard would 'drive local actions' to ensure this outcome was achieved.²⁰ When asked what kind of things they would like to see included in a new national standard, CHA explained:

We see three main platforms... there needs to be a consistent assessment process, so that when a consumer, through the healthcare system, reaches that time when these discussions are appropriate, there should be consistency in how assessment is provided. There has then got to be consistent care planning, and that speaks to the option for the consumer to have all of their options made available to them and that, with the specialist

16 Mr Martin Laverty, Chief Executive Officer, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 36.

17 ACSQH – the Australian Commission on Safety and Quality in Healthcare.

18 Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 33.

19 Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 35.

20 Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 35.

services that are either on site or by remote, are able to provide informed care planning decisions for them and the families that are involved in that care planning decision as well.

Importantly, the third step is that no matter where you are located there should be that equitable access to a specialist service, be it in person or be it via telehealth via the phone.²¹

2.23 CHA explained how they propose a national standard linked to accreditation would operate:

Prison hospitals are subject to accreditation. Disability services interact with the health system that is subject to accreditation. As such, our proposal for a national standard would mean that when a person interacts with the health system, that provider should be accredited in accordance with the national standard. A prison hospital or indeed a public hospital that a person being cared for in a disability service might interact with has to ensure that they have access to that standard of care. That is why we think, whether you are a person with a disability or someone who is incarcerated, whether you live in a country area or in the city, a national standard across all of these care settings ensures that everyone would have an entitlement to that consistent care everywhere, subject to fulfilment of that accreditation.²²

2.24 CHA informed the committee that the work on the national standard for palliative care service provision which they espouse has already commenced, not only through the recently established ACSQHC but also through agencies like CHA and PCA. CHA informed the committee that implementation of such an approach would not have a 'significant dollar cost' as the ACSQHC 'has the statutory ability to require hospitals to comply through their accreditation' and the 'Commonwealth has the ability to require compliance as part of aged care accreditation.'²³

Views on the call for a new national standard

2.25 The committee sought the views of stakeholders in relation to CHA's proposal.

2.26 PCA explained their view that increased regulation or accreditation standards should not lead to a greater administrative burden on palliative care service providers, many of whom are aged care providers and subject to existing accreditation regimes:

The other thing I wanted to say about residential aged care is that as a clinician, and talking to my clinician colleagues, we struggle with the massive and deleterious effect of the regulators on decision making in residential aged care. The fear that the regulators create in residential aged care management around issues such as swallowing and loss of weight leads to decision making that is not in the best interests of the quality of life of the patients. Often the decisions around those issues are taken out of the

21 Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 36.

22 Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 40.

23 Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 40.

clinical role and you find that protocols and pathways are introduced to tick the boxes of the regulator, not to tick the boxes of the quality of life of the patient. I must admit that it is a personal goal of mine to reclaim that space into clinical decision making. But I only work in half a dozen residential aged care facilities. A few of my colleagues who do mainly this sort of work have similar aims. But it is important. We are, I guess, buoyed by the fact that this does get a mention in the Productivity Commission's report on ageing—that there is an aim to try to reduce the impact of the regulators on residential aged care.

There needs to be a better focus on better regulatory processes so they do not impact on quality of life; better training and education in end-of-life matters right down to the people who provide the personal care for people in residential aged care; and there needs to be an investment in team building in residential aged care so that we can provide the type of palliative care that fits the formula that I created at the beginning.²⁴

2.27 Professor Jane Phillips, a professor of palliative care nursing, indicated broad support for the proposal as a means of reducing the variation in the level and standard of care that is delivered through the current system, which she explained is akin to a 'postcode lottery':

As you know, the Commonwealth has invested quite significantly in palliative care services across Australia but we have varying levels of depth and breadth of those services ... [a]nd access. And you cannot assume that what happens in one area will happen in another area... Having said that, I do not necessarily believe that everybody needs to have access to specialist palliative care, but specialist palliative care needs to be available to support our other healthcare colleagues who are delivering it. Standards are definitely one way of starting to get some consistency in practice and the way in which services are organised.²⁵

2.28 Similarly, SilverChain expressed general support for a national standard linked to accreditation but suggested that the focus of any new standards linked to accreditation should focus 'much more on outcomes that are driven from the service delivery model rather than ticking boxes.'²⁶

2.29 Other service providers however qualified their support for CHA's proposal, expressing concern that rather than ensure consistency in the quality and provision of care, it would instead introduce another layer of government regulation to an already heavily regulated sector.

2.30 Resthaven explained this view:

24 Dr Scott Blackwell, President, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 11.

25 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, p. 58.

26 Mr Mark Cockayne, General Manager, Health and Director, Hospice Care Service, Silver Chain; Mr Stephen Carmody, Chief Operating Officer, Silver Chain, *Committee Hansard*, 5 July 2012, pp. 38–39.

The challenge is that there already is a huge amount of regulation in aged care, so while we would certainly be supportive of anything that continues to promote quality of care and sets a platform in terms of expectation, the challenge of focusing on one particular area when there are a broad range of areas is difficult to contemplate.

But I think that, along with the whole question of the definition of palliative care, there is already a set of good palliative care standards—I cannot remember the correct terminology—that is expected to be a palliative approach in aged care. Also, there is a set of standards that relate to that for residential care and for community care. There are also statements and standards in the existing residential standards.

The thing we would not want to do would be to say, 'Here is a set of standards for people who are not in a palliative phase and here is another set of standards for people who are in a palliative phase.' It becomes inordinately challenging to manage that.²⁷

2.31 Aged and Community Services Australia (ACSA) also explained the difficulty they consider aged care service providers would confront in complying with the introduction of a set of mandatory palliative care standards:

I was on the technical reference group that looked last year with the National Standards Assessment Program at implementing the palliative care standards in residential aged care. As was said, most aged care services would aspire to those standards but, because of existing resource limitations in the residential aged care setting, it would be quite difficult to implement yet another set of standards on top of the mandatory aged care accreditation standards that they already have to meet. I will just say that the principles espoused in the aged care accreditation standards are very similar to the principles espoused in the palliative care standards, but the latter are obviously much more directed towards palliative care.²⁸

2.32 ACSA went on to explain that aged care providers who provide palliative care services 'want to do things better' but they require funding to do that:

Aged care people want to do things better. They really want to care for people appropriately and provide good quality care and they are open and amenable to whatever means they can do that. But they need some additional resources to be able to facilitate that. We would like to be able to introduce better quality palliative care but... we need some assistance to do that in terms of resourcing.²⁹

2.33 The committee sought to understand the levels of regulation that currently apply in the palliative care sector.

27 Ms Susanne McKechnie, Resthaven Inc., *Committee Hansard*, 5 July 2012, p. 15.

28 Mr Nicolas Mersiades, Senior Aged Care Adviser; Ms Wendy Porter, Residential Care Manager, Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, pp. 20–21.

29 Ms Wendy Porter, Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, pp. 25–26.

2.34 PCA explained that the existing regulation that applies to many palliative care service providers, particularly residential aged care providers often keeps recipients of care safe but very bored and unhappy:

We are so risk averse now. The regulators put so much stress on this that we find ourselves in conflict with the residential aged care facility managers who insist on it being a certain way.³⁰

2.35 The challenge, according to PCA is:

...understanding the reality that you have had for the whole of your life the choice to take risks. Having the ability to take risks taken away from you is in actual fact a loss of choice. In their space this is a loss of quality of life which is important. The weight loss one is a little more insidious at times in that I have seen people put on food supplements and so on without the clinicians knowing. Often it is months later that you are asked to see them because they have a distended abdomen, they are feeling nauseous and miserable and they have been for some time. Yet if it had come into the clinical decision-making area—indeed these people were pretty much at the end stage of dementia or some such thing—and a decent palliative care plan had been done, those supplements would have been considered to have been unnecessary. The supplements have made the quality of life of that person less than it should have been. These are the things that we have to consider.³¹

2.36 It did become clear to the committee however that there are palliative care providers throughout Australia who have developed models of care that are delivering effective palliative care to the community despite the many challenges of the federated system. These models of service delivery and care are examined in more detail in chapter 7.

Committee comment

2.37 The committee is concerned by the level of variance in the standard and quality of palliative care. The committee considers there could be merit in the introduction of a mandatory national standard linked to accreditation that would cover the provision of palliative care.

2.38 The committee acknowledges and shares the concerns of stakeholders that any new accreditation regime would divert funds from service provision to administration and 'red tape'. The committee considers that the development of mandatory standards or guidelines linked to accreditation of any one sector of the health care system should be developed in the context of the wider health system to avoid duplication and unnecessary administrative burden.

30 Dr Scott Blackwell, President, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 13.

31 Dr Scott Blackwell, President, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 13.

Recommendation 1

2.39 The committee recommends that the Australian Commission on Safety and Quality in Healthcare (ACSQH) consider the proposal to implement a national standard linked to accreditation, noting that reforms should not result in increased regulatory burden or complexity.

Chapter 3

The federal funding of palliative care in Australia

Introduction

3.1 Funding of the Australian health system is complex and governed by a number of agreements of the Council of Australian Governments (COAG). Responsibility for providing and funding health care services is shared between the commonwealth and the states and territories. Generally:

- (i) the states are the system managers of the public hospital system; and
- (ii) the Commonwealth has full funding and program responsibility for aged care (except where otherwise agreed) and has lead responsibility for GP and primary health care.¹

3.2 The responsibility for palliative care service provision remains with the state and territory governments although funding support is provided by the Commonwealth.²

The Australian Government does not directly fund palliative and hospice care services but does provide financial assistance to state and territory governments to operate such services as part of their health and community service provision responsibilities. The use of this funding and the delivery of palliative care services in each jurisdiction is the responsibility of individual state and territory governments.³

3.3 This chapter examines the current funding arrangements for palliative care. It explores how funding is distributed and whether or not the current models of funding are resulting in the efficient use of resources and the effective provision of care.

How palliative care is funded in Australia

3.4 The Department of Health and Ageing (DoHA/the department) explained how the federal government provides funding to support the states and territories in their palliative care service provision. The department informed the committee that financial assistance is provided by the federal government as a part of its national

1 Council of Australian Governments, National Health Reform Agreement, 2 August 2011, p. 4.

2 Australian Health Ministers Conference, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, 2010, p. 5.

3 Department of Health and Ageing, answer to question taken on notice (question 2), received 23 May 2012.

health agreements with the states and that the funding for palliative care is provided as a part of the funding for subacute care services:⁴

There are two national partnership agreements that have specifically provided funding for subacute care...: the National Hospital and Health Workforce Reform and the National Partnership Agreement on Improving Public Hospital Services.

...subacute care includes palliative care, rehabilitation, geriatric evaluation and management and psychogeriatric care—and in this NPA it also included subacute mental health.⁵

National Partnership Agreement on Hospital and Health Workforce Reform

3.5 The National Partnership Agreement on Hospital and Health Workforce Reform (the workforce reform agreement) was agreed to by the Council of Australian Governments (COAG) on 29 November 2008.⁶ The agreement committed \$3.042 billion 'to improve efficiency and capacity in public hospitals'. The two (of four) components of the workforce reform agreement of interest to the committee's inquiry include the introduction of an Activity Based Funding approach, and the commitment to enhance the provision of subacute services.⁷

Activity based funding

3.6 The workforce reform agreement described activity based funding (ABF) as 'a management tool that has the potential to enhance public accountability and drive technical efficiency' by:

- (a) capturing consistent and detailed information on hospital sector activity and accurately measuring the costs of delivery;
- (b) creating an explicit relationship between funds allocated and services provided;
- (c) strengthening management's focus on outputs, outcomes and quality;

4 Mr David Butt, Deputy Secretary, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 12.

5 Ms Ann Smith, Assistant Secretary, National Partnership Agreement Branch, Acute Care Division, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 10–12.

6 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p. 3.
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

7 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p. 3.
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

- (d) encouraging clinicians and managers to identify variations in costs and practices so these can be managed at a local level in the context of improving efficiency and effectiveness; and
- (e) providing mechanisms to reward good practice and support quality initiatives.⁸

3.7 ABF will achieve this through 'the development and implementation' of:

- (a) activity based funding for public hospital services;
- (b) nationally consistent classifications and data collections for hospital provided care including admitted care, sub-acute care, emergency departments, outpatient sub-acute and hospital-auspiced community health services [including palliative care, hospital in the home and other services for which public hospitals are responsible]; and
- (c) a nationally consistent costing model and, if COAG agrees, a nationally consistent funding model for hospital provided treatment (in admitted care, sub-acute care, non-admitted care emergency departments and hospital-auspiced community health services) as well as non-clinical hospital services including teaching and research.⁹

3.8 The Independent Hospital Pricing Authority (IHPA), established under the National Health Reform Agreement, has been given the authority to progress ABF and although ABF will not commence for subacute care until 1 July 2013 the IHPA has:

...a process in place now with all jurisdictions. It also has called for public submissions to see how activity-based funding is best structured to meet the needs in subacute care, because, while I would hesitate to say that acute care is simple, it is much simpler than subacute care because of the venues where subacute care can be provided and what is covered under the National Health Reform Agreement.¹⁰

3.9 The department explained to the committee that ABF is 'the long-term real answer to the consistent measurement.'¹¹ Stakeholders however, are not without concerns as to how ABF will be implemented.

8 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p.11
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

9 Council of Australian Governments, National Partnership Agreement in Hospital and Health Workforce Reform, p.11
<http://www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf> (accessed 27 August 2012).

10 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

11 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

3.10 The Victorian Healthcare Association¹² expressed some concerns of moving palliative care funding into the ABF model:

It is imperative that appropriate funding arrangements acknowledge the priorities of providing palliative care and do not overlook patient preferences. However, the current funding arrangements and other monetary factors, such as patient co-payments and accommodation, skews palliative care provision towards bed-based options in a hospital as opposed to services provided 'in place'.

The introduction of activity based funding (ABF) in hospital-auspiced palliative care from 1 July 2013 is still yet to be articulated. The current Palliative Care Resource Allocation Model (PCRAM) weights funding based on a number of variables including rurality and low socioeconomic status. It is unclear whether the application of ABF will include a similar weighting structure. This is of particular concern for block funded small rural hospitals in Victoria that may be unable to provide the same level of services under ABF as under the PCRAM if the extra costs inherent are not taken into account.

VHA members have expressed some concern regarding the implications of moving these palliative subacute services into an ABF model as it places restriction on the capacity to truly cater for patient needs. The transition of subacute services into ABF must allow the mobility of funds into programs that are in the home and community, not just in hospitals. Home and community based programs provide specialised, patient-centred medical care and care coordination that are enabled by block funded grants.¹³

3.11 The Victorian Healthcare Association explained its concerns to the committee:

Our members have expressed some concern regarding the federal introduction of activity based funding through the IHPA, or Independent Hospital Pricing Authority, mechanisms, and how those mechanisms might play through to some of the subacute and blended community hospital type models that many of our members here in Victoria are currently involved in. There are also discrepancies between what might be available through some palliative care funding mechanisms and for aged care providers who in fact provide palliative care at end of life within the residential setting. We need to remember that the whole construct of residential care is to create a homelike environment. That environment essentially becomes the substantive home for that resident and really the access to some of the funding mechanisms that meet the more deliberate and, perhaps at various stages, the more resource intensive nature of palliative care should be

12 The VHA is the major peak body representing the public healthcare sector in Victoria. Its members include public hospitals, rural and regional health services, community health services and aged care facilities. Established since 1938, the VHA promotes the improvement of health outcomes for all Victorians, from the perspective of its members. Source: Victorian Healthcare Association, *Submission 57*, p. 1.

13 Victorian Healthcare Association, *Submission 57*, p. 3.

available within that setting. Currently, it is quite convoluted and complex for that to occur.

When we talk about efficiencies in palliative care, I note there is a suggestion that palliative care can reduce costs by reducing hospital admissions but this part of the conversation is not a cost-saving driven conversation; it is more to talk about the effectiveness of care providing the best economic outcome and the best economic outcome will have a range of considerations including price efficiency, quality of care for the patient and the consumer driven element of it from an economic perspective.¹⁴

3.12 Palliative Care Australia expressed a view that the ABF model may be too simplistic, particularly in the multidisciplinary team setting:

At the moment with activity based funding the concept of a service event is of one patient and one clinician. It does not include people such as pastoral workers; it only includes the specific clinician. So, if care was given by, say, a pastoral worker, that would not count within the activity based funding. And, whilst bereavement care does count, other care of the family group does not count. That is something that we really need to address while we are putting the activity based funding together. It does not come into effect for subacute care until next year, so we certainly have enough time to address this now, but we need a rethink of what it means.¹⁵

3.13 Eastern Palliative Care Association Inc (EPC)¹⁶ suggested that ABF will not enable innovation in service delivery as service providers will no longer be able to allocate the funding they receive as they consider appropriate and effective. EPC explained how the current funding method, what they refer to as 'bucket' funding, enables them to do this:

Because we have a bucket of funding that we do not have to acquit—and the government has said that we must spend 25 per cent on nursing—we have been able to work around things. We have also been able to get some philanthropic funds straight to health support. So we have used our funding very innovatively. The priority assessment team cost us \$130,000 for the year, for a pilot, but the results were so good we just had to incorporate it.

14 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

15 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 14.

16 Eastern Palliative Care is an organisation that was developed following the competitive tendering of community based palliative care in 1997. Three agencies—the Order of Malta, St Vincent's Melbourne and Melbourne East Palliative Care Association—tendered for the right to provide services. They were successful and invited Outer East Palliative Care Service to be part of EPC so that the new organisation could provide services right across the entire eastern region of 2,963 square kilometres, and that includes a lot of metropolitan areas. Since 1997, members of these partner bodies have been the governing body. Source: Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc, *Committee Hansard*, 4 July 2012, p. 1.

Down the track, particularly with activity based funding, we are worried a little bit about our funding coming in; we really are. But we find that that program is so beneficial that we have to look at other things to trim rather than that, because when someone is desperately needing a service—they are going to die within seven days—we need to be able to respond to the community well because that actually helps our profile, that helps the community and that builds a capacity within the community and people can see that death is not that awful thing that should happen in a hospital.¹⁷

3.14 EPC also identified the importance of recognising the role of the carer and the complexity of palliative care in ABF and identified that these are just two of the risks for the future funding of palliative care:

Ms Moody: Recognition of the carer in ABF. I actually think that is our biggest one.

Ms Pedley: The complexity of care too... There is the increased number of carers that we are getting, either who have mental health histories themselves or their clients have mental health histories. We are palliative care specialists, but we are dealing with an enormous amount of complexity within families. More and more, we have people with quite extreme mental health conditions that make caring for people at home quite difficult. We do it well, I think, but it is certainly becoming increasingly more demanding, and that does require more of our time—more planning and input into them.

Ms Moody: One more risk is the impost of occupational health and safety on our staff. Our staff are out there at night, driving alone in a car. We provide them with some resources. The technology is not really out there to monitor them in their car that well. So the impost of occupational health and safety on our staff and how we have to manage that is another risk.¹⁸

3.15 Although stakeholders were cautious of the ability of the IHPA to adequately determine the funding needs for palliative care, particularly at the 'more end-of-life palliative care and the higher level symptom management,'¹⁹ the committee heard that the IHPA has established a sub-acute care advisory committee comprising palliative care medicine specialists, geriatricians and rehabilitation positions. The establishment of this committee had allayed the concerns of some. The Royal Australasian College of Physicians (RACP), a member of the sub-acute care advisory committee welcomed the establishment of the advisory committee.²⁰

17 Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 7.

18 Ms Jeannette Moody, Chief Executive Officer, Ms Christine Pedley, Manager, Allied Health, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 8.

19 Mr Nicolas Mersiades, Senior Aged Care Adviser, Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, p. 26.

20 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

3.16 The Council of the Ageing (COTA) were supportive of the IHPA being given the role of 'pricing' palliative care provided it is regarded as a specialist health service and not merely a component of aged care:

I do not think there needs to be a separate pricing authority for palliative care. I would have thought that IHPA would be doing it for the health system as the full suite of health services.

It is important that specialist palliative care is seen as a health service and that aged care is not asked to pick up a health service.

...Our view is that it is a health service and should be priced by IHPA, and that pricing should be able to have a look at what is done with aged care.²¹

The National Partnership Agreement on Improving Public Hospital Services

3.17 As DoHA explained, funding for the provision of palliative care services is also provided under the National Partnership Agreement on Improving Public Hospital Services.

3.18 The National Partnership Agreement on Improving Public Hospital Services, (the agreement) signed in February 2011, is intended to 'drive major improvements in public hospital service delivery and better health outcomes for Australians' by facilitating 'improved access to public hospital services, including elective surgery and ED [emergency department] services, and subacute care.'²² The agreement specifies that the federal government will:

...provide up to \$1.623 billion dollars in capital and recurrent funding from 2010–11 to 2013–14 to States and Territories to deliver and operate over 1,300 new subacute care beds nationally, in hospital and community settings, by the end of this period.²³

3.19 The agreement identifies where the new subacute beds will be established:

21 Mr Nicolas Mersiades, Aged and Community Services Australia; Ms Jo Root, National Policy Manager, COTA, *Committee Hansard*, 10 July 2012, p. 26.

22 Council of Australian Governments, *The National Health Reform Agreement – National Partnership Agreement on Improving Public Hospital Services*, p. 4
[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/\\$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf) (accessed 27 August 2012).

23 Council of Australian Governments, *The National Health Reform Agreement – National Partnership Agreement on Improving Public Hospital Services*, p. 43
[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/\\$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/npa-improvingpublichospitals-agreement/$File/National%20Partnership%20Agreement%20on%20Improving%20Public%20Hospital%20Services.pdf) (accessed 27 August 2012).

Table E1: Estimated Distribution of New Subacute Beds across States and Territories

Year	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Total
2010-11	107	82	66	34	24	8	5	3	329
2011-12	215	163	133	67	49	15	11	7	660
2012-13	321	245	199	101	73	23	16	10	988
2013-14	428	326	265	135	97	30	21	14	1,316

Source: National Health Reform Agreement—National Partnership Agreement on Improving Public Hospital Services, Schedule E, p. 45.

3.20 It also sets out how the \$1.623 billion in funding will be allocated to deliver these outcomes:

E31 State and Territory funding allocations for these reforms are as follows:

Table E3: Estimated Distribution of New Subacute Beds Guarantee Funding^{1,2,3}

Year	NSW (\$m)	VIC (\$m)	QLD (\$m)	WA (\$m)	SA (\$m)	TAS (\$m)	ACT (\$m)	NT (\$m)	Total (\$m)
2010-11	76.0	58.2	46.9	24.1	17.0	5.7	3.6	2.1	233.6
2011-12	102.6	78.4	64.4	32.1	23.9	7.0	5.6	3.6	317.6
2012-13	145.0	111.1	89.8	45.9	32.8	10.6	7.0	4.3	446.5
2013-14	203.8	154.7	125.9	64.3	46.0	14.0	9.9	6.9	625.5

¹ Estimated funding allocations are contingent on performance, and assume a national roll-out.

² Funding for subacute beds has been estimated by estimated population distribution.

³ Columns and rows may not add due to rounding. Actual payments will be calculated to the nearest dollar.

Source: National Health Reform Agreement—National Partnership Agreement on Improving Public Hospital Services, Schedule E, p. 48.

3.21 In response to the committee's questions concerning progress of the creation of the new subacute care beds, the department explained that as at 30 June 2011, 104 of the new beds created since the government's commitment had been dedicated to palliative care:

National Partnership Agreement on Improving Public Hospital Services – Total Planned Palliative Care Beds and Bed Equivalent Services and Palliative Care Funding by jurisdiction – 2010-11 to 2013-14 (as at 30 June 2011)

Planned State and Territory Palliative Care Beds / Bed Equivalents and Funding under Schedule E of the NPA IPHS (as at 30 June 2011)*			
	NPA Target (by S/T)	Total Palliative Care Beds/Equivalents identified by States	Total Funding for Palliative Care Beds/Equivalents identified by States
STATE		Beds and Bed Equivalents	Allocated Funding
NSW	428	51.00	\$27,893,925
VIC	326	22.10	\$644,515
QLD	265	25.50	\$16,960,000
WA	135	4.00	\$2,200,000
SA	97	0.00	\$0
TAS	30	0.00	\$0
ACT*	21	0.00	\$86,935
NT	14	2.00	\$2,075,376
Total	1316	104.6	\$49,860,751

* Whilst the ACT is not planning to deliver any palliative care beds or equivalent services, it has allocated funding for the purchase of palliative care equipment to support people in the community.

Source: Department of Health and Ageing, answers to questions on notice (question 4), received 23 May 2012.

3.22 The department explained however that the national partnership agreements provide the states and territories with flexibility to 'redirect funds allocated across the elective surgery, ED [emergency department] and subacute Schedules to the highest priority within their jurisdiction'. As a result, given that subacute care is bundled,²⁴ it is 'extremely difficult' to determine exactly how much each state and territory spends on palliative care and therefore how many of the subacute care beds will be specifically set aside for palliative care:

[t]he states and territories decide on what they are going to spend and where they are going to spend it. The Commonwealth has no direct control in determining that palliative care beds should go to Queensland or that rehabilitation beds should go to Victoria. The states and territories provide that. What they then do is provide the Commonwealth with an implementation plan about how they plan to spend the money, obviously for all of the NPA funding but this area particularly. Then they provide us with progress reports on a six-monthly basis.²⁵

24 'Bundling' refers to the fact that the category of subacute care includes palliative care, rehabilitation, geriatric evaluation and management, psychogeriatric care and in some cases subacute mental health.

25 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 10–12.

3.23 While explaining the difficulty associated with determining the amount that each state and territory spends on palliative care, the department also informed the committee that at present the federal government has no consistent or standard reporting mechanism to review how the states and territories allocate the funding they receive under the agreements:

It has been an ongoing concern for the Commonwealth. Most states report in a similar manner, but not all states do. They all come out of very different reporting systems. We looked at subacute care as a total. Rehabilitation is the most advanced in reporting because they simply seem to have had more systems in place for a longer period of time. All of the other areas of subacute are still under some level of development and the states and territories have taken individual approaches to that.²⁶

3.24 As explained above, the new NPA on Hospital and Health Workforce Reform has introduced a requirement for standardised reporting. The department advised the committee that progress on standardising reporting has been made and that they hope to have 'something' that has a 'fairly consistent approach' to the COAG Reform Council in the 'next couple of months'.²⁷ The department explained that this information should eventually be published and although complete consistency will not be possible, explanatory information will be provided where it differs.²⁸

3.25 The department explained that the information will be used for 'measurement and counting' under the ABF model.²⁹

3.26 Professor David Currow, professor of palliative and supportive services at Flinders University, suggested to the committee that the 'key challenge' of funding is to ensure that it is maintained at a level 'that genuinely reflects the improvement in health that can be delivered across the community by good palliative care'.³⁰ Professor Currow suggested that what was needed was a review of how resources are utilised within current budgets.³¹

3.27 In addition to funding provided under the National Partnership Agreements, the government also provides funding for palliative care through the National Palliative Care Program (NPCP) which was established in 2002.

26 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

27 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

28 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

29 Ms Ann Smith, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, pp. 11–12.

30 Professor David Currow, Professor of Palliative and Supportive Services, Flinders University, *Committee Hansard*, 2 July 2012, p. 63.

31 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

The National Palliative Care Program (NPCP)

3.28 The NPCP funds initiatives to ensure quality palliative care and to improve access to services for people who are dying and their families.³²

3.29 The NPCP aims to achieve these outcomes by providing funding support in the following four areas:

- support for patients, families and carers in the community;
- increased access to palliative care medicines in the community;
- education, training and support for the workforce; and
- research and quality improvement for palliative care services.³³

3.30 Support for patients, families and carers in the community is provided by the NPCP through the provision of grants to 'local groups, health and aged care providers and church and charitable organisations' to assist these groups provide services and support for palliative care recipients and their families.³⁴

3.31 Funding to support increased access to palliative care medicines in the community is provided to the Palliative Care Clinical Studies Collaborative (PACCSC). The PACCSC:

...manages multi-site clinical drug trials in order to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and possible listings on the PBS.³⁵

3.32 The NPCP supports education, training and the palliative care workforce through the Program of Experience in the Palliative Approach (PEPA). PEPA is 'a work placement training program for health professionals in a specialist palliative care service of their choice.'³⁶

3.33 The fourth area through which the NPCP supports improved access to and quality of palliative care services is through the provision of funding for:

32 Department of Health and Ageing, *Submission 96*, p. 6.

33 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

34 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

35 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

36 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

- [the Palliative Care Outcomes Collaboration (PCOC)] a consortium of four universities forms the Australian Palliative Care Outcomes Collaboration. PCOC supports services to consistently compare and measure the quality of their outcomes, and through this ensure continued quality improvement.
- [t]he Palliative Care Research Program, managed by the National Health and Medical Research Council, [which] aims to improve the quality of palliative care, inform policy development, improve clinical practice and develop researcher capacity, by funding priority driven research grants, training awards and research development grants;[and]
- [t]he Palliative Care Knowledge Network (CareSearch)... a web-based one stop shop of information and practical resources for clinicians, other health care professionals providing palliative care, researchers, patients and carers.³⁷

Calls for funding changes

3.34 Throughout its inquiry, the committee received evidence which suggested there is much inconsistency in the standard of palliative care delivered in Australia. The committee sought to understand the inconsistencies by reviewing the funding of palliative care. The committee's findings suggest that the inconsistencies may be in part the result of the complexity of the funding framework.

3.35 In their submission to the inquiry, Palliative Care Australia (PCA), the peak national organisation 'representing the interests and aspirations of all who share the ideal of quality care at the end of life for all' explained that there is not enough funding dedicated to palliative care and as the method of funding these services has changed over time there is 'definite jurisdictional inconsistency'.

3.36 Stakeholders were consistently critical of the current way in which funding for palliative care was distributed and although views differed as to what should or could be done, the theme common amongst all was the need for increased transparency in how 'bundled' funding was allocated.

3.37 PCA were of the opinion that funding should be 'ring fenced':

I think you have to ring fence the funding for palliative care... So long as it is bundled in with subacute care, and the different states and territories will make a decision as to how that is divided up, it will tend to be spent on things other than palliative care. That has been the indication thus far.³⁸

37 Department of Health and Ageing, *The Australian Government's National Palliative Care Program* <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 19 September 2012).

38 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 14.

3.38 PCA identified in their submission that:

Of its \$39,973 sub-acute funding South Australia committed \$11,970 to palliative care. On the other hand, Queensland allocated none of the sub-acute funding to palliative care, but committed to undertake a review of the current palliative care service system in 2009-2010 from within existing state funding, and develop a strategic direction for palliative care. This service provision review has been undertaken, but not publicly released.³⁹

3.39 Palliative Care Nurses Australia raised similar concerns regarding bundled funding:

At present, that funding comes from the Commonwealth to the states, who then decide how that funding is disbursed in that state. Most palliative care takes place in the community, but the funding break-up does not always reflect that. While this is anecdotal—they do not have statistics to back it up—a lot of palliative care funding goes into the more acute areas, rather than the community.⁴⁰

3.40 PCA, which has membership across Australia went further to state that:

We know that many more Australians would benefit from access to palliative care, yet it is clear that bundling funding allocations within the sub-acute category is not leading to improved service provision and access across the country.

If such bundled allocations continue, whether or not in conjunction with Activity Based Funding, a significant level of funding must be specifically allocated to palliative care (as a minimum) to ensure greater access to quality end of life care for Australians in need.⁴¹

3.41 Despite these concerns however, the RACP explained that in their view, funding for palliative care must remain flexible to 'encourage innovative service delivery' and ensure 'the population has access to the right care at the right time and in the right location with the right provider:'

Funding arrangements must encourage palliative care services in a location that best reflects the patient's needs and the patient's choice. The college fully supports adequate funding for modern, responsive palliative care services which allow for this quality service.⁴²

3.42 In its submission to the inquiry, the Australia New Zealand Society of Palliative Medicine (ANZSPM) explained that processes should be introduced to

39 Palliative Care Australia, *Submission 94*, p. 80.

40 Mr John Haberecht, President, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 58.

41 Palliative Care Australia, *Submission 94*, p. 81.

42 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

ensure that state and territory governments are accountable for the spending of bundled funding:

A major source of funding over the last few years has been the NPA subacute care funding. This money has been distributed to States and Territories, and covers four areas of subacute care – Palliative care, Geriatric Evaluation and Management, Psychogeriatrics and Rehabilitation. In the initial funding round all States and Territories were required to publish their implementation plans; these were available to the public. The detail of these plans varied from having no breakdown of monetary allocation, to detailed distribution of funds between the different subacute care areas.

Unfortunately, in the second round of funding, there has been no publication of the allocations. The difficulty with the way in which the money has been distributed, is that our members have experienced frustration, firstly at the lack of actual distribution of money, and secondly at what is seen as distribution according to political motives rather than the needs of patients. Many members have complained at the lack of benefit from this money for palliative care provision across Australia.

Recommendation 6. That the Commonwealth ensures that funding for the National Partnership Agreement (NPA) for subacute care:

- is allocated according to population-based needs;
- has its distribution linked to a clear improvement in the quality of service; and
- is transparent, and that details of allocation/distribution are made publicly available to ensure that State and Territory governments and LHHN (Local Health and Hospital Networks) are accountable for the use of this funding stream.⁴³

3.43 Although it did not directly comment on the bundling or unbundling of care, Mercy Health also suggested to the committee that in their experience a speciality like palliative care should not be funded episodically:

...episode funding is not an appropriate way to fund a speciality which provides services across both the acute and non-acute sector. Specifically, palliative care provided in the acute setting is not recognised in the current funding model.⁴⁴

3.44 Submitters however suggest that without sufficient data, the effective allocation of resources will be difficult to achieve. PCA explained that funding is linked to data and at present the data collected for palliative care purposes is deficient:

...we need to find out and get good data about how and where palliative care is delivered now... We need to know how it is delivered now so that we know exactly how large the gaps are and where the gaps are.

43 Australian and New Zealand Society of Palliative Medicine Incorporated, *Submission 33*, p. 10.

44 Mercy Health, *Submission 58*, p. 5.

Another way that we can look at it is to ring-fence some funding for palliative care in the funding that goes out to the states. If there is money going out in the subacute bucket, we need to ensure that there is money ring-fenced for palliative care. It is not necessarily the easiest thing for states to disseminate funding in palliative care. It is often easier to build a bed in a rehab ward than it is to set up a good palliative care service that reaches into the community or to better support such a service.⁴⁵

The complexity of funding palliative care

3.45 Throughout the committee's inquiry it became clear that the nature of palliative care is extremely complex. The fact that palliative care can be required for people from all ages and backgrounds, not just the elderly who reside in aged care facilities, adds to the complexity that is introduced by the joint funding of care by both the federal government and the states and territories.

3.46 Mr Peter Cleasby, President of Palliative Care New South Wales, succinctly explained the complexity when he informed the committee:

As long as we have a federated model, there will clearly be issues about who is responsible for what. What we want to say is that we have the situation in Australia where Palliative Care Australia, which works primarily with the Commonwealth, is the national entity and a good number of great things have been delivered...but, unfortunately, at the state level across the country, the state bodies are struggling big-time to play their role with their local jurisdictions.

...There is a problem with the coordination and I think the Commonwealth is missing out on an opportunity to get a better return on investment. There does not seem to be an overall strategic management of these projects and taking them elsewhere, and finding out what has developed in one state actually can be translated to another state without each state having to do it themselves.⁴⁶

3.47 Dr Yvonne Luxford, Chief Executive Officer of Palliative Care Australia, suggested that although there are both advantages and disadvantages of the federated system, simply consolidating the responsibility for funding the provision of care would not guarantee 'the best possible care or the best possible equitable division of funding':

Just having one funder does not guarantee that you get the best possible care or the best possible equitable division of funding. Perhaps what we need, rather than moving towards one funder, is for the funding to really

45 Dr Yvonne Luxford, Chief Executive Officer; Dr Ian White, National Policy and Communications Manager, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 19.

46 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, pp. 56–57.

recognise what is needed and the level of need out there and to ensure that the funding is fairly distributed.⁴⁷

3.48 When discussing the issue of whether or not funding of palliative care should rest with the federal government or the state and territory governments, submitters pointed to the example of aged care which has, through the decisions of COAG, become the sole responsibility of the Commonwealth and is funded through the Aged Care Funding Instrument (ACFI). However, given the complexities involved in the provisions of palliative care, palliative care services provided through the ACFI, which primarily funds aged care facilities, will not apply to those people requiring palliative care yet who do not meet the aged care threshold requirements.

3.49 Catholic Health Australia explained that although the ACFI '...as a tool is a very useful way of funding services into residential aged-care providers' it does not extend past residential aged care provision and into the community aged-care setting.⁴⁸

3.50 BlueCare identified other limitations of the provision of palliative care under the ACFI:

At the moment, often providers do not claim for the palliative care component of ACFI and there are two reasons for that. Firstly, it comes under the complex care needs area. Often if you have already reached your ceiling point under the ADL section then you do not need to add the ten points that you would get from palliative care because you will not get any more money. The number of claims that go in for palliative care probably do not reflect the number of palliative care clients that are in the system because from a paperwork perspective there is no added value to reclassifying people when they become palliative care patients. I am not sure if that will be changed; we have advocated for that.⁴⁹

3.51 Professor Parker further explained the difficulty accessing palliative care funding under the ACFI given the requirements that 'a GP or specialist nurse sign off on a palliative care plan', both of which are rare in the residential aged care setting.⁵⁰

3.52 Professor David Currow, a professor of palliative and supportive services at Flinders University suggested to the committee that the 'key challenge' is to ensure that funding of palliative care is maintained at a level 'that genuinely reflects the improvement in health that can be delivered across the community by good palliative

47 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 24.

48 Mr Martin Laverty, Chief Executive Officer, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 37.

49 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre, *Committee Hansard*, 2 July 2012, p. 5.

50 Associate Professor Deborah Parker, *Committee Hansard*, 2 July 2012, p. 5.

care.⁵¹ Professor Currow suggested that what was needed was a review of how resources are utilised within current budgets. He told the committee that:

This is not about more money; this is about ensuring that we distribute that money in a way that genuinely engages in ensuring that the health of the whole community is a focus.⁵²

3.53 PCA explained that what they consider is needed is for:

...all levels of government to fund palliative care services using appropriate, equitable and needs based models. Funding needs to be flexible and delivered both as block funding and as activity based funding. Development of the new activity based funding models must recognise that palliative care is unique in its holistic and multidisciplinary nature and that its caring encompasses loved ones and carers in addition to the person with the terminal illness. We need to maintain an effective and appropriate high quality service through ensuring that all locations engaged in end-of-life care adhere to the national palliative care standards. Such national standards will ensure a basis for uniformed consistency in approach to palliative care across the country.⁵³

3.54 In the Productivity Commission's (PC) recent inquiry report into aged care in Australia,⁵⁴ the PC recommended that aged care services be provided through an entitlement system which would involve Australians being assessed to determine their needs and therefore their entitlement to different care services. Throughout its inquiry process the committee sought to explore how palliative care service providers consider the introduction of an entitlement based system would address the needs of palliative care recipients.

3.55 Dr Alan Rouse of the Tasmanian Health Organisation (North West) told the committee how the Tasmanian Health Organisation would be able to provide more services for palliative care if the funding for those services was available on an entitlement schedule:

[An entitlement schedule – a Medicare schedule]... would be a great idea. One of the examples that I will put to you is: these medications that people need within nursing homes, for example, to stop pain. I am talking, for example, about the person who falls very near the end of their life and has a fractured hip. One of the options is a hospital spending \$15,000 to \$20,000 fixing it so that they can either die in hospital or come back to the residential aged-care facility and die in the days after. We have medications that cost, maybe, \$50, which people are reluctant to purchase because they have no money. The alternative is \$50 versus \$15,000. If these aged-care

51 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

52 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

53 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 19.

54 Productivity Commission, *Caring for Older Australians*, August 2011
<http://www.pc.gov.au/projects/inquiry/aged-care/report> (accessed 8 October 2012).

facilities had access to these medications that were able to afford them on the residents behalf, then we would see even more savings.⁵⁵

3.56 Ms Angela Raguz, General Manager of Residential Care at HammondCare said of the PC's report:

The Productivity Commission has done a good job in understanding and looking at what the issues are that are facing aged care and the reality of how this industry is going to be sustainable over the period of time where we have an explosion of older people. What is lacking is the answer to the workforce question... we can do a lot in our aged-care services and we can certainly do that at a more efficient price for a long period of time, especially with the entitlements system coming into place, than what the public health system is able to offer.

The challenge is making sure we have got the people with the skills, the knowledge and the experience to do that across a broader base. Without that, it can get stuck. We have seen it with our palliative care suite: if we were not an organisation that had a schedule 3 hospital that provided specialist palliative care services, it would really not be that easy to get those things up and running and off the ground. It is about how we get those experts to come on board and to move beyond that view: 'Oh, it's aged care—that's a bit daggy. I don't want to spend time in aged care.' For young doctors and nurses it is not the sexiest part of the industry to select. So it is about getting it within undergraduate training, looking at training people on the ground in the nursing homes across a broad scale. And it is not just about setting up distinct units, even though that is an ideal. It is about lifting the bar across the whole of aged care, be it in people's homes or in facilities.

... It is a whole-of-system question that needs to be answered. If GPs are the primary care physicians, there needs to be a lot of effort and emphasis put at that level as well.⁵⁶

3.57 Associate Professor Rohan Vora, President of Palliative Care Queensland agreed that the Productivity Commission's entitlement system would go some way towards addressing the funding of palliative care in the community palliative setting, particularly if there were an entitlement for case management:

It could do. I guess we would need to have a look at and see what system You have the MBS item system for Medicare. There are a whole lot of gaps in that as to how you fund allied health, how you fund coordination of services—it is a range of things. GPs face exactly the same problem. Their phone calls and coordination of services are not funded; it is your patient in front of you at the time. Of course, in palliative care it is not just the patient

55 Dr Alan Rouse, Tasmanian Health Organisation—North West, *Committee Hansard*, 5 July 2012, p. 5.

56 Dr Peta McVey, Clinical Nurse Consultant, Palliative Care, HammondCare, *Committee Hansard*, 2 July 2012, p. 21.

in front of you; it is the family in front of you or the family that cares for the patient that needs to somehow be in that.⁵⁷

3.58 Professor David Currow, Professor of Palliative and Supportive Services at Flinders University informed the committee of his view in relation to an entitlement based system, in particular, a system which included palliative care services in the entitlement system:

The issue is that palliative care permeates the entire health and social system. The question is: how do we best ensure that people, wherever they have contact with services, are going to be able to get timely, well-planned, proactively considered services? As we think about entitlements, we are talking about the ability to actually say, 'This person now has a life-limiting illness.' At a community level, that will be a huge shift. I think the United Kingdom, particularly England, have made that shift in the last few years, and they have started to create primary-care registers, which have a whole lot of flow-on effects in terms of the entitlements for that person and their carers.

As I pointed out, the one thorn in the side in Commonwealth paperwork at the moment is the carers allowance, which asks a professional to actually prognosticate—and we are either very good at that or very bad, depending on which literature you read—and then hand it back to that family to take to Centrelink. We have to change it.

... We need to change that. If there is one really practical thing we can do today, it is to change that Centrelink paperwork, because it is abhorrent.⁵⁸

3.59 Professor Currow also informed the committee that should an entitlement approach to funding be taken it would be important to ensure that it did not result in 'perverse' outcomes:

By way of how we best provide services, we need to ensure that there is continuity and that there are no perverse incentives, as we think about an entitlement system. We need to think through that very carefully. There are times that hospital—not a hospice, not an aged-care facility—is actually the best place to provide care. And we need to make sure that we do not go down the path of the American system, where their entitlement system has in fact limited hospice and palliative care services and led to some very perverse incentives in how those services then work.⁵⁹

3.60 The Victorian Healthcare Association (VHA) informed the committee that the PC's recommendation to move to an entitlement system was 'consistent with a consumer focus':

57 Professor Rohan Vora, President, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 31.

58 Professor David Currow, *Committee Hansard*, 2 July 2012, pp. 67–68.

59 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 68.

I would say that would not be inconsistent with some of the key themes that we would see as potentially adding value, particularly from that funding side of the equation. If the person in receipt of the care is actually in control of the funding and determining from an appropriately referenced panel of providers, presumably, where they purchase their services from, I think that is a terrific model.⁶⁰

3.61 The VHA suggested that if such a system were to provide fairer access to services and resulted in greater funding flexibility they would 'generally' be supportive:

I say generally. The proviso and the concerns that we have had in the past have been around some of the smaller rural communities, where there is not an active market. Sometimes in those communities you can get skewed outcomes, or unintended outcomes as opposed to skewed outcomes, as a result of that type of approach. The viability of those public health services in smaller rural communities is really quite critical to the way in which those communities see themselves. So we have got to be careful with all of the funding leavers that those unintended consequences do not flow. With that proviso, I think generally where there is an active market then that should be supported.⁶¹

3.62 The VHA went on to explain that the difficulties associated with those in residential care receiving better access to resources could be 'overcome' through such a system:

If the person in residential care ended up requiring palliative care they should, by definition, because that is their principal place of residence, be just as eligible to the entitlement voucher as the person still living in the community. The complicating factors always are that the person is an environment where they are already receiving some care so to what extent should that be discounted or should that other care be taken into account that?

...You have the one element where the person in the community might still be living at home and therefore not paying 87½ per cent of their pension for the residential care they are in receipt of, but then the person in residential care does not have the maintenance cost of a home. There is a variety of debates. The fundamental thing is that the entitlement should not be any different because of the percentage of pensioners paying for residential care, not necessarily for palliative care.⁶²

3.63 The Special Interest Group of the Occupational Therapists also explained that given the importance of multidisciplinary teams in the provision of palliative care, any move to an entitlement system would need to be coupled with a broadening of the

60 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 13.

61 Mr Trevor Carr, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 13.

62 Mr Trevor Carr, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 15.

definition of 'health professional' to ensure that allied health professionals were included particularly to support people staying longer in the community before necessarily entering aged care or hospice facilities:

Ms Bourke: I think that is an access issue that occurs outside of the specific pall care units where there is a higher profile. There is that trickle-down effect. Someone sees the patient and has to think to refer to you. If they do not, it does not happen. Or they might then ask someone to write the referral, and it might not happen. I would be interested to know the people who probably need it and have it translate into an actual referral, but I think it would be a very tiny number compared to the unmet need that has been written about.

Ms Boffa: I had an interesting conversation with someone in the community yesterday. It was very clear that this person is receiving in-home palliative care. The focus of that care is very much about bed based care and not acknowledging that there were functional goals or quality of life issues that might also be addressed as part of that care. I think that nursing, bed based terminal care thought process or view of things does limit the likelihood of the generation of a referral and acknowledging and identifying functional goals and quality of life.⁶³

3.64 When Resthaven, a service provider, was asked to comment on the Productivity Commission's suggestion they identified a number of issues that may present in developing an entitlement funding framework:

What we would understand is that an entitlement assessment is an assessment at a point in time. If the pricing was correct at that time then the matching of, as you describe it, the assessed need and the payment that goes with that assessed need would work at that time. The challenge that I think we all face is what happens five minutes, five days or five months after that time and, in a system which requires a sense of independence in the assessment of that need, how does that practically work for people who are in a changing phase? That is the whole dilemma with anything associated with palliative care; it is often not until after the person is deceased that you can map back and see what the signs were where you could say that this person was very obviously in their terminal phase for the last few days of their life. But the practicality of having an assessment in a timely way which then gets those resources in—particularly if that assessment has to be done by an independent, separate body making those assessments before the provider could move into that space—those are the procedural and technical issues that go with designing these systems. What we are saying at the moment is that there is provision in the existing ACFI system and there is a pay point associated with making a claim for palliative care. Our

63 Ms Jenni Bourke, Senior Occupational Therapist, Representative, Occupational Therapy Oncology Group, Occupational Therapy Australia; Ms Rebekah Boffa, Acting Co-Convenor, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 21.

experience of that has been that it is very legitimate to make that assessment.

The process of reviewing that decision sometime later by somebody who is reviewing the paperwork rather than reviewing the person, and therefore making that assessment—

... It is really problematic. So what we see is either that there is an underclaiming of those payments [or a subsequent clawback] ... because with hindsight people are being very cautious in terms of when they are making those claims, which is probably too late, so then the funding is not necessarily supporting that as well as it might.⁶⁴

3.65 Resthaven explained that one of the problems facing the sector and reform is the fact that there has never been a mechanism to formally cost any aspect of aged care, including palliative care:

The point that we have made in our submission is that there has been no formal costing study of the actual costs of care for any aspect of aged care. There is a historical pattern in terms of designing that.

...So I think that if we were going to move down a path which assumes some relativities in terms of the payment models as you are describing them—which is effectively how funding works in health as you have described it—then as an industry we would want to be very comfortable that the starting point was actually a real rather than a theoretical starting point.⁶⁵

3.66 Professor David Currow reminded the committee however that although the majority of palliative care recipients may be residing in aged care facilities, palliative care applies across the entire spectrum of the population, not just aged care, and that one in three people who die expected deaths are under the age of 65:

We also need to be incredibly clear about the demography of the people who are seen by palliative care services—that is, the people who die expected deaths in our community. One in three of those people are under the age of 65. It is important that we acknowledge the full age spectrum as we start to think about the services that need to be provided. Excluding dementia, for every two people seen with cancer it would be expected that a person with a non-cancer diagnosis would also be seen. We have a national strategy; we need to back that, to resource it and to implement it.⁶⁶

Settings of care – cost, effectiveness and efficiency

3.67 Throughout its inquiry the committee received much evidence from palliative care service providers. The information detailing the different ways in which services

64 Ms Susanne McKechnie, Executive Manager, Community Services, Resthaven Inc., *Committee Hansard*, 5 July 2012, p. 11.

65 Ms Susanne McKechnie, Resthaven Inc., *Committee Hansard*, 5 July 2012, p. 11.

66 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

are delivered further highlighted the complexity of adequately funding the provision of quality palliative care.

3.68 Palliative care is provided in many settings: in hospitals; in the community through not-for-profit organisations/charities; and in aged care facilities and hospices. As discussed above, funding of the services provided through these different models is a complex arrangement of state and territory government money, federal government funding and grants, and bequests and donations from community members.

3.69 The committee consistently received evidence which clearly identified that the cost of providing palliative care in the community setting is cheaper and often more effective as the majority of people prefer to die at home or in a community setting rather than in a hospital.

3.70 Palliative Care Queensland highlighted the risks of not adequately funding the provision of services:

For a lot of us, the issue almost becomes can we afford palliative care? ... if we do not do it they [people requiring palliative care services] end up in the acute system. They queue at emergency, they ramp at emergency and end up in an acute bed, so you are doing it anyway. It is just that you are doing it not in a very good way and it is costing a lot of money. It is hard to know how much cheaper it is... we know that an acute bed in the ICU is \$4,000 to \$7,000 a day. If you are talking about an acute bed in a hospital it is probably around \$1,000 to \$1,300 a day... a palliative care bed in Queensland is costed at about \$950 a day. We know that if you go down to a step-down facility where maybe you do not have as much need for acute intervention, pain management and a whole lot of ancillary services, it is probably around \$600 or \$700 a day. And in a nursing home, as we heard before, maybe it is \$150 to \$200 a day above what is already subsidised to put in the extra care. So it all depends on where the person is.

Of course, we know that, if they are at home and looked after by a carer and want to exploit the carer and pay them nothing, it may be \$60 or \$100 a day—⁶⁷

3.71 EPC highlighted to the committee that the cost of community based care is significantly less than hospital based care even though the average length of stay in the community setting is much greater than that of a hospital stay:

In 2009, the average cost per episode of care in a sub-acute hospital was \$7,654; in the community the average cost per episode was \$2,546. An episode in a hospital was 14.7 days; the average length of stay in the community was 133 days. People may have many hospital admissions during their condition. The cost benefits are clear, however, there are really much more than cost-benefits. We have become so used to going to the

67 Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 29.

specialist each time we are sick that we fail to realise how much we can manage at home and what our real wishes are.⁶⁸

3.72 Dr Leslie Bolitho AM, President of the RACP suggested that at present the sector faces a 'perfect storm' – 'an ageing population, increasing rates of complex and chronic disease and ever-tightening resources.'⁶⁹ In view of the benefits that could be gained, not only in terms of patient preference, but also to health care budgets, the RACP suggest shifting the provision of palliative care to the community sector rather than relying on the hospital system.⁷⁰

Committee comment

3.73 The committee supports the development and introduction of nationally consistent classifications and data collections for hospital provided care and the development of a nationally consistent costing and funding model for hospital provided treatment which will flow from the introduction of activity based funding (ABF). The committee however does share the concerns of witnesses and submitters to its inquiry that ABF will not adequately account for the complexity of palliative care including the different disease trajectories associated with life limiting illnesses, the different settings in which palliative care can be provided and the key role that multidisciplinary teams, including allied health professionals, play in the provision of care.

3.74 The committee acknowledges that the Independent Hospital Pricing Authority, responsible for progressing ABF, has established a sub-acute advisory committee which includes palliative care specialists in its membership. The committee is not convinced however that the establishment of such a committee will go far enough in ensuring that the unique attributes of palliative care, including the fact that the outcome being sought is rarely curative, will address the specific funding requirements which it has identified throughout its inquiry.

3.75 The committee notes that under the National Partnership Agreement on Improving Public Hospital Services, funding for palliative care is bundled with funding for subacute care and states and territories are given the flexibility to redirect the funding as they consider is necessary. The committee acknowledges the need for flexibility in funding palliative care given the many settings in which care is provided however is concerned that at present there is no consistent or standard reporting mechanism in place to review how money provided to the states and territories is allocated. The committee is concerned by this situation despite the requirement of the

68 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 2.

69 Dr Leslie Bolitho AM, President, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

70 Dr Leslie Bolitho AM, Royal Australasian College of Physicians, *Committee Hansard*, 2 July 2012, p. 9.

COAG process that each state and territory government to provide implementation plans.

3.76 The committee recognises that ABF will introduce a method of measuring and collecting data but considers that the complexity of providing palliative care make its funding a unique challenge. The committee considers that some flexibility needs to be retained as to how each state and territory allocates its funding given their differences in terms of geographic size, dispersion, population, and demographics. However, the committee regards accountability as critical and calls on the government to ensure sufficient governance structures are in place.

3.77 The committee suggests that palliative care differs in nature from the other types of 'sub-acute' care, and this warrants it being considered as a separate funding category. The committee also considers that recognition needs to be formally given to the role of the community sector in the funding arrangements for palliative care, given that evidence clearly shows the cost benefits that can be achieved by transferring the provision of palliative care to the community setting rather than the hospital based environment.

3.78 The committee received evidence in relation to the Productivity Commission's suggestion that the aged care sector moves to an entitlement system (one in which diagnosis would determine funding entitlement and the funding entitlement would follow the patient through the system). The Committee recognises that life limiting illnesses are not limited to those Australians who are aged – palliative care service recipients cross the age spectrum and although generally it is assumed the majority reside in aged care facilities or within the community, this is not always the case. The Committee recognises the concerns that this raises, however, this ought not necessarily preclude palliative care being included in any future move to an entitlement system in the aged care system. Reforms should take account of the complexities of palliative care.

3.79 The committee considers that at times it is forgotten that disease does not discriminate. Although longevity increases the incidence of incurable illnesses such as dementia, incurable and life-limiting illnesses can be suffered by anyone, from the very youngest to the very oldest members of community. Funding mechanisms should reflect this fact, and ensure care is delivered in accordance with the WHO definition of palliative care.

Recommendation 2

3.80 The committee recommends that the Australian government considers extracting palliative care from the sub-acute care category and create a new funding category of 'palliative care'.

3.81 The committee recommends that in determining the appropriate costing for palliative care services the costs of providing care in the community sector also be calculated and allocations made to support the provision of palliative care services by this sector. The committee acknowledges that any allocations of funds

to community sector service providers would require rigorous and transparent governance arrangements to be established.

Recommendation 3

3.82 The committee recommends that the creation of a new palliative care funding category should result in the establishment of a palliative care advisory committee by the Independent Hospital Pricing Authority to advise the Authority on appropriate costing for palliative care services consistent with the activity-based funding approach.

Recommendation 4

3.83 The committee recommends that the development and introduction of consistent national data collection specifically provide for the recording and reporting of palliative care data.

Chapter 4

State palliative care services

Introduction

4.1 As noted in chapter one, the majority of palliative care funding is provided by states and territories, with services often delivered by organisations that operate in a single state or region. Despite the significance of state funding arrangements, the committee received submissions from only three state or territory governments: Tasmania, New South Wales and South Australia. The committee also found that there was relatively little discussion in other submissions of state funding arrangements. The committee did not receive submissions from the governments of those states that witnesses often regarded as having strong service delivery models: Victoria and Western Australia.

4.2 This chapter examines the funding of palliative care services in the states and territories and whether funding arrangements contribute to variations in the standard of care.

4.3 In describing these arrangements it is noted that as a result of decisions through the Council of Australian Governments, (COAG), the Commonwealth assumed responsibility for the provision of aged care health services for all non-indigenous people aged 65 and over and all Aboriginal and Torres Strait islanders aged 50 and over from 1 July 2011.¹ As a result of that COAG agreement, government funded services provided through the Home and Community Care program (HACC) to older people, and younger people with a disability, will transition to a 'Basic Community Services for Older People' program, with service providers being paid by the Commonwealth from 1 July 2012.² The provision of HACC equivalent services for younger people with a disability will remain a responsibility of the states and territories.³

Services and funding provided by the states and territories

4.4 As identified earlier, (in chapter 3) at present there is no consistent reporting or data collection available that accurately sets out how the states and territories

1 Council of Australian Governments, *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*, 1 January 2009, p. 2.

2 Council of Australian Governments, *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*, 1 January 2009, p. A1.

3 Council of Australian Governments, *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*, 1 January 2009, pp. A1–A2.

allocate the subacute funds they received from the federal government. The committee however received evidence which suggests that although services are provided in each jurisdiction, the complexity of funding arrangements results in variations in the standard of care provided.

Victoria

4.5 Professor Rohan Vora, President of Palliative Care Australia and President-elect of the Australasian Chapter of Palliative Medicine considered that Victoria's model overall was the 'gold standard'.⁴ Palliative Care Victoria representatives spoke on the system of palliative care that is provided in that state. Like Professor Vora, they suggested it is 'perhaps one of the most comprehensive in the country':

[t]he Victorian specialist palliative care system is well supported by the Victorian State Government...In 2011-12 expenditure by the Victorian State Government on specialist palliative care services [was] around \$108 million.⁵

4.6 Palliative Care Victoria suggested that the approach used in that state, the Palliative Care Resource Allocation Model (PCRAM), which is based on a model developed by Palliative Care Australia, could be applied nationally to overcome the current disparities:

The PCRAM provides a formula for more equitable allocation of new funding based on the needs of the population within defined geographical catchment areas. PCRAM takes account of changes in the population, age structure, rurality and socio-economic status and can be used to address historical funding anomalies and facilitate greater equity in funding allocation and access to services over time. Victoria is also progressing the implementation of a service capability framework for palliative care services, which, amongst other things, articulates the roles and responsibilities of each service capability level (for inpatient, community and consultancy services respectively) to support patient care, service linkages, education and research within and across regions.⁶

4.7 Professor Vora nevertheless indicated that the excellent general model can belie significant service variations:

Even within Victoria it is very patchy. Once you then move to Queensland or other states it gets even more patchy. Metro South is very different from Metro North. As soon as you move out of Metro-anything you suddenly start thinking that maybe you have got to a rural area. It all depends.⁷

4 Professor Rohan Vora, President, Palliative Care Australia and President-Elect, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 15.

5 Palliative Care Victoria, *Submission 108*, p. 1.

6 Palliative Care Victoria, *Submission 108*, p. 3.

7 Professor Rohan Vora, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 15.

4.8 Professor Vora explained that the application of Victoria's model in other jurisdictions should be considered, as it would be one way of guaranteeing that 'wherever you are in Australia... you will get a high quality of palliative care.'⁸

4.9 Victorian Healthcare Association confirmed that a key reason for the strength of Victoria's system is not merely the quantum of funding but the delivery model:

The enablers for an efficient use of health resources arise from good governance. Victoria's devolved governance model has enabled local boards of governance to bring a community perspective to strategic decisions about health service structure and how to meet local demands with limited resources. These decisions should be based on the broad understanding of the social determinants of health and the wide range of health and community services available to address identified community needs. This has been a major strength of the Victorian health system.⁹

Western Australia

4.10 Like Victoria, palliative care services in Western Australia are well supported by government funding. Silver Chain, a Western Australian community based service provider, explained that 'probably 95 per cent or a little bit above' of its funding is provided by the Western Australian (WA) state government.¹⁰

4.11 Aged and Community Services WA described the Western Australian system, agreeing that services were of a high standard, but that the system did limit the availability of some:

Community palliative care services are provided in WA by visiting specialist teams, including Silver Chain Palliative Care and Palliative Ambulatory Services. The Ambulatory Service, funded by the WA Department of Health, can provide consultancy advisory support, on-site patient reviews and consultations regarding complex palliative care needs, and staff education services to support clinical staff in various settings including residential aged care. It is however only accessible from Monday to Friday during normal working hours.

Silver Chain in WA also receives state government and Department of Veterans Affairs funding (with additional bequests and donations), for home palliative care, and is widely acknowledged as the benchmark for quality community palliative care services.¹¹

8 Professor Rohan Vora, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 15.

9 Victorian Healthcare Association, *Submission 57*, p. 4.

10 Mr Mark Cockayne, General Manager, Health and Director, Hospice Care Service, Silver Chain, *Committee Hansard*, 5 July 2012, p. 32.

11 Aged and Community Services WA, *Submission 66*, p. 3.

4.12 Silver Chain, which now has operations in South Australia and Queensland, explained the differential they have observed between the level and standard of care in the different states in which they operate. In respect of its operations in Queensland they identified that at present community based palliative care is quite limited and the majority of services are provided through HACC:

The resources in Queensland in terms of specific community based palliative care are very limited. It is probably a differential of about 1000 per cent ...in comparison to what is provided in Western Australia. The majority of services for people in terms of the care that they are receiving is supported predominantly through HACC funding. That provides a level of nursing care and support, but probably not the level that people require at the end of life.¹²

Queensland

4.13 Silver Chain's observations of the Queensland system were echoed by Palliative Care Queensland (PCQ) which stated in its submission to the committee that:

The current situation in relation to palliative care service provision in Queensland is dire and requires immediate review and attention. Overall, the system lacks coordination at all levels:

- There is no state-wide plan for palliative care service delivery;
- Access to palliative care is inequitable;
- Services are poorly funded and inadequately resourced;
- There are severe shortages of specialist doctors, nurses and allied health staff;
- There are significant gaps in education and research at local level, and
- No Queensland specific awareness raising/community education initiatives exist.¹³

4.14 The committee acknowledges that the provision of palliative care in Queensland is currently the subject of a Queensland Parliamentary Committee inquiry. Although the committee did not receive evidence from the Queensland Government to its inquiry, the Queensland Government's submission to that current state inquiry into palliative care services and home and community care services, detailed the palliative care services the state government provides in Queensland:

Palliative care in Queensland is provided in hospital (private and public) and nonhospital environments (including residential facilities, hospices or in a person's home) via a complex service network of providers with multiple funding sources (including the State Government, Australian

12 Mr Mark Cockayne, General Manager, Health and Director, Hospice Care Service; Mr Stephen Carmody, Chief Operating Officer, Silver Chain, *Committee Hansard*, 5 July 2012, p. 38.

13 Palliative Care Queensland, *Submission 130*, p. 3.

Government and private contributions) and diverse governance structures. It is an intrinsic component of health and human service care delivery.¹⁴

4.15 The Minister explained that palliative care is provided both in the community and in the hospital (in-patient) setting and that in addition to community palliative care, specialist in-patient palliative care services were provided:

...in designated units which are located at the following hospitals: Bundaberg, Caloundra, Gold Coast, Gympie, Ipswich, Logan, Mt Isa, Redcliffe, Rockhampton, The Prince Charles Hospital in Chermside, Toowoomba and Townsville.¹⁵

4.16 The Minister also identified that in addition to the statewide paediatric palliative care service operating from the Royal Children's Hospital, palliative care is also delivered in 'non-designated areas of hospitals':

...data for 2010/11 shows that a further 18 hospitals ...also delivered services under what is termed a designated palliative care program... [a]ll remaining Queensland public hospitals provided some type of palliative care subacute service where palliative care type was the principal clinical intent [and that] Queensland Health has increased the number of admitted patient episodes for palliative care in Public Acute Hospitals by 66% since 2004/05 and non-admitted occasions of service for palliative care nearly four-fold since 2006/07.¹⁶

4.17 PCQ explained their view that remoteness and distance impact on the allocation of funding and suggested that the current bundling of funding for subacute care meant that the area was not getting sufficient money. PCQ explained that ring-fencing of palliative care is necessary to ensure adequate funding, and to prevent patients who require palliative care from ending up in the acute care setting:

When the first lot of the equivalent of NPA subacute care funds came out we knew that 99 per cent of it was spent in rehab. The next time it came out we gained probably around 10 per cent. Geriatrics, geriatric evaluation and management, and psychogeriatrics also do badly. What tends to happen is the idea is that it goes to rehab because everybody wants to get everybody better—which is fine. The problem is that not everybody does get better. So what happens to those people who do not get better? They end up taking up

14 Minister for Health, Queensland Health, *Submission 35* (to Queensland Parliamentary inquiry into palliative care services and home and community care services in Queensland), 4 August 2012, p. 3.

15 Minister for Health, Queensland Health, *Submission 35* (to Queensland Parliamentary inquiry into palliative care services and home and community care services in Queensland), 4 August 2012, p. 4

16 Minister for Health, Queensland Health, *Submission 35* (to Queensland Parliamentary inquiry into palliative care services and home and community care services in Queensland), 4 August 2012, p. 4.

acute care beds. That is where they end up: in emergency and acute care beds.¹⁷

4.18 PCQ reiterated that implementation of the Victorian approach, PCRAM, should be considered:

To go back to Victoria again, look at the Victorian palliative care resource allocation methodology. They look at population size. They look at the socioeconomic profile, the age profile and the remoteness factor. Queensland remoteness factor is a whole different ballgame again.

Those are the things you need to look at. When you block grant someone you say, 'What is your population' and all that. If that money goes to the health and hospital service, it will be spent on something. It may be spent in subacute care, but whether or not it gets spent in palliative care is going to be an issue of the transparent service agreement between the service manager and the hospital service. That is why I am saying we need to have some ring fencing or idea about how much needs to be allocated for palliative care.¹⁸

4.19 They suggested that of the current funding allocated to subacute care, 25 per cent should be dedicated to palliative care:

The last payment of subacute funding was \$327 million for Queensland... We believe that we need 25 per cent of the \$327 million... We did not get any in the last round and all we have got in this round is less than 10 per cent. It is impossible for services to keep being funded if we do not get any money federally.¹⁹

4.20 In addition to the need for ring fencing of palliative care from subacute care, PCQ also explained that the money provided under the NPCP to support community based care needs to increase as populations in service areas grow:

...there is this thing called palliative care program funding in Queensland, and that is an amount of money that is given from the Commonwealth to the states each year. We are unsure how much Queensland gets, but that money is given to all of the health service districts and used for home based palliative care. In talking to the services in each region, we can see that that money has never been increased—or at least no-one has ever seen an increase in that money. That means that you have populations that are growing by as much as 25 per cent a year and the money not growing to

17 Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, pp. 30–31.

18 Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, pp. 30–31.

19 Mr John-Paul Kristensen, Chief Executive Officer, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, pp. 30–31.

look after them... Their referral rate is growing significantly, and the money has just not kept pace.²⁰

4.21 Blue Care is one of Australia's largest not-for-profit providers of residential aged and community care, which supports community based clients, residents of aged-care facilities and families throughout Queensland and northern New South Wales. It was also of the view that Queensland's current system of funding palliative care, which involves secondary funding through hospitals, requires reform. Blue Care explained that in Queensland:

[t]here is no specific funding available for early intervention, after hours on-call services or grief recovery programs. End of life services are funded by Queensland Health and managed by the local health service districts. Community care providers, which include not-for-profit providers such as Blue Care, apply to the hospitals for funding when they determine that the person may be entering the terminal stage of their illness and within the last three months of their life. As it is difficult to determine when someone will die, people with life-limiting illnesses often receive significantly less than the allocated three months available; or, occasionally, they just run out of funding at the very end stage of their lives.

The average Blue Care hospital funded palliative admission for 2011 covered only 20 visits, which represented less than three weeks of seven days a week service. At the other end of the scale, where time until death is unpredictable, the client lives longer than the three-month time frame and funding may be ceased. Funding can often be limited to one hour of care per day. However, one nursing visit for an unstable, deteriorating or terminally palliative client can take up to three hours. Personal care, domestic assistance and allied health services and respite support are often not funded.²¹

South Australia

4.22 The South Australian government funds palliative care using a casemix approach:

All inpatient activity is funded as sub-acute on the casemix funding model using the diagnostic related group codes. All out of hospital (community) and outpatient activity is currently funded through weighted outpatient occasion of service.

As a result of implementing the [*South Australian Palliative Care Services Plan 2009-2016*], sub-acute funding is now being directed to expand the community based component of palliative care services and is enabling

20 Mr John-Paul Kristensen, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, pp. 30–31.

21 Mrs Marie Robinson, Community Care Adviser, Blue Care, *Committee Hansard*, 2 July 2012, pp. 1–2.

increased numbers of people, if they choose, to remain at home at the end of their life.²²

4.23 At the committee's hearing in Adelaide, The South Australian Department of Health provided an overview of their palliative care program:

SA Health has fostered a very solid framework for palliative care on two fronts. One was the launch of the statewide Palliative Care Services Plan, which runs from 2009 to 2016.

Also, the development and endorsement of the clinical network for palliative care came into effect in February 2010 to support the plan, which provided a whole lot of strategies around how we can move palliative care forward, taking into account the ageing population and the factors that we are going to have to deal with as we move forward.

...[W]e have had to rework the way in which business is done, moving away from local palliative care services towards regional palliative care services, with greater requirements to partner with country services in particular. This is so that the choice of people who want to die at home can be realised, so that they have services that are equipped and able to provide the care that they need.

The structure of the palliative care plan looked at palliative care services in terms of their levels of expertise and what they offer. They were designated as level 6, level 4 and level 2, which kind of correlate with Palliative Care Australia's level 3, 2 and 1 services. So you just multiply those levels by two and you get the equivalent. Level 6 services are full tertiary palliative care services, regionalised with requirements to be engaged in providing research evidence and input into the education programs across the undergraduate and postgraduate curriculums as well as primary health care. They support level 4 services, which are largely based in the peri-urban parts of Adelaide but are now also in four of the major country hospitals—Whyalla, Port Lincoln, Riverland at Berri and Mount Gambier.

They would then have a responsibility, as their capacity builds, to invest in services to support the smaller services that exist out there, like in Kangaroo Island or out on the Eyre Peninsula, where the distance and remoteness is quite a factor. There has been a clinical network to support the rollout of this plan. The clinical network, until very recently, was largely the palliative care clinicians... We have broadened that out to include our community partners so that district nursing, domiciliary care and Indigenous health will be represented at the steering committee level. It will be broadened out so it really works with partners' right across the whole healthcare arena.²³

22 South Australian Government, *Submission 27*, p. 5.

23 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 22.

4.24 Unlike the 'dire' situation in Queensland,²⁴ the committee heard from stakeholders that the palliative care services being provided in that state were effective.

4.25 Silver Chain was complimentary in the observations it made of the South Australian system in which they now operate:

Community based care is predominantly a nursing led service, with support from the in-patient environment and consultancy services that feed back into the community ... the difference with that model is that it has a very clear focus on beds and consultancy services and outreach then into the community. So the expertise sits in those environments in trying to outreach back into the community, rather than being based in the community itself, and giving true community based solutions to the problems that arise for people at home.²⁵

4.26 Professor Vora considered that elements of South Australia's system based on their palliative care plan are admirable.²⁶ Similarly, Resthaven, which employs approximately 4,000 staff, has 1,000 residential beds and supports 'around 7,000 people a year and around 3,000 people at any given time',²⁷ explained that in South Australia, the expert and specialist care and intervention that is required for palliative patients 'is not directly funded into the aged-care system' but relies instead on 'good relationships with the public health system' which is a responsibility of the state government.²⁸

4.27 Resthaven went on to explain this situation to the committee suggesting that it was this systemic issue that needed to be recognised – the fact that there are no 'natural linkages' between aged care and specialist palliative care as aged care is 'predominantly outsourced by governments to the non-government sector, whereas predominantly the funding for any form of specialist palliative care service is retained within the public system.' In South Australia this care is provided through community palliative care teams, staffed by public sector employees:

The natural connections in the system are with the health system, not with the aged-care system. We have very good relationships with some general medical practitioners who have taken a special interest in palliative care, but there are not a lot of general medical practitioners who are in that space.

24 Palliative Care Queensland, *Submission 130*, p. 3.

25 Mr Mark Cockayne, Silver Chain, *Committee Hansard*, 5 July 2012, p. 38.

26 Professor Rohan Vora, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 15.

27 Ms Susanne McKechnie, Executive Manager, Community Services, Resthaven Inc., *Committee Hansard*, 5 July 2012, pp. 9–10.

28 Ms Susanne McKechnie, Resthaven Inc., *Committee Hansard*, 5 July 2012, p. 10.

That definitely makes a difference to how easy it is for aged-care staff to effectively manage an individual who has high palliative care needs.²⁹

New South Wales

4.28 NSW Health explained that at present in that state palliative care services 'are provided at primary, specialist, and paediatric care levels, within both metropolitan and rural service models':³⁰

Primary palliative care services cover the continuum of care for all people who are experiencing a life limiting illness with little or no prospect of cure. This service incorporates general practitioners, community nurses, allied health staff, and other specialist services such as oncology and aged care professionals, working in the community, residential aged care or acute care facilities. These professionals may have existing relationships with the patient, or be providing interventional care in conjunction with more palliative approaches.

Specialist palliative care services include clinicians with recognised skills, knowledge and experience in palliative care. This level of service is appropriate for patients with a life limiting illness whose conditions have progressed beyond curative treatment, or patients who choose not to pursue curative treatment. Specialist teams include Directors of Palliative Care, medical practitioners with qualifications in palliative medicine, clinical nurse consultants with qualifications in palliative care nursing, palliative care nurse practitioners and social workers with experience in palliative care. Formalised bereavement support and pastoral care is also provided within the specialist team.

Palliative care services in metropolitan NSW Local Health Districts typically include patient beds in acute or sub-acute public hospitals or in a third schedule hospital, inpatient consultations, and community medical and/or nursing services. In rural Local Health Districts palliative care services comprise nursing services, fly in/out doctors are funded through the Medical Specialist Outreach Assistance Program. Inpatient beds are provided on a clinical needs basis. There are particular challenges for rural and regional palliative care services where there is no locally based specialist medical palliative care service. To attempt to address this shortfall medical specialists from metropolitan Local Health Districts make regular visits to some regional/rural areas.

Specialist paediatric palliative care is provided by metropolitan Children's Hospitals, each offering an integrated palliative care service in the home, hospital and respite/hospice care through the NSW statewide children's hospice.³¹

29 Ms Susanne McKechnie, Resthaven Inc., *Committee Hansard*, 5 July 2012, pp. 9–10.

30 New South Wales Health, *Submission 71*, p. 2.

31 NSW Health, *Submission 71*, p. 2.

4.29 In its submission to the inquiry New South Wales Health (NSW Health) informed the committee that it is in the process of mapping 'palliative care services against population needs and investigat[ing] appropriate palliative care population planning tools used in other jurisdictions to assist in future service planning' to ensure that adequate services are provided across the state.³²

4.30 Despite NSW Health's statement that palliative care is currently being delivered at all levels to all parts of the state, palliative care service providers operating in the state suggested to the committee that funding from the state government was lacking.

4.31 HammondCare is a service provider specialising in dementia care, palliative care, rehabilitation, older persons' mental health and other health and aged services. It explained that, although demand for services had increased, funding from the NSW state government had not:

Sub-acute funding from the NSW Government for inpatient palliative care services has not kept up with demand. Activity targets for sub-acute hospitals have remained unchanged for too long, despite an increase in the number and acuity of palliative care patients as the population ages, and there is no mechanism for adjusting ongoing funding to meet these challenges.³³

4.32 HammondCare told the committee that over the past three years they had increased the number of palliative care beds at their facility by '47 per cent' yet had not received any additional funding to support the extra services. They also suggested that there is a need for government funding to be provided for capital works in addition to operational expenses:

...the funding that is available only covers operational costs, with no provisions for construction work or building depreciation. An additional source of funding in this area is crucial, given that the National Health and Hospitals Reform Commission (NHHRC) identified sub-acute services as the 'missing link' in the health system and called for a "major capital boost" for these facilities.³⁴

4.33 HammondCare suggested that the bundling of COAG funds for palliative care into the subacute care category was resulting in less funds being allocated to palliative care:

In NSW, COAG funding intended for sub-acute services is distributed varying through local health districts (LHDs), limiting the scope of

32 New South Wales Health, *Submission 71*, p. 1.

33 HammondCare, *Submission 41*, p. 3.

34 HammondCare, *Submission 41*, p. 3.

services that specialist affiliated health organisations (AHOs) are able to deliver to people living in their own homes or in residential aged care.³⁵

4.34 Like HammondCare, the Bega Valley Community Health Service (BVCHS), located in the Bega Valley Shire with a population of 30,060 and covering 6,052 square kilometres,³⁶ were also concerned that state government funding for palliative care was inadequate. They explained that primary level palliative care funding is provided through a mixture of general funding mechanisms including general practice rebates, public hospital and community health budgets, residential care subsidies and community services funding. They were concerned that funding received for enhanced primary palliative care services under the Commonwealth's NPCP:

...is inadequate and is unable to meet the present and future palliative care demand. Currently, this funding is used locally to fund the part time Palliative Care Registered Nurse position and provide a weekend generalist community nursing service for people requiring palliative care.³⁷

4.35 The BVCHS explained that it provides services through two general district hospitals as well as through a variety of nursing and allied health professionals.³⁸ As the majority of its staff are employed on a part time basis, including the specialist palliative care registered nurse, the BVCHS informed the committee that any future additional funding would:

... best be directed towards service support aimed at meeting the often complex psychosocial needs of people requiring palliative care [and a] suitably qualified professional such as a Social Worker, Counsellor or Psychologist could be employed to fulfil this role.³⁹

4.36 The Hunter New England Local Health District Palliative Care Clinical Stream informed the committee in its submission that due to the fragmented approach to data collection and inconsistencies in reporting palliative care services, it is difficult for service providers to make a case for additional palliative care funding.⁴⁰

Tasmania

4.37 The Tasmanian Department of Health and Human Services (TDHHS) in their submission to the inquiry informed the committee that following a 2004 state government commissioned review of the provision of palliative care, they had been working on implementing the recommendations which the review made. The Model for Palliative Care service delivery was developed as a result of the review and is now

35 HammondCare, *Submission 41*, p. 3.

36 Bega Valley Community Health Service, *Submission 120*, p. 1.

37 Bega Valley Community Health Service, *Submission 120*, pp. 4–5.

38 Bega Valley Community Health Service, *Submission 120*, pp. 4–5.

39 Bega Valley Community Health Service, *Submission 120*, pp. 4–5.

40 Hunter New England Local Health District Palliative Care Clinical Stream, *Submission 6*, p. 3.

in use in the three Tasmanian Area Health Services.⁴¹ The TDHHS explained that although the three Area Health Services operate independent palliative care services they have a consistent approach and meet monthly to 'facilitate good networking and problem solving between services.'⁴²

4.38 In its submission to the inquiry, the Tasmanian Association for Hospice and Palliative Care Inc. informed the committee that of the areas requiring additional funding identified in the 2004 Review, although progress has been made, more needs to be done in terms of 'designated palliative care beds across the State' and the palliative care workforce which is still experiencing a shortfall.⁴³

Committee comment

4.39 The evidence received by the committee on state and territory funding was limited. However, there were recurring themes in the evidence. First and foremost was concern about the lack of data about palliative care service provision and expenditure, particularly as a component of sub-acute care in hospitals. This makes it difficult to determine whether services are being appropriately provided.

4.40 Other themes included whether funding was for services at the appropriate level and for round-the-clock care; whether funding growth was matching service demand; and the consistent message, noted in other chapters of this report, that the funding and delivery of palliative care as part of sub-acute health care was not efficient, whether considered from a funding or a service delivery perspective.

4.41 The committee is concerned by the level of variation in the standard of care being provided. Given the differences in service models and demographics between jurisdictions, a one-size fits all approach to funding and the provision of care may not be appropriate. Nevertheless, the current variability appears undesirable. The committee acknowledges the work going on at COAG, and in individual states such as Western Australia (which took a new approach in 2008), in South Australia, and the current review in Queensland. These are positive signs that palliative care funding and delivery is getting attention from policy-makers. The challenge will be to translate this attention into adequate resourcing, effective team-based care, and sufficient support outside hospital care, both to ensure efficient use of funds, and effective support of people's wishes to 'die well' and, often, to die at home or in an appropriate non-hospital setting.

4.42 In later chapters, the committee looks at some of the problems – and solutions – that will help address these issues, such as workforce planning, service delivery models and case management. However, the committee first considers the role of the largest workforce in palliative care: carers.

41 Tasmanian Department of Health and Human Services, *Submission 22*, p. 3.

42 Tasmanian Department of Health and Human Services, *Submission 22*, p. 8.

43 Tasmanian Association for Hospice and Palliative Care Inc., *Submission 116*, pp. 2–3.

Chapter 5

Carers

5.1 This chapter will examine the valuable role played by carers in the palliative care environment, the support currently offered to them from government and other sources, as well as how existing services such as respite care, counselling, bereavement support and information services could be improved. The chapter will also consider some issues around recognising the work of carers in palliative care funding models.

The valuable role of carers

5.2 Carers of people receiving palliative care make up a significant part of the palliative care workforce. They are in a sense separated from the professional palliative care workforce because they are often unpaid, untrained volunteers who are also usually close family members of patients. The work undertaken by carers goes largely unseen and unrewarded by society. The committee heard that this lack of recognition of the vital role of carers was reflected in the absence of well-coordinated support and funding arrangements which would be beneficial to carers and the challenges they face.

5.3 Palliative Care Australia noted that:

Regardless of the place of death, it is estimated that up to 90% of people in the terminal phase of a life threatening illness spend the majority of their time at home supported by a carer.¹

5.4 The Eastern Palliative Care Association (EPC) described carers as 'the lifeblood of community palliative care'. Ms Jeannette Moody, Chief Executive Officer of the EPC, told the committee:

Without carers, the care of the person with a terminal illness cannot be managed at home. Carers can be partners, family, friends, neighbours, church groups or local tennis clubs—in fact, any person you see as being able to provide support, help and assistance at your time of need. As I have stated in my submission, care for the carer is critical to people being able to die in their place of choice...

Many of our carers, particularly co-resident carers, are older themselves. If we have an 80-year-old client who has a terminal condition and lives with a partner, that partner is likely to be pretty much the same age. The carers themselves may have a chronic illness. For Eastern Palliative Care, 60 per cent of our clients have a co-resident carer and another 10 per cent have a non-resident carer. Just under 26 per cent of our clients have no carer whatsoever, and that is a huge proportion and a great worry for us. The

1 Palliative Care Australia, *Submission 98*, p. 139.

options available to these clients are very limited, unless they can afford to pay a live-in carer.²

5.5 Noting that a lot of palliative care and aged care is provided by a non-remunerated older workforce, Mr Trevor Carr, Chief Executive of the Victorian Healthcare Association, stated there would be some challenges into the future around workforce availability:

As we all live longer and live longer more healthily we are also more likely to work longer ourselves, so that is likely to create a deferral of opportunity for people to engage in volunteerism. Some of these elements certainly need to be taken into consideration in looking at where the hours of care are provided to these sorts of services and who is providing it.³

5.6 The committee notes that an ageing workforce should not be seen as only posing challenges, but also opportunities to harness the wisdom and experience of older people who take on the role of carer.

5.7 Ms Moody emphasised that carers themselves undergo a great deal of change in their own lives as part of the experience of caring for someone with a terminal illness. Carers experience:

...the reality that the person they care for is going to die, the dynamics of having to provide 24-hour care and the sense of loss and grief that they are experiencing.

Carers must be supported by all levels of the community and government. The need for registered nurse respite is critical to assisting carers to manage as death comes closer. Physical care at end of life can be very complex, with medications, turning and continence issues. Carers need to be able to access out-of-hours support and assistance as they need. Eastern Palliative Care has out-of-hours services, triage and visits by nurses as needed. We encourage clients and carers to ring if they have any inquiries—we actually encourage them. We do not say to them, 'Only use us as an emergency service;' we actually encourage them. The more we can keep them comfortable at home, the better for them.⁴

The challenges faced by carers

5.8 Carers are usually individual family members, an caring is a role frequently taken on by a partner, parent or child. As carers shoulder these responsibilities, pressure and exhaustion can easily build up and affect both the carer and the person being cared for, despite carers' genuine preference and desire to care for the person themselves.

2 Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 1.

3 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 14.

4 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 1.

5.9 Ms Brynnie Goodwill, Chief Executive Officer of LifeCircle Australia, noted that knowledge of how to support people with palliative care needs used to be more prevalent throughout whole communities:

There are still communities where this is normal course of business—someone gets sick and everybody rotates and looks after them. People know where to turn to get support from the community, whether it is practical like who can mow the lawns, because everyone is too busy, or who can do the grocery shopping or which palliative care, if there were a palliative care helping, who could help out to do this sort of looking after somebody at the very end and provide support.⁵

5.10 The EPC noted that the presence of carers was crucial to be able to supplement specialist palliative care services. For example, regarding pain relief medication, the EPC explained:

We will not visit and provide injections for medications if there is no-one to stay with the client for at least four hours after that medication. We cannot leave a client unsupervised during this time and we do not have the resources to stay with them. So if they do not have a carer we cannot provide that service.⁶

5.11 The committee also heard that people generally still want to provide care at home but that there are also caveats on the capability to do this, such as practical limitations:

One of the caveats is that between seven and nine per cent of people cannot identify a primary care giver—not theoretically but as they face a life-limiting illness. Secondly, many people say, 'I'm really happy to look after you at home while ever I can,' or, 'I'm happy to look after you at home, but if you become unconscious that's just not going to be a time that I can continue that care.' The third caveat is the practical issues of home based care.⁷

5.12 Professor David Currow, Professor of Palliative and Support Services at Flinders University, emphasised to the committee that the experience of caring for someone with a terminal illness should not be 'romanticised':

For a spouse to look after their partner and have to come home to that same double bed that night as the only place in the house to sleep when someone has died there earlier in the day is not to be underestimated. The number of hats that any person can wear at any one time is finite. To be nurse, cook, cleaner, bottle washer and everything else and then try to be friend, confidant and lover is just not possible for many people. In fact, the

5 Ms Brynnie Goodwill, Chief Executive Officer, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 53.

6 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 1.

7 Professor David Currow, Professor of Palliative and Supportive Services, Flinders University, *Committee Hansard*, 2 July 2012, p. 64.

transition to inpatient care at times allows for conversations that just have been blocked out by the busyness of 24-hour care, seven days a week.⁸

5.13 Professor Currow also told the committee that the ageing population would pose challenges for the provision of home-based care. In the next fifty years, there will be many more people living alone who simply may not have a person to take on the role of primary care giver if required. He noted that having someone who identifies as a primary care giver is the most important predictor of home-based care.⁹

5.14 The committee also discussed with Professor Currow the issue of carers' expectations when faced with the reality and difficulty of providing care:

Senator SMITH: ...I thought that your comment at the beginning about romanticising palliative care at home was very powerful.

Senator BOYCE: I do not imagine that anyone who has ever done it has romanticised it, though.

Prof. Currow: No. But when we poll people in Macquarie Street everyone says that they want to die at home. What is the reality of that? We have looked at it longitudinally. We have watched people's decisions change. It is for the practical stuff. It is not that services are not available—

Senator BOYCE: Bed pans.

CHAIR: If you ask people their opinion about caring for someone dying at home, do you get different responses?

Prof. Currow: We ask them quite separately. We ask the person with the life-limiting illness. At a separate time, out of earshot, we ask the carer. The answers do not always line up. It is not as though the patient is always going to say, 'Yes, I wanted to stay at home,' and the carer is always going to say, 'Yes, I want to look after this person at home.' It is far more complex than that. As we think about policy, there is a tendency at the moment to say that home death is a good death while institutional death is a bad death. That changes so easily into the idea of us having to put funding models in place to enable that. That is a huge cost shift.¹⁰

5.15 Professor Katherine Clark of Catholic Health Australia observed the urgent need for appropriate palliative care services to encompass the carer's needs at the same time as those of the patient. She noted that not providing adequate support to carers has 'public health implications for bereaved Australians' and that 'there is significant morbidity associated with being a carer'. Professor Clark also stated that the carer's role is one that 'a number of people who have been carers are choosing not to take on again, because the implications are so significant'.¹¹

8 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 64.

9 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 64.

10 Senator Dean Smith, Senator Sue Boyce and Professor David Currow, *Committee Hansard*, 2 July 2012, p. 70.

11 Professor Katherine Clark, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 35.

5.16 The Cancer Council NSW and LifeCircle's submission also noted that caregiving is often associated with a negative impact on financial security and wellbeing, as the primary caring role reduces a person's chances of being employed, or they may have to work fewer hours or be employed in a lower paid job. The submission also noted that over half of primary carers report a government pension or allowance as their principal source of income.¹²

5.17 Associate Professor Rohan Vora, President of Palliative Care Queensland, acknowledged the risks of stress, depression and burn-out for carers. He noted that for many ageing carers, a key question that the health system faces is: 'At what stage does the other person become a patient, and do they really have the ability to care?'¹³

5.18 Carers NSW summed up the challenges that carers encountered and also highlighted the importance of recognising and acknowledging in practical ways the rights and unique role of carers:

The role of caring for a person with a life limiting illness and providing care for someone nearing end of life can be both deeply rewarding and extremely challenging, and carers require support themselves in order to sustain this role. Carers deserve recognition for their work and respect for their knowledge and experience.

Carer recognition is especially important in palliative care, as often carers of people who are dying feel disempowered and undervalued in their role as a carer by the health services and professionals they are dealing with.

...The Commonwealth *Carer Recognition Act 2010* and the National Carer Strategy provide a national framework for improving the rights and recognition of carers in Australia. In line with the principles of the *Statement for Australia's Carers*, carers 'should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.' With consent from the patient, services and health professionals must work in partnership with carers in order to ensure the best possible outcomes for the patient, must respect the relationship between carers and the persons requiring care, and must recognise the unique knowledge of carers.¹⁴

National Carer Strategy and other government support for carers

5.19 The National Carer Strategy, launched in August 2011, sets out the Commonwealth Government's plans to provide better support for carers and included the announcement of \$60 million in new funding over four years. The Strategy has the support of all state and territory governments. 'Carers' are defined under the Strategy as 'people who provide personal care, support and assistance to people with a

12 Cancer Council NSW and LifeCircle, *Submission 83*, p. 5.

13 Associate Professor Rohan Vora, President, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 30.

14 Carers NSW, *Submission 61*, p. 2.

disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age'.¹⁵

5.20 Some of the new funding announced under the National Carer Strategy will support the following initiatives:

- \$10.3 million to continue the Carer Adjustment Payment, a one-off payment for families who, following a catastrophic event involving a child aged 0-6 years, need additional support to cater to the needs of their child;
- \$2.9 million to improve access to the Carer Supplement for carers who are working when the Supplement is paid in July each year, which will help carers to maintain paid employment;
- \$2.1 million to ensure fairer access to Bereavement Payment, which will provide some assistance to carers receiving Carer Allowance and an income support payment at the difficult time following the death of the person they are caring for; and
- \$1.6 million for a national and targeted campaign to raise awareness of the role of carers.¹⁶

5.21 The Commonwealth Government also noted its support for Australia's carers through some of the initiatives set out below:

- Australia's first national Carer Recognition legislation;
- increases to the Carer Payment delivered in 2009, now worth \$128 extra per fortnight for singles on the maximum rate and \$116 extra for couples combined on the maximum rate;
- a permanent \$600 annual Carers Supplement; and
- a simpler and fairer assessment process for Carer Payment (child) and Carer Allowance (child).¹⁷

5.22 As part of its aged care support package announced in April 2012, the Commonwealth also committed \$54.8 million to help carers access respite and other

15 Commonwealth of Australia, National Carer Strategy, p. 13
http://www.fahcsia.gov.au/sites/default/files/documents/06_2012/national_carer_strategy.pdf
 (accessed 20 September 2012).

16 The Hon Jenny Macklin MP, Minister for Families, Housing, Community Services and Indigenous Affairs, Senator Jan McLucas, Parliamentary Secretary for Disabilities and Carers, the Hon Nicola Roxon MP, Minister for Health and Ageing, 'National Carer Strategy launch', media release, 3 August 2011 <http://www.jennymacklin.fahcsia.gov.au/node/1198> (accessed 20 September 2012).

17 The Hon Jenny Macklin MP, Minister for Families, Housing, Community Services and Indigenous Affairs, Senator Jan McLucas, Parliamentary Secretary for Disabilities and Carers, the Hon Nicola Roxon MP, Minister for Health and Ageing, 'National Carer Strategy launch', media release, 3 August 2011 <http://www.jennymacklin.fahcsia.gov.au/node/1198> (accessed 20 September 2012).

support.¹⁸ It appears that the support for carers announced in this package covers carers of people who are over 65 or who have a disability. This may include people in these groups who have terminal or life-limiting illnesses and who may be receiving palliative care.

5.23 Palliative Care Victoria's submission also outlined to the committee the Victorian Government's support for carers:

In the 2011 Victorian Budget, the \$34.4 million in new funding allocated over 4 years included \$500,000 additional funds to be added to existing flexible funding to support the specific needs of carers with costs of caring such as respite, equipment, and other out-of pocket caring expenses. The funding also covers improved after-hours support for carers across all regions, drawing on the findings of several successful regional pilots and feedback from carers on the need for improved access to support outside usual business hours.¹⁹

5.24 Palliative Care Australia's submission made comments regarding Commonwealth, state and territory support for carers, noting that the National Carer Strategy is:

...an integral part of the Australian Government's broader social inclusion agenda and it sits alongside and complements the National Disability Strategy. In conjunction with the *Carer Recognition Act 2010*, it forms part of the Australian Government's National Carer Recognition Framework. Within the National Carer Strategy, carers include family members, friends, relatives, siblings or neighbours, grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers. Most states and territories also have carer recognition legislation.

There is still much to be done to improve access to timely and appropriate information and support for carers by the Commonwealth and State/Territory Governments. For the most part, the strategies have been identified and articulated; the priority now is for adequate resourcing so that they can be implemented effectively. It is important that implementation is responsive to the diversity of our communities, including cultural and linguistic differences, rural and remote locations and special needs.

The Australian Government needs to ensure that the National Carer Strategy, the National Palliative Care Strategy 2010 and the National Disability Strategy are resourced so that the priorities to improve information and support for carers are addressed. This will impact on the sustainability of community based, out-of-hospital models of care, which

18 See Living Longer, Living Better – Aged Care Reform Package, Department of Health and Ageing, April 2012
<http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-aged-care-reform-measures-toc~ageing-aged-care-reform-measures-chapter4.htm> (accessed 12 September 2012).

19 Palliative Care Victoria, *Submission 108*, p. 7.

align with most people's preferences for place of death and more effective use of health resources.²⁰

Other support services for carers

5.25 The committee heard that carers of people with palliative care needs often themselves require specific assistance and support while undertaking their caring role. Different forms of support can involve respite care as well as information, education and telephone helplines. Witnesses called for improved support services for carers and families including: better access to counselling and bereavement support; additional respite support for families of children, young adults and older people with terminal illnesses; funded volunteer support programs; and high-quality training for people working in palliative care as volunteers.²¹

Respite services for carers

5.26 Many carers benefit from access to respite care as they are afforded a break from their caring responsibilities. This can involve 'in-home respite' where the carer may be 'relieved' of duties by a registered nurse, or overnight stays for the carer over one or a number of days in a place outside of the home, while alternative care arrangements are provided for the patient. The committee heard that the availability of more respite services would help to 'reduce carers' long-term stress'.²²

5.27 The urgent need for respite to be available to carers was described by Ms Jeanette Moody, Chief Executive Officer of the Eastern Palliative Care Association. She noted that professional support which allowed the carer to rest and recover was essential and often critically important for issues like medication management:

Often carers are exhausted; they just cannot go on. A client may need care every one to two hours; there is no rest for the carer. The carer needs to be relieved to have a rest knowing that looking after the client is a professional who can particularly manage medications. Often in palliative care we use medications at a very high level. It is not appropriate for a non-trained staff member to look after the client in this condition. In some states trained nurses are available for up to six nights per client to support the carer. If this was available across Australia, I am sure a number of clients would be able to be supported to die at home much more than currently.²³

5.28 Ms Moody also told the committee that sometimes families and carers need extra support during the very last few days of their loved one's life:

Sometimes that last little bit families just cannot cope with, and that is a lot to do with the exhaustion I was talking about. If we could have access to respite right up to the very end, I really seriously believe that the family's

20 Palliative Care Australia, *Submission 98*, p. 139.

21 Associate Professor Rohan Vora, President, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 25.

22 See for example Mrs Marie Robinson, *Committee Hansard*, 2 July 2012, p. 1.

23 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, pp. 2–3.

journey would be easier, the carer's journey would be easier and we would be able to have more people dying in the community.²⁴

5.29 The availability of Home and Community Care (HACC) services, sometimes believed to be only for patients themselves, is critically important for carers. Professor Jane Phillips, Professor of Palliative Nursing at the University of Notre Dame and St Vincent's Sacred Heart, Sydney, observed that palliative care policy does not necessarily articulate that 'people can only stay at home with an invisible network of people supporting them to remain there. That is unpaid carers, augmented with paid carers'.²⁵

5.30 For example, Mr Gary Coleman, whose partner, Ms Kim McCartney, has a terminal brain tumour, told the committee that through Ballarat Hospice there were trained carers available to take over from him if he needed a break from his caring role:

Mr Coleman: ...Nurses give us a call and come around once a week just to help with any medical questions or issues we might have. Everybody has been really good. We go and see the doctors in Ballarat Base Public Hospital, and, because we have been doing it for so long, they are almost part of the family. So it is all good there. Kim is now doing treatment up in Melbourne, and they are terrific up there. They give us all support. Whenever we ask them something, they have answers for us or, if they do not, they find them.

Senator MOORE: Do you feel as though the service is there for you as much as for Kim?

Mr Coleman: Yes, I do... When the nurses come around they always ask me how I am going and whether I need any respite. They say, 'If you want half a day off, we'll get a nurse to come around and look after Kim for you.' They are great.²⁶

5.31 The EPC noted that respite 'enables carers to stay focused' and that because a carer has usually been with the sick person for such a long time, they are best suited to remain as the carer 'as long as they can get backup support'. Organisations like the EPC provide specialist support, understanding and information which helps the patient stay at home for much longer.²⁷

5.32 The Commonwealth Government is providing \$1.1 billion over five years for the National Respite for Carers program. A network of Commonwealth Respite and Carelink Centres, which are run by a variety of community organisations in

24 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 6.

25 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, Sydney, *Committee Hansard*, 2 July 2012, p. 60.

26 Mr Gary Coleman and Senator Claire Moore, *Committee Hansard*, 4 July 2012, p. 44.

27 Ms Christine Pedley, Manager, Allied Health, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 9.

metropolitan, rural and remote regions across Australia, assist carers by offering a single contact point for assistance to organise, purchase or manage respite assistance packages for carers.²⁸

5.33 Carers NSW commented that waiting for respite assistance packages to become available was sometimes difficult:

In some cases patients and carers have to wait until a care package becomes available, which could take weeks or months. One service provider explained to Carers NSW how patients and families often struggled to access the support that they had been assessed as eligible to receive due to the limited number of care packages available.²⁹

Respite for parents

5.34 Mr Richard Burnet, parent and carer of two children with terminal illnesses, appeared before the committee. He stressed the real need for respite care to be available for parents in his situation across all states and territories, acknowledging the very good existing work of Very Special Kids, who run a children's hospice in Victoria and provide family and sibling support³⁰, and the work of Bear Cottage at Westmead Children's Hospital NSW.³¹ Regarding the respite services offered by Very Special Kids, Mr Burnet said:

I do not know what other parents would do when they desperately need respite, although I do know what you would have to do: you would probably have to pay for a live-in carer or somebody like that to come and stay at your house while you go away. That is if you can afford it. With Very Special Kids it is probably \$800 or \$900 a night, as the equivalent cost, to send a child there where they are paying for having medical staff handy—and that is not cheap. They do a great job, but their share of voice in the community is in many ways lost by the breast cancers of the world or the things that are much more prevalent. So they find it hard to get cut-through to get the support from not only the community but also from the government.³²

5.35 He praised the services offered by Very Special Kids as helping to ease the caring responsibilities of him and his wife:

Because of their medication and feeding needs, we cannot leave them with family when we need to take a break, so Very Special Kids give us the

28 See National Respite for Carers Program <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-carers-nrcp.htm> (accessed 20 September 2012).

29 Carers NSW, *Submission 61*, p. 3.

30 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 27.

31 Mrs Fiona Engwirda and Mr John-Paul Kristensen, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 26.

32 Mr Richard Burnet, *Committee Hansard*, 4 July 2012, p. 38.

comfort we need that the boys will be more than looked after while we are away and they will be genuinely loved. A full night's sleep is becoming increasingly rare as Sebastian needs to be turned and often wakes up in pain, and when Charlie gets worse it will be pretty tough, so taking a break is really important for our sanity and also for our marriage.³³

Other support services for carers

5.36 The committee heard from a number of organisations whose role is to support carers.³⁴ These include LifeCircle and the Amaranth Foundation who gave evidence at public hearings. LifeCircle is a volunteer-based counselling and support organisation that is funded through organisational and individual donations and sponsorships.³⁵ Amaranth Foundation provides 'support and assistance to people living in rural communities, who are living with serious and advanced life limiting diseases'.³⁶ It has received a number of Commonwealth grants that have funded some of its work.³⁷

LifeCircle

5.37 LifeCircle explained that its primary role is to support carers of people who are terminally ill, as well as to support the family and community more broadly. Its services include a mentoring program, telephone counselling, information events and an annual conference. Its submission highlighted a number of challenges faced by carers, such as poor access to support services including 24-hour support; the need for increased access to respite care and other types of in-home support; and bereavement support.³⁸ LifeCircle's submission also provided data about difficulties faced by carers in NSW in getting access to in-home support through Home and Community Care Services.³⁹

5.38 Ms Brynnie Goodwill, Chief Executive Officer of LifeCircle, explained that their support of the carer does not abruptly end following the patient's death but continues on for 13 months⁴⁰ (past the first anniversary of death). Mentors stay involved, providing continuity:

As you would know if you have had someone near you pass away, right after the funeral everything drops off. People go back home and families

33 Mr Richard Burnet, *Committee Hansard*, 4 July 2012, p. 35.

34 Cancer Council NSW and LifeCircle, *Submission 83*; Amaranth Foundation, *Submission 105*; Carers NSW, *Submission 61*.

35 LifeCircle, Our partners <http://www.lifecircle.org.au/about-us/our-partners> (accessed 8 October 2012).

36 Amaranth Foundation, Home <http://www.amaranth.org.au/> (accessed 8 October 2012).

37 Amaranth Foundation, *Submission 105*, p. 2.

38 Ms Gillian Batt, Director, Cancer Information and Support Services, Cancer Council NSW, and Director, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 50.

39 Cancer Council NSW and LifeCircle, *Submission 83*, pp. 5–6.

40 The Eastern Palliative Care Association also provides support to the carer for 13 months after the death of the patient. See Ms Jeanette Moody, *Committee Hansard*, 4 July 2012, p. 2.

reconvene in their own circles. So the mentor stays involved all the way through. The mentor does not provide everything. They are not a trained counsellor. They may say: 'Gee, maybe it's time to see a bereavement counsellor. I can take you this far.' They will continue to look for issues and spot how the carer can best be supported through the transition period, and often carers and mentors stay connected long afterwards.⁴¹

5.39 LifeCircle explained how the hospital system is increasingly being put under pressure as the population ages and that carers should be offered better support to enable elderly and dying people to remain in their homes or in high-care facilities where family and carers can be close by. Ms Goodwill added:

So we are saying that if the healthcare system of hospitals is not going to be able to cope from a practical point of view and a financial point of view, where are people going to die, how are they going to be cared for? What LifeCircle is endeavouring to do, with tremendous support from the Cancer Council, is to actually make it possible for communities to re-engage in this whole process so that people can die at home. It could be in a retirement village, it could be in high care facility, but they have community around them and the tools and resources to be able to help that happen. With our increasing ageing population at this point it is probably a pretty realistic place to go, and other developed countries around the world are beginning to look at these models, especially the UK.

...Again, it has been identified in report after report that it is the carer who is the material piece in this picture—that, if the carer has support, stress, burnout and all of that is reduced, their access to information services changes and they are able to utilise the dollars spent in the healthcare system much more effectively. So it is creating that model that actually allows the interface between community and a healthcare model that will help provide for our ageing and our dying population at whatever age.⁴²

5.40 Ms Goodwill also explained how LifeCircle supports carers in what traditionally was a role supported by the wider community and how its telephone counsellors will speak to anyone affected by a patient's illness:

They will talk to anyone and help support them through what is happening—provide personal support, practical ideas, be an independent sounding board, someone who [has] no skin in the game. They are an independent sounding board. And they will also help you link up with local services.⁴³

5.41 The mentoring service provided by LifeCircle was spoken of highly by Mrs Oxana Paschuk-Johnson who cared for her mother who had motor neurone disease:

They matched me up with someone called Caroline, who had been through a similar process to me. She understood. Her mum had already passed

41 Ms Brynnie Goodwill, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 55.

42 Ms Brynnie Goodwill, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, pp. 53–54.

43 Ms Brynnie Goodwill, LifeCircle Australia Ltd, *Committee Hansard*, 24 April 2012, p. 53.

away. In fact, all LifeCircle mentors have been through this experience. It is something that they care passionately about and it is something that they want to give back to other people. I saw Caroline walk into the coffee shop. I took one look at her and I knew it was going to be a really good, really special relationship.

She helped me mentally, physically, emotionally and spiritually. And probably one of the most important ways she helped me with all that was through information that I could not get my hands on from anybody. At the fantastic place where my mum was, at the war veterans home, she got great care. I kept asking, when it was really towards the end of mum's life, 'What's happening? How come mum is like this? Should we send her to hospital? How come she can't breathe properly?' I asked these questions to my mentor and she said, 'Oxana, I'm going to send you a brochure about the carer's last farewell.' She gave me this document and it told me everything I needed to know. It told you what would happen with your loved one eight months out from when they pass away; what to expect; what not to worry about. It told you how to make that a good experience; what happens four weeks out and the differences in your loved one. It told you what not to worry about two weeks in, one week in, a few days, a few hours, and right up to the time they pass away.

Because I am an only child every time my mum sneezed I would worry. After being with my mentor—I could call her any time: text, phone or in person, it did not matter—I could stop worrying about what was happening with mum. I could just enjoy being with her and saying goodbye to her. It was precious. It was probably one of the best experiences I have had with my mother in all the years that I have known her. I know she loved me, but this was special. LifeCircle and Caroline—she was totally a volunteer, did not know me from a bar of soap—gave me one of the best experiences.⁴⁴

Amaranth Foundation

5.42 The committee heard from the Amaranth Foundation and its Director, Mr Gregory Santamaria, who spoke to the committee about his experience of being a five-year home carer (with his family) for his father who passed away from cancer. He described the blockages and 'miscommunication' that carers encountered within the health system:

That whole five-year journey lacked support. We do not have the disease, but we have the mental anguish that comes with dealing with the vast array of services that are available. Don't get me wrong: the department of health funds an enormous number of services, but it is very inconsistent. It is dictated too much by GPs and there is a lot of miscommunication between your specialist all the way down to a case manager. We found that the case managers worked for the family or tried their best to work for the family, but the blockage was at the GP and specialist level.⁴⁵

44 Mrs Oxana Paschuk-Johnson, *Committee Hansard*, 24 April 2012, p. 52.

45 Mr Gregory Santamaria, Director, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 33.

5.43 Mr Santamaria told the committee that the Amaranth Foundation's model of support is based on having essential information being given to carers. He described carers as having different needs to the patient and a different focus from the clinicians who care for the patient:

You are not given information to assist what you are trying to deal with, which is not the disease; it is the person. The eye is on the disease for the clinicians, but for carers the eye is on the person. That is a fundamental difference in the way we tried to access palliative care services. I must say that, for an educated family, we were very, very unsuccessful.⁴⁶

5.44 Mrs Julianne Whyte, Chief Executive Officer of the Amaranth Foundation, emphasised that support for the carer through coordination with the patient's GP was critical, especially recognition of any of the carer's mental health needs:

As part of [the Amaranth Foundation's] responsibilities to Medicare we often have to write to the GP. We have to state what some of the issues are and on many occasions we have said that perhaps the carer could do with another mental health referral, so that in the bereavement process they can access 10 psychological based therapeutic approaches.⁴⁷

5.45 Mrs Whyte also explained the support given to the carer in terms of 'bereavement training'. The Amaranth Foundation starts family conversations around bonding, grief and loss. They 'normalise the conversations' about death and after death has occurred, follow-up support is provided.⁴⁸

Information for carers

5.46 The committee notes that one of the stated priorities in the National Carer Strategy is that carers should have access to appropriate and timely information which makes it easier for them to get support.⁴⁹

5.47 The Palliative Care Outcomes Collaboration (PCOC) highlighted the CareSearch⁵⁰ website, which is funded by the Department of Health and Ageing, and is a 'one-stop web-based resource' which provides evidence-based information on all aspects of palliative care for clinicians, researchers, educators, students, health

46 Mr Gregory Santamaria, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 33.

47 Mrs Julianne Whyte, Chief Executive Officer, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 35.

48 Mrs Julianne Whyte, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 35.

49 Commonwealth of Australia, National Carer Strategy, p. 20
http://www.fahcsia.gov.au/sites/default/files/documents/06_2012/national_carer_strategy.pdf
 (accessed 20 September 2012).

50 See CareSearch, *CareSearch palliative care knowledge network*
<http://www.caresearch.com.au/Caresearch/Default.aspx> (accessed 20 September 2012).

professionals, carers, families and patients. For carers specifically it includes information on finding support and self-care.⁵¹

5.48 The PCOC's submission described CareSearch as:

...an online resource providing health professionals and patients, their carers and families with access to palliative care information and evidence. Evidence is important in quality improvement and change management as it can help services learn about what has been shown to be effective.⁵²

5.49 The Commonwealth also funds the National Carer Counselling Program, delivered through the Network of Carer Associations around Australia, which offers short-term counselling and emotional and psychological support for carers.⁵³

5.50 The committee heard however that the manner in which some patients, their carers and families are receiving information is not appropriate:

I was diagnosed with a terminal, malignant, incurable brain tumour in December 2008 and went down to the Royal Melbourne Hospital to have it removed. On leaving the Royal Melbourne, we brought home, I think, three or four show bags full of brochures on how to deal with chemotherapy, how to do this and how to do other things...

The second time ...they were sending us home and I dug my heels in this time. I said, 'I'm not going home, because last time you sent us home it was a nightmare. You sent us home with show bags full of brochures that I didn't want to look at. We had no idea where we were going, what we were doing, what would happen next and how we were going to deal with this.'⁵⁴

Bereavement services

5.51 The submission from the Cancer Council NSW and LifeCircle called for better bereavement support services, including more intensive support for those considered 'at risk of complicated bereavement reactions'.⁵⁵ It cited the findings of a survey of palliative care bereavement services:

An Australian survey of palliative care bereavement services, conducted in 2007, found that the most common obstacles to bereavement service delivery were lack of sufficient staff time (73%), funding pressures (44%), lack of personnel (35%), lack of organisational support of bereavement services (29%). The work of bereavement care was commonly co-ordinated by a nurse, often on top of his/her other duties and in some cases it was co-

51 Department of Health and Ageing, 'The Australian Palliative Care Knowledge Network, CareSearch' <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-factsheet-caresearch-apckn>, (accessed 20 September 2012).

52 Palliative Care Outcomes Collaboration, *Submission 111*, p. 13.

53 See National Carer Counselling Program <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-carers-nrcp.htm> (accessed 20 September 2012).

54 Kim McCartney, *Committee Hansard*, 4 July 2012, p. 39.

55 Cancer Council NSW and LifeCircle, *Submission 83*, p. 7.

ordinated by a social worker. Most organisations surveyed reported that less than 5% of the palliative care budget was allocated to bereavement services.⁵⁶

5.52 Noting that the National Palliative Care Strategy 2010 includes an action area directed at ensuring that palliative care providers offer appropriate 'bereavement expression' support, LifeCircle encouraged all governments to work together with key stakeholders to establish and fund minimum levels of bereavement service provision to families and carers of people with a terminal illness.⁵⁷

Committee view

5.53 The committee was glad to hear of the high-quality support services available to carers of terminally ill people through organisations such as LifeCircle, the Amaranth Foundation and Very Special Kids. The range of services offered such as in-home support, respite, mentoring, telephone counselling and information on grief and bereavement is critically important to support carers and should make up the suite of measures for best practice palliative care provision. The committee agrees with witnesses who called for improvements in these support services for carers.

5.54 As outlined above, many carers find access to relevant information about palliative care services very difficult to locate. Mr Richard Burnet told the committee about his wife's suggestion of a 'simple website that has everything you need that you can go to, work out what your steps should be and how you should follow some sort of a process to work out who is going to help and when'. He noted that existing services, while very good, are 'disparate and all over the place'.⁵⁸ The committee notes the CareSearch website helps to address this need and encourages the provision of simple, timely and relevant information, through this website and other appropriate media, to families and carers, consistent with the aims of the National Carer Strategy.

5.55 The committee also considers that better provision of bereavement support services should also be prioritised in recognition of support for carers needing to continue after a patient's death.

Recommendation 5

5.56 The committee recommends that the government, with the assistance of the Council of Australian Governments, take steps to improve the provision and timeliness of information to palliative care patients, their carers and families. Processes should be put in place to ensure that patients, their carers and families are provided with the right amount of information, in the right format, at the right time and that a 'show bag' approach be avoided.

5.57 The committee recommends that this process begin with a review of the CareSearch website.

56 Cancer Council NSW and LifeCircle, *Submission 83*, p. 7.

57 Cancer Council NSW and LifeCircle, *Submission 83*, p. 7.

58 Mr Richard Burnet, *Committee Hansard*, 4 July 2012, p. 36.

Recommendation 6

5.58 The committee recommends that all governments work together to fund minimum levels of bereavement service provision for all families and carers of people with a terminal illness.

Other issues for carers

Carer Allowance

5.59 The committee heard comments from a number of witnesses about Carer Allowance which is a Commonwealth supplementary payment for parents or carers who provide additional daily care to an adult or dependent child who has a disability or medical condition or is frail aged.⁵⁹

5.60 If a person is caring for someone who is 16 years or older, eligibility for Carer Allowance is described as follows by the Department of Human Services:

You may receive Carer Allowance (caring for a person 16 years or over) if you:

- are looking after a person aged 16 or more who has a disability or medical condition or is frail aged and needs additional care and attention on a daily basis and
- provide the care for that person in either your home or that person's home.

You may receive Carer Allowance for up to two adults in your care.

If the person you care for goes into respite care or hospital, you can still receive Carer Allowance for up to 63 days in a calendar year when the person you care for:

- is temporarily out of your care or
- is in hospital.

[In relation to medical reviews] the person you care for will generally be reviewed every two years to check whether there are any changes to his or her medical condition.

If the person you care for has a disability or medical condition and requires high care, he or she is unlikely to have many medical reviews.⁶⁰

5.61 If a person is caring for a child under 16 years, eligibility for Carer Allowance is described as follows by the Department of Human Services:

You may receive Carer Allowance (caring for a child under 16 years) if:

59 See Carer Allowance <http://www.humanservices.gov.au/customer/services/centrelink/carers-allowance> (accessed 10 September 2012).

60 See Eligibility for Carer Allowance <http://www.humanservices.gov.au/customer/enablers/centrelink/carers-allowance/eligibility> (accessed 20 September 2012).

- you look after a child with a disability or medical condition who needs additional care and attention on a daily basis or
- care for two children with disabilities and the children do not individually qualify you for Carer Allowance (child) but together create a substantial caring responsibility and
- you live with the child (or children) you are caring for.

...You can take a number of breaks from caring, up to 63 days per calendar year (1 January to 31 December) for respite, and still be eligible for Carer Allowance.

If the child goes into hospital...you can continue to receive Carer Allowance if the child you are caring for goes into hospital, as long as you continue to provide care for the child while he or she is in hospital and you intend to resume caring for the child when he or she returns home.

...To check your eligibility for Carer Allowance, the child you care for may be required to have a medical review on reaching these developmental milestones:

- four years and eight months
- 10 years
- 13 years.

If the child's disability or medical condition is on the list of recognised disabilities, he or she will not have milestone reviews.⁶¹

5.62 The payment rate of Carer Allowance (caring for a person 16 years or over) is \$114 per fortnight. The payment rate of Carer Allowance (caring for a child under 16 years) is either a fortnightly payment of \$114 and a Health Care Card for the child, or a Health Care Card for the child, depending on the child's care needs.⁶²

5.63 Professor David Currow noted that Carer Allowance constituted a 'thorn in the side in Commonwealth paperwork' where the onus is still on the family of the patient to follow up with Centrelink for the payment to flow on after an assessment has been made by a health professional. He commented:

As we think about entitlements, we are talking about the ability to actually say, 'This person now has a life-limiting illness.' At a community level, that will be a huge shift. I think the United Kingdom, particularly England, have made that shift in the last few years, and they have started to create

61 See Eligibility for Carer Allowance
<http://www.humanservices.gov.au/customer/enablers/centrelink/carers-allowance/eligibility>
(accessed 20 September 2012). Note: the list of recognised disabilities is available at:
<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carers-allowance/guide-to-the-revised-lists-of-recognised-disabilities>.

62 See Payment Rates for Carer Allowance
<http://www.humanservices.gov.au/customer/enablers/centrelink/carers-allowance/payment-rates>
(accessed 20 September 2012).

primary-care registers, which have a whole lot of flow-on effects in terms of the entitlements for that person and their carers.⁶³

5.64 The committee also heard from Mr Richard Burnet, the father and carer of two young children with terminal illnesses, who is not eligible for Carer Allowance, although his family does receive the childcare rebate. He told the committee that if stopped working he would become eligible for Carer Allowance:

Mr Burnet: ...It would allow our costs for the full-time carers and maybe \$45,000 a year, and we would get \$15,000 of that back through the childcare rebate—\$7,500 per child.

CHAIR: But if you got the allowance you would not be able to pay for all the others?

Mr Burnet: Yes. You would pay for your carers, but I do not know what you would live on.

CHAIR: Exactly.

Senator BOYCE: I am still trying to work out how we get to the situation where we stop forcing people to become impoverished before we help them and at the same time satisfy the taxpayer that they are not supporting people to live in luxury.

Mr Burnet: Exactly. The recent news that scared the daylights out of us was the possible abolishment of the childcare rebate or having it means-tested, because that would include me. The government would not say, 'You're a special exemption because you've got disabled children.' They do not do that. That is not the purpose of the childcare rebate, but luckily for us it is the only support we get from that perspective.⁶⁴

Carer payment

5.65 Although the committee did not receive evidence concerning the adequacy of the Carer Payment, it acknowledges that monetary support is provided by the federal government to carers who are unable to work as a result of taking on that role. Such support is provided through the Carer Payment. The Carer Payment:

provides financial support if you are unable to work in substantial paid employment because you are providing full-time daily care to someone with a severe disability or medical condition, or to someone who is frail aged.⁶⁵

5.66 The Department of Human Services identifies the eligibility requirements:

63 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 68.

64 Mr Richard Burnet, Senator Rachel Siewert and Senator Sue Boyce, *Committee Hansard*, 4 July 2012, p. 39.

65 Department of Human Services, *Carer Payment* <http://www.humanservices.gov.au/customer/services/centrelink/carers-payment> (accessed 3 October 2012).

You may be eligible for Carer Payment (caring for a person 16 years or over) if you provide constant daily care in the home of the person you care for and he or she:

- is aged 16 or more with a severe disability or medical condition or is frail aged, or
- is aged 16 or more with moderate care needs and has a dependent child who either is under six or is aged 6–16 and eligible for Carer Allowance.

The person you care for must also either:

- receive an income-support payment from us or from the Department of Veterans' Affairs,
- be unable to receive an income-support payment from us or the Department of Veterans' Affairs because they have not lived in Australia long enough to be eligible, or
- meet the care-receiver income and assets tests.⁶⁶

Committee view

5.67 The committee has concerns about how families in circumstances such as those of Burnet family with terminally ill children may become vulnerable if changes to eligibility are made to Commonwealth family and carer payments in the future. The committee emphasises the need for any changes to Carer Allowance and/or the Child Care Rebate⁶⁷ to account for the special circumstances of families in these extremely difficult situations. In particular, the committee notes that any move to abolish or means-test the Child Care Rebate may have significant financial impacts on families such as the Burnets who care for terminally ill children.

Recommendation 7

5.68 The committee recommends that Government give careful consideration to the special circumstances of families caring for terminally ill children when considering future changes to the eligibility criteria for the Carer Allowance and/or Child Care Rebate.

Recognising carers in funding models

5.69 The committee heard that the activity-based funding (ABF) model for sub-acute care (coming into effect on 1 July 2013, as described in chapter seven) does not accurately reflect the nature of palliative care, nor place enough value on the role of carers. Dr Yvonne Luxford, Chief Executive Officer of Palliative Care Australia

66 Department of Human Services, *Carer Payment* <http://www.humanservices.gov.au/customer/services/centrelink/carers-payment> (accessed 3 October 2012).

67 The Child Care Rebate is not income-tested and it pays up to 50 per cent of out-of-pocket expenses for child care up to an annual cap. For the 2012-13 income year, the Child Care Rebate annual cap is \$7,500 per child per year. See Child Care Rebate <http://www.mychild.gov.au/childcarerebate/default.aspx> (accessed 20 September 2012).

(PCA), noted that an activity-based health funding model assumes that 'a service event is one patient with one clinician'.⁶⁸ The submission from PCA argued that the pricing model for activity-based funding should include an expanded notion of the 'patient' to include family and carers.⁶⁹ It explained:

The concept of the patient in palliative care is unique within the health system. In addition to the person with a terminal illness, palliative care treats and supports the family, carers, loved ones, and others. This care delivery to all related individuals, and inherent expansion of meaning of the concept of the term patient is integral to the philosophy of palliative care. It is essential that this expanded notion of a patient is recognised within the funding models.

Given that the plans for ABF indicate a service event is between one patient and one health professional, it is essential that an expanded concept of patient be applied to palliative care. PCA understands that it is already the intention of the Independent Hospital Pricing Authority (IHPA) to treat bereavement services delivered to the carer/s and loved one/s of a deceased patient as a service event, this conceptual expansion may offer a mechanism to expand the overall concept of patient in palliative care delivery.⁷⁰

5.70 PCA argued that non-clinicians such as a care worker assisting with showering or a volunteer carer who needs funding for training needs should be properly recognised within the costing model.⁷¹

5.71 Similarly, the submission from the Eastern Palliative Care Association drew attention to the problems with activity-based funding in being unable to recognise the complex contributions of carers:

Activity Based Funding in sub-acute care as proposed pays no attention to the needs of carers. As stated previously, the needs of carers are critical to allowing the clients to die in their place of choice. To only count face to face treatment with the client does not acknowledge the support needed for the carer. Work with the carer needs to be recognised and funded accordingly in the new funding system.⁷²

5.72 Associate Professor Rohan Vora, President of Palliative Care Queensland, illustrated to the committee the estimated costs of institutional care, compared to the costs of home-based care:

Prof. Vora: ...If you are talking about an acute bed in a hospital it is probably around \$1,000 to \$1,300 a day for an acute bed. We know that a

68 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 25.

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

70 Palliative Care Australia, *Submission 98*, p. 82.

71 Palliative Care Australia, *Submission 98*, p. 82.

72 Eastern Palliative Care Association, *Submission 42*, p. 4. See also Ms Jeanette Moody, *Committee Hansard*, 4 July 2012, p. 8.

palliative care bed in Queensland is costed at about \$950 a day. We know that if you go down to a step-down facility where maybe you do not have as much need for acute intervention, pain management and a whole lot of ancillary services, it is probably around \$600 or \$700 a day. And in a nursing home, as we heard before, maybe it is \$150 to \$200 a day above what is already subsidised to put in the extra care. So it all depends on where the person is.

Of course, we know that, if they are at home and looked after by a carer and want to exploit the carer and pay them nothing, it may be \$60 or \$100 a day—

Senator BOYCE: For them.

Prof. Vora: That is right—and then the carer gets stressed, depressed and all the issues that go around that, so how do we pull those costs in? You might do that and exploit all the carers. They get burnt out.⁷³

Committee view

5.73 The committee commends the work of unpaid carers around Australia who put tremendous effort and energy into caring and serving those receiving palliative care. These carers are often the very close family members and loved ones of the patients. The strain experienced by carers often goes unnoticed and the committee heard that the experience of caring is often an escalating, stressful burden which does not end when the patient dies, but continues during the time of grief and bereavement. The committee especially thanks the carers who took the time to share their experiences during this inquiry.

5.74 The committee agrees that the new activity-based funding model for healthcare should take into account the complexity of palliative care provision (that is, not just one patient and one clinician) and recognise the crucial role played by carers in relieving additional healthcare cost burdens on governments and society. Carers volunteer countless hours in the service of patients and loved ones with terminal illnesses and this contribution should be reflected in the design of appropriate funding models.

Recommendation 8

5.75 The committee recommends that processes be put in place by the Independent Hospital Pricing Authority to ensure that the calculation of activity based funding for the provision of palliative care takes into account its complexities, including the contribution of carers, and the desirability of its provision across a range of different settings.

73 Associate Professor Rohan Vora, Palliative Care Queensland and Senator Sue Boyce, *Committee Hansard*, 2 July 2012, p. 29.

Chapter 6

The professional workforce and its development

6.1 This chapter will examine the composition of the professional palliative care workforce and its ability to meet the needs of the ageing population. It will begin by considering the role of palliative care specialists, including doctors, nurses and occupational therapists. Ways to improve and support workforce education and training in palliative care, including through scholarships and funding arrangements, will be discussed. Finally the chapter will look at the scope for changes and enhancements to the current healthcare curriculum and the need to embed awareness of palliative care more broadly across the health workforce (including in general practice) will also be covered.

The palliative care workforce profile and challenges

6.2 The committee heard evidence of the need for capacity building within the palliative care workforce. The following section provides an overview of the current workforce profile, the concept of multidisciplinary teams and future workforce challenges. It also looks at different workforce roles including specialist physicians and nurses as well as occupational therapists and general practitioners.

6.3 Most information the committee received about workforce was in relation to specific professions or roles. The Victorian Healthcare Association's submission noted that 70 per cent of the total palliative care workforce was over 40 years of age and that almost 35 per cent is over 50 years of age.¹

6.4 In relation to aged care workers, Ms Wendy Porter, Residential Care Manager, Western Australia, for Aged and Community Services Australia, told the committee that the aged care workforce would need to treble over the next 30 to 40 years 'and a large proportion of that workforce will need generalist skills in a palliative approach to care'.² Ms Angela Raguz, General Manager, Residential Care for HammondCare, also commented that a shift in perception was needed to make aged care a more desirable area in which to specialise:

It is about how we get those experts to come on board and to move beyond that view: 'Oh, it's aged care—that's a bit daggy. I don't want to spend time in aged care.' For young doctors and nurses it is not the sexiest part of the industry to select. So it is about getting it within undergraduate training, looking at training people on the ground in the nursing homes across a broad scale. And it is not just about setting up distinct units, even though

1 Victorian Healthcare Association, *Submission 57*, p. 5.

2 Ms Wendy Porter, Residential Care Manager, Western Australia, for Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, p. 19.

that is an ideal. It is about lifting the bar across the whole of aged care, be it in people's homes or in facilities.³

6.5 Professor Patsy Yates, President Elect of Palliative Care Australia, told the committee that addressing workforce issues in palliative care entailed not only providing education opportunities and up-skilling the existing workforce, but also being 'bold and brave in looking at new and innovative models that might actually be more sustainable in addressing the future that we are going to face in terms of increasing demand'. For example, the role of nurse practitioners has been successfully implemented in the palliative care environment, although not yet to a consistent degree, particularly in aged and community care settings.⁴

6.6 At a public hearing, Mr Trevor Carr, Chief Executive of the Victorian Healthcare Association, also illustrated the broad challenges to the palliative care workforce profile over coming decades:

I think that in aged care and some elements of palliative care—so moving aside from the science of palliation to the emotional welfare side of palliation—there is a tremendous opportunity for people to specialise in this sort of area, just as there is for people, through TAFE VET qualified education, to specialise in home care type services. So our view is that we need to be moving towards that. There is no dataset that I have seen recently that suggests that in 20 years time we are going to have anywhere near the university qualified clinical profile that we have today, so that leaves us with two choices: either we change the models of care and the range of people providing them or we become more aggressive importers of clinicians—and generally that is not a good solution because of a range of issues, not least of which is: what does that leave in the countries that you are actually taking them from?⁵

6.7 The committee heard that the palliative care workforce needed to be based around multidisciplinary team approaches, supported by appropriate funding models. Multidisciplinary teams include specialist palliative care physicians and nurses, general physicians, general practitioners, nurses, psychologists, occupational therapists and carers.⁶ The Australian Nursing Federation described 'new and emerging roles' within palliative care teams which include palliative psychological medicine specialists, general practitioners with special interests in palliative care, caregiver network facilitators and advanced practice roles such as palliative care consultants in physiotherapy or pharmacy.⁷ The Pharmacy Guild of Australia's

3 Ms Angela Raguz, General Manager, Residential Care for HammondCare, *Committee Hansard*, 2 July 2012, p. 21.

4 Professor Patsy Yates, President Elect of Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 12.

5 Mr Trevor Carr, Chief Executive of the Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 14.

6 See Australian Nursing Federation, *Submission 85*, p. 11.

7 Australian Nursing Federation, *Submission 85*, pp. 11–12.

submission stated that community pharmacists should be integral members of all interdisciplinary palliative care teams 'as good palliative care depends enormously on teamwork and effective symptom control'.⁸

6.8 Mr Trevor Carr, Chief Executive of the Victorian Healthcare Association, argued that the multidisciplinary team approach had not been achieved due to the constraints of current funding drivers.⁹ He emphasised the 'proof of concept' around the nurse practitioner¹⁰ model for palliative care, particularly medication management:

The early conceptualisation of nurse practitioners in Australia was that nurses would have access to billing through the MBS. Whether we use that mechanism or not, we need to break down the barrier to ensure that practitioners who have clinical skills and the understanding of the drivers of the need for care for that particular care model have access to delivering and designing care for the consumer, rather than it being a professionally demarcated decision based on funding models.¹¹

Palliative care medicine specialists

6.9 The committee heard that currently there are around 160 to 200 palliative care physicians nationally,¹² although data does not indicate whether they are full-time equivalents and the estimates do vary. When asked how many palliative care physicians there should be per 100 000 population, Associate Professor Rohan Vora told the committee that the Australian and New Zealand Society of Palliative Medicine (ANZSPM) advocated a figure of one per 100 000.¹³ The Royal Australian College of Physicians estimated that the current supply of palliative care doctors was approximately half of the ratio recommended by the ANZSPM.¹⁴ Palliative Care Australia's submission stated that 1.5 palliative care physicians per 100 000 would be the preferred ratio.¹⁵

6.10 The Royal Australasian College of Physicians (RACP) gave evidence that there was an undersupply of specialist palliative care medicine physicians. Dr Leslie Bolitho, President of the RACP, commented on some of the key workforce challenges for palliative care:

8 Pharmacy Guild of Australia, *Submission 51*, p. 9.

9 Mr Trevor Carr, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

10 Nurse practitioners are registered nurses educated to a master's degree level.

11 Mr Trevor Carr, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

12 Associate Professor Rohan Vora, President-Elect, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 16, suggested around 200, and indicated that Health Workforce Australia had made a lower estimate of 162.

13 Associate Professor Rohan Vora, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 16.

14 Royal Australian College of Physicians, *Submission 29*, p. 7.

15 Palliative Care Australia, *Submission 98*, p. 19.

We have to also take into special consideration the rural, remote and culturally sensitive communities, including Indigenous health, and children and adolescent palliative care is another specific area requiring attention. We see the federal government specialist training program and the potential of tele-health's role in the training and supervision of trainees and provision of services to our patients as a step in the right direction. Many of the members of this committee will be familiar with the dual training pathways which the college is promoting in order to address underprovision of specialist services in rural areas. While this model currently focuses on general medicine paired with other specialties, there is potential that this could also include palliative care services in the future.¹⁶

6.11 Dr Yvonne McMaster, a retired palliative care doctor, described to the committee the critical and highly specialised role of palliative care physicians, who look after not only the patient's physical symptoms but a range of other complex needs:

How do you help people deal with all the practical, emotional and spiritual problems they face at the end of life? What can help when the going gets tough is regular contact with highly competent, reliable clinicians who can guide the patient on a well-trodden path—well trodden for the clinicians but new and scary for the patient. We walk the path with the person and their family, and it helps. As ANZSPM, the Australian and New Zealand Society of Palliative Medicine, say in their excellent submission to you, they 'listen to the spirit of the patient' and attend to 'the multiple fears, concerns and regrets that proximity to mortality entails'. Some doctors or nurses are able to do this on their own; many need the help of a multidisciplinary team. Palliative specialists also have a role in encouraging wise decision-making regarding appropriate practice goals: whether to persist in trying to prolong life in the face of serious side-effects of treatment or to focus mainly or wholly on improving quality.¹⁷

6.12 Dr McMaster stated that the current palliative care workforce was deeply demoralised. She described a 'tremendous contraction' in the New South Wales workforce over the last 15 years and advocated better pay as well as specific Medicare item numbers for palliative medicine to better recognise the work undertaken by specialists, which would help to attract more people into the workforce:

It has been so sad to see that services which were flourishing and people coming in were very interested to do palliative medicine are not doing as much now.

...They are not paid as well as procedural specialists of course but they can be better recognised in pay. There could be specific item numbers such as the geriatricians have. They have a very good item number for a very

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

17 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 70.

complex assessment. There could be item numbers like that for palliative medicine, because most of palliative medicine is complex assessments.¹⁸

6.13 Associate Professor Mark Boughey, Co-Deputy Director of the Centre for Palliative Care, told the committee that nationally the number of doctors wanting to train as a specialist in palliative medicine was on the rise:

The positions around Australia are increasing. As a membership, we have over 250 fellows in Australia who would be considered specialists in palliative medicine. That does not mean they are all actively practising.

We have a two-pronged approach in the training process. The chapter allows for people who have had training in any other clinical specialty to come in and retrain as a palliative medicine specialist or we can have people going by the direct route as a physician going on to be a specialist. There is also the capacity to do a six-month diploma in clinical palliative medicine. You get bidirectional training of GPs, geriatricians, respiratory physicians and other people who are in the medical arena for whom palliative care becomes important to them.¹⁹

6.14 Associate Professor Boughey also observed that for those who choose to work in palliative care, 'financial reward does not tend to factor into it'.²⁰

6.15 The committee discussed the need for paediatric palliative care specialists with Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Group. She noted that while the demand for such specialist positions was not likely to be great, she spoke of the need for a system that would be sustainable into the future.²¹

Palliative care nurses

6.16 Nurses will be the main carers for most people who are dying, regardless of care setting.²² Ms Angela Raguz, General Manager, Residential Care of HammondCare, told the committee that the aged care sector does not currently have a lot of palliative care trained nurses:

In fact, in aged care, your ratio of registered nurses to direct care staff is, in a good nursing home, one registered nurse for probably 25 residents. In

18 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 73. See also Mr Peter Cleasby, *Committee Hansard*, 2 July 2012, p. 51.

19 Associate Professor Mark Boughey, Co-Deputy Director, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 54.

20 Associate Professor Mark Boughey, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 55.

21 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 33.

22 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, Sydney, *Committee Hansard*, 2 July 2012, p. 59.

some nursing homes you may have one registered nurse looking after 70-odd residents.²³

6.17 The Australian Nursing Federation (ANF) explained the benefits of having certified specialist palliative care nurses working in the provision of palliative care. While registered nurses, within their scope of practice, can provide palliative care and can administer prescribed medicines, specialist palliative care nurses have expertise in the palliative requirements of people as they progress through their illness:

So, as far as scope of practice goes, all nurses can provide palliative care and they determine their own scope of practice. They are responsible and accountable for the care that they provide, and they would only provide care to their level of competence. So they look for support and expertise from other health practitioners where they determine that that is not their scope of practice any further. Where we have nurses who have qualifications in palliative care, they are providing a greater level of care according to their competence, right up to the point where they are a nurse practitioner.²⁴

6.18 Ms Catherine Pigott, Member of the ANF, explained the role of specialist palliative care nurses further, particularly in providing information to the family of the patient about what is happening and why:

Some of the things that we would be doing around medication in particular would be providing information to the patient and the family about why that medication has been started—particularly around morphine; people have a number of different myths about morphine, so it gives them information about why they might be on morphine—what we are doing, why we have changed it from perhaps oral medication to syringe driver medication, what is happening with the person, why things might be changing and why we might be having a different type of medication or perhaps no medication. We would add an adjuvant medication if they have a different type of pain. That is what the nurse's role is: to talk to the patient, and particularly the family, about what is happening with the person, why things are changing, where we are going, what to expect and what sort of side effects to look for when we administer the medication—because people might be a little bit nervous if we give them some morphine, but in fact what is happening, of course, is that their body is deteriorating and that is what they are dying from, not from an overdose of morphine. So it takes a lot of education, a lot of information provision and a lot of family support for us to be able to do that, and that is where your specialty nurse knowledge comes in particularly.²⁵

23 Ms Angela Raguz, HammondCare, *Committee Hansard*, 2 July 2012, p. 21. See also Palliative Care Nurses Australia, *Submission 45*, p. 5.

24 Ms Julianne Bryce, Senior Federal Professional Officer, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 37.

25 Ms Catherine Pigott, Member, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 37.

6.19 The ANF told the committee that there were slightly in excess of 330 000 nurses and midwives in Australia²⁶; however, the ANF also stated it was difficult to estimate the numbers of nurses with palliative care qualifications in the Australian workforce. This was because there is no regulatory requirement to have a palliative care qualification to be able to work in the area:

Ms Pigott:...It is a similar thing to cancer nursing in that people can say that they are a specialist palliative care nurse, but that does not necessarily mean they have the education completed...

Ms Bryce: Some obviously have experience from having done further education in continuing professional development. Others have a formal postgraduate qualification up to master's level. So there is quite a variance in the preparation for working in the area of palliative care. There is no regulatory requirement to have a palliative care qualification in order to be able to work in palliative care, because there is such a range of care that is provided.

Ms Coulthard: Good basic general nursing care is palliative care, so the specialist add-on of knowledge of medications and knowledge of specific clinical care for palliative care does not deny that most nurses are already able to provide good palliative care. There is also a range of nurses who have developed good clinical skills through clinical work and who have had very little extra training or education.

Senator MOORE: But there is no regulation.

Ms Coulthard: No.²⁷

Occupational therapists

6.20 The committee also heard from occupational therapists who described their role in palliative care as a 'newer' development. Their focus is 'looking at how people actively live until they die'.²⁸ This includes self-care activities such as showering and dressing, home and domestic duties, community activities, work and leisure/recreational activities.²⁹ According to Ms Deirdre Morgan, Senior Occupational Therapist, Palliative Care for Peninsula Health:

Palliative care was developed initially as a service to provide terminal care. With advances in health care and people living for longer now, people have palliative care for a much longer period of time. They are living for much longer with impaired function, much longer at home with families, where

26 Ms Julianne Bryce, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 39.

27 Ms Catherine Pigott, Ms Julianne Bryce, Ms Robyn Coulthard, Member, Australian Nursing Federation, Senator Claire Moore, *Committee Hansard*, 24 April 2012, p. 36.

28 Ms Deirdre Morgan, Senior Occupational Therapist, Palliative Care, Peninsula Health, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 17.

29 Occupational Therapy Australia, Victoria Division Oncology and Palliative Care Services in Australia, *Submission 59*, p. 2.

the burden is greater. So we are newer in the palliative care sphere partly because of the changes and medical advances.³⁰

6.21 Some of the main workforce issues raised with the committee by occupational therapists were:

- the lack of community occupational therapists in most community palliative care services;
- the current workforce structure having a medical, nursing and supportive care focus, influenced by symptom control and psychospiritual support, with less of a focus on enabling people to participate in everyday activities; and
- a distinct lack of broader allied health input to provide holistic care including physiotherapy, speech therapy, social work and psychology.³¹

The rural workforce

6.22 The committee heard that getting enough palliative care staff to work in rural and regional areas was always going to be a challenge. Dr Yvonne McMaster advocated a scheme which would create incentives for palliative care specialists to practise in rural areas:

I believe that we could really do something dramatic in the country if we advertised overseas and got people in the rural towns. They would then have to have a rotating registrar coming from city practices backwards and forwards every term, and all those young doctors doing palliative medicine would have the experience of country life because attracting people to the country has been hard.³²

6.23 Professor Katherine Clark of Catholic Health Australia emphasised the need for hubs of palliative care specialists to ensure there is adequate care and support right across Australia:

We cannot have specialist hospices and specialist clinicians in every small hamlet across Australia. Our country is too vast and our population is too sparse. We cannot have that, so we need formalised agreements between different parts of Australia and we need to ensure that the hub is upskilled and adequate enough to provide support that does not become burdensome to that unit, so we can promise care to all Australians who require it.³³

6.24 Similarly, Mr Peter Cleasby, President of Palliative Care New South Wales, stated that it was unrealistic to expect a palliative care specialist to be available in every country town or even major regional town. However, he outlined to the

30 Ms Deirdre Morgan, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 17.

31 Occupational Therapy Australia, Victoria Division Oncology and Palliative Care Services in Australia, *Submission 59*, pp. 4–5.

32 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 73.

33 Professor Katherine Clark, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 35.

committee some concerns about the availability of palliative care doctors, despite the presence of excellent palliative care nurses servicing rural communities:

We have struggled in New South Wales. There was a time when we had one specialist trained palliative care doctor outside the Newcastle-Sydney-Wollongong metropolitan basin; there was only one for the rest of the state and she was up in Lismore. There are now two between Newcastle and Lismore and there is no-one west and there is still no-one south. So specialist palliative care physicians in regional and rural New South Wales is a significant issue still not addressed. That is part of our major workforce issue. In most of those rural and regional areas we currently have fabulously experienced and appropriately trained specialist palliative care nurses doing a great service. There are limitations to their services. As the presenter in the session before us said, nurses cannot prescribe so they have to rely on another prescriber to accept the thoughts that they are offering and to act upon them. Those rural nurses, who are, as I say, the backbone of good palliative care in those areas, have themselves expressed concern about succession planning. Many of them are older, nearing the end of their career, and the system is not allowing opportunities for people to be trained up to replace them. That is a major concern in New South Wales about how one is going to go about doing that when budgets are so tight.³⁴

The role of general practitioners

6.25 The committee heard views about the role of general practitioners (GPs) in palliative care. As primary care physicians, the role of the GP has changed significantly over time. Gone are the days when home visits and after-hours consultations were commonplace. Dr Yvonne McMaster said the expectations that GPs become heavily involved in end-of-life care were too high as they are so busy.³⁵

6.26 Ms Angela Raguz, General Manager, Residential Care for HammondCare, commented that 'we do struggle to get GPs who have the knowledge and the expertise to be able to deal with people at the end of their life well'.³⁶ Dr McMaster also made the observation:

A proportion of the GP workforce is made up of overseas born and trained doctors with no palliative care knowledge or understanding or willingness to take advice from specialist palliative care nurses—'You make too much fuss about dying; you have to expect to suffer', one nurse was told. Another nurse wrote, 'GP competence in palliative care in rural areas is vital but sadly lacking'.³⁷

34 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, p. 49.

35 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 70.

36 Ms Angela Raguz, HammondCare, *Committee Hansard*, 2 July 2012, p. 21.

37 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 71. To meet the psychological, social and clinical needs of people who need palliative care in rural areas, Dr McMaster advocated for more social workers and case coordinators.

6.27 The Australian Nursing Federation observed that in many rural communities, GPs themselves are not easily accessible. Its submission outlined a number of other concerns in relation to GPs and appropriate provision of palliative care:

...General Practitioners with an interest and specialty in palliative care are rare in rural and remote areas. There is sometimes a disinclination for General Practitioners to participate in the process of teamwork in delivery of quality palliative care, in particular due to lack of understanding of current principles of palliative care; and a focus only on pain management. It is fair to say that General Practitioners in rural areas have issues similar to nurses in accessing education and professional development. Further, General Practitioners are often unavailable on weekends and after hours, leading to unnecessary hospitalisation of patients requiring care which would be deemed by a palliative care team nurse to be uncomplicated palliative care.³⁸

6.28 The South Australian government noted workforce limitations in general, and mentioned GP availability in particular:

One of the impediments to increasing the capacity of primary health care providers is inadequate funding and staffing to meet increasing demand. The ability for general practitioners in particular to provide visits to patients at the end of their life in their home or in a residential care facility is currently limited.³⁹

In this case, the issue appeared to be not the GP workforce in general, however, but the capacity to visit palliative care patients 'in place'.

6.29 Associate Professor Deborah Parker, Director of Blue Care Research, told the committee about a study she conducted where GPs were encouraged to attend a palliative care case conference. About 50 per cent of residents in aged care facilities who had been given a prognosis of less than six months to live had their GP attend a case conference. She explained:

This study specifically focused on the use of case conferences and engaged the GPs with well-organised timeslots, coordinated by the nurses and a clear process to be followed to ensure that time limits were adhered to and that the GPs could claim, using the EPC [Enhanced Primary Care] Medicare items. In this instance, with this support of a well-funded research project, we can achieve the 50 per cent of GPs coming to a palliative care case conference for residents. You can imagine what the norm is when that sort of support is not available. I can tell you that the incidence of getting a GP to come to a residential-care facility to conduct a palliative case

38 Australian Nursing Federation, *Submission 85*, p. 3.

39 South Australian Government, *Submission 27*, p. 6.

conference is almost non-existent. This project showed significant improvements in family satisfaction and resident outcomes.⁴⁰

Education and training in palliative care

6.30 The committee heard from witnesses that education and training for the palliative care workforce could be improved in some crucial areas. This could occur as part of both undergraduate and postgraduate training of healthcare workers, as well as through continuous professional development of both specialists and the broader health profession. Improvements in training and education could also be achieved through increased Commonwealth funding for training and places and scholarships.

6.31 Professor Patsy Yates, President Elect of Palliative Care Australia, described the 'ad hoc' approach to education in palliative care over the last few decades:

More recently in Australia we have a recognition that people are dying in all sorts of areas of our communities and in our health services and so we need to have all health professionals prepared with at least some capability in providing end-of-life care. In Australia we have gone some way in understanding that and trying to tackle the issue of getting it integrated into undergraduate programs. There has been some progress but still there is a great difference across the country in how that is taken up.⁴¹

6.32 Qualification and skill levels must be improved to ensure that palliative care in Australia is supported by an appropriately skilled workforce. Mr Nicolas Mersiades, Senior Aged Care Adviser for Aged and Community Services Australia, argued:

There is a lot more work to be done to ensure that the qualifications and the skill levels of staff are adequate to deliver a palliative care approach and that there is also ready access to specialist information and advice where needed in those cases where symptom management is much more complex.⁴²

6.33 Palliative Care Nurses Australia advocated for palliative care education for all health professionals, including Indigenous health workers and personal carers in the aged care setting at both undergraduate and postgraduate level.⁴³

40 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre, Blue Care, *Committee Hansard*, 2 July 2012, pp. 2–3. See <http://www.uq.edu.au/bluecare/comprehensive-evidence-based-strategy-to-address-the-palliative-care-needs-of-people-residing-in-residential-aged-care-facilities-racfs-cebparac> (accessed 12 September 2012). Associate Professor Parker also informed the committee of a palliative approach educational toolkit, funded by the Department of Health and Ageing.

41 Professor Patsy Yates, President Elect, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 12.

42 Mr Nicolas Mersiades, Senior Aged Care Adviser, Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, p. 20.

43 Mr John Haberecht, President, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 58.

Commonwealth funding for workforce training

6.34 When questioned as to how the Commonwealth Government supports training for the aged care workforce, the Department of Health and Ageing (the department) explained to the committee a range of initiatives to address training requirements. Since 2007, more than \$252 million has been invested in more than 41,800 aged care training places:

Included as part of these training places is education to improve the palliative care skills and knowledge of people working in aged care. This includes understanding the needs of people approaching the end of life, understanding the palliative approach to care of people and their family, and developing and implementing a care plan for people at the end of life.

Support also includes funding for people working in aged care to undertake specific units from the palliative care skill set. The skill set comprises a set of training units and enables people working in aged care to gain targeted skills that can be transferred readily into their caring role.⁴⁴

6.35 The department also noted that it provides funding through the Encouraging Better Practice in Aged Care initiative to 'support the uptake of evidence-based, person-centered and better practice in aged care'. This initiative focuses on improving staff knowledge and skills and resource development. Three projects funded under this initiative are specifically targeted at encouraging a palliative approach in residential aged care:

1. A good death in residential aged care: optimising the use of medicines to manage symptoms in the end-of-life phase.
2. ...Encouraging best practice palliative care in residential aged care facilities from rural and remote communities.
3. The implementation of a comprehensive evidence-based palliative approach in residential aged care.⁴⁵

6.36 In addition, the department stated it was supporting the development of a program to look at 'appropriate models of practice for aged care nurse practitioners':

The program aims to test and evaluate a range of financially viable practice models that can be implemented across both home care and residential aged care settings. In this program nurse practitioners are working in a range of clinical specialties, including palliative care, to assist in improving the care of older people.⁴⁶

6.37 The recently announced Commonwealth aged care reform package includes \$1.2 billion for a Workforce Compact to be implemented over four years from July

44 Department of Health and Ageing, answers to questions on notice (question 5), received 23 May 2012.

45 Department of Health and Ageing, answers to questions on notice (question 5), received 23 May 2012.

46 Department of Health and Ageing, answers to questions on notice (question 5), received 23 May 2012.

2013. The government says that this is aimed at improving the capacity of the aged care sector to attract and retain staff through higher wages, improved career structures and enhancing training and education opportunities.⁴⁷

6.38 The ANZSPM called for Commonwealth funding for accredited positions for training in palliative medicine.⁴⁸ Its submission stated:

To meet the future workforce need it is imperative that more doctors are trained in the specialty of Palliative Medicine. Currently a major rate limiting step is the funding of positions by State and Territory governments. A minority of positions are funded through the STP [Specialist Training Program].

Accreditation of training positions is performed independently by the RACP (Royal Australasian College of Physicians) Palliative Medicine Education Committee. As such, there are more accredited positions than there are trainees. To increase the number of Palliative Medicine Specialists for the future ANZSPM proposes that funding is provided according to numbers of accredited positions, rather than on the basis of historical allocations, usually to public hospitals.⁴⁹

6.39 Some other issues raised by witnesses in relation to Commonwealth support for training included:

- calls for funding of Commonwealth training places to match assessments by Health Workforce Australia of future palliative care workforce needs, both generalist and specialist⁵⁰; and
- the level of workforce support and training being provided by the Commonwealth to allied health professionals. This equated to around \$12.5 million per year across Australia according to Mr Rod Wellington, Chief Executive Officer of Services for Australian Rural and Remote Allied Health (SARRAH). Mr Wellington observed that this was far less funding for support and training than what is provided to general practitioners and nurses.⁵¹

47 See Living Longer. Living Better – Aged Care Reform Package, Department of Health and Ageing, April 2012
<http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-aged-care-reform-measures-toc~ageing-aged-care-reform-measures-chapter6.htm> (accessed 12 September 2012).

48 Australian and New Zealand Society of Palliative Medicine, *Submission 33*, pp. 13–14. See also Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 70.

49 Australian and New Zealand Society of Palliative Medicine, *Submission 33*, pp. 13–14.

50 Ms Wendy Porter, Residential Care Manager, Western Australia, Aged and Community Services Australia, *Committee Hansard*, 10 July 2012, p. 19.

51 Mr Rod Wellington, Chief Executive Officer, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, p. 30.

Training and scholarships for nurses

6.40 Palliative Care Nurses Australia (PCNA) and the ANF appeared before the committee to discuss qualifications and training options for post-graduate study in palliative care nursing.

6.41 The ANF described undergraduate nursing courses as having 'a very full curriculum', noting the optional Palliative Care Curriculum for Undergraduates program (mentioned in further detail below). For the specialist palliative care nurse, there are a number of graduate certificates, graduate diplomas and masters degrees that are run by institutions such as the Australian Catholic University, Edith Cowan University, La Trobe University and the University of Melbourne.⁵²

6.42 Professor Jane Phillips noted that postgraduate palliative care nursing qualifications were expensive to obtain and particularly prohibitive for many nurses.⁵³ Ms Catherine Pigott, Member of the ANF, outlined the costs of postgraduate study:

Ms Pigott: The cost of them ranges. For a graduate certificate you are talking between \$5,000 and \$10,000. Around \$6,000 and \$7,000 is the average mark for a graduate certificate in university. For a graduate diploma it would be double that. For masters it is variable depending on whether it is masters by research or masters by coursework.

CHAIR: It is expensive, in other words.

Ms Pigott: For nurses, yes.⁵⁴

6.43 Mr Jason Mills, National Committee Secretary for PCNA, described his nursing training at the University of Canberra and his graduate year in Victoria:

In the curriculum where I studied palliative care was not an elective and it was not a core unit, per se. It was embedded within a subject of chronic illness ... [T]here is discrete representation and it does differ across the university sector across the different states. For example, some universities have a subject on spiritual care whereas others do not.⁵⁵

6.44 He told the committee that he decided he wanted to be a palliative care nurse after volunteering in a hospice. He also spoke of encountering a passion among his fellow students to pursue palliative care but also then coming across a systemic resistance to this desire in his graduate year:

... among the cohort that I studied with, my peers, I did see that flame being sparked within the subject. It was very well articulated in the course and I witnessed it amongst my peers. I was pleasantly surprised that there was within the future generations of nurses a passion there if it were given a chance to be linked. In my graduate year I in some ways met some

52 Ms Catherine Pigott, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 35.

53 Professor Jane Phillips, *Committee Hansard*, 2 July 2012, p. 59.

54 Ms Catherine Pigott, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 35.

55 Mr Jason Mills, National Committee Secretary, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 59.

resistance. There seems to be a perception, which perhaps stems from a society with the view of protecting young people from death, that we need to shield people from it. That runs counter to it; it is not so productive. I came across the view in many forums that you should not and cannot work in palliative care until you have at least ticked off five or six years in general medical surgical nursing. I was a little shocked at that because that was the whole reason that I wanted to become a nurse.⁵⁶

6.45 Mr Mills told the committee he received a competitive scholarship from the Victorian Government which was administered through Palliative Care Victoria to do his graduate certificate in palliative care. The scholarship was worth about \$2,600 and the course itself was about \$7,500.⁵⁷

6.46 Access to funding for further education in palliative care is complicated by the breadth of the healthcare sector and competition for the same pool of funding. PCNA suggested to the committee that dedicated funding be set aside, which 'would go a long way to nurturing the future workforce in palliative care'.⁵⁸ PCNA's submission recommended dedicated scholarship funding for postgraduate studies in palliative care on a national level, rather than palliative care clinicians competing for the generic and highly competitive Postgraduate Nursing and Allied Health Scholarship and Support Scheme (NAHSSS):

Many clinicians wanting to further their clinical knowledge and develop advanced practice skills in palliative care are consistently missing out on funds through the generic NAHSSS. This results in frustration and disillusionment regarding any higher education aspirations such clinicians may have held. Such barriers to further education ultimately impede quality improvement of clinical staff practising in a dynamic environment of evidence-based practice (with an everchanging evidence base) and adversely affect bedside care of palliative patients.⁵⁹

6.47 PCNA also called for recognition of the specialist skills acquired by palliative care nurses:

We recommend creation of a credentialling program to recognise specialist palliative care nurses and a national rollout of the existing competency standards for specialist palliative care nurse.⁶⁰

6.48 The ANF also discussed with the committee the issue of postgraduate scholarship funding for nurses to gain further qualifications in palliative care. However, the shortcomings of these current arrangements were noted (the ANF has made representations to the Department of Health and Ageing to have scholarship

56 Mr Jason Mills, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 60.

57 Mr Jason Mills, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 59.

58 Mr Jason Mills, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 60.

59 Palliative Care Nurses Australia, *Submission 45*, p. 8.

60 Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 59. See Palliative Care Nurses Australia, *Submission 45*, p. 8.

funding increased).⁶¹ The ANF also cited the difficulty for staff to get time off to actually undertake intense further studies. Workforce shortages in regional areas make this particularly difficult. For rural and remote area nurses, postgraduate study can be hard to access, so continuous professional development is usually undertaken through short courses, including through online education.⁶²

Other training issues

Better training of aged care staff

6.49 The committee heard concerns about the level of training in palliative care principles being provided to staff working in aged care. For example, Dr Yvonne McMaster pointed to the urgent need for training by palliative care specialists on symptom control and end-of-life care for nursing home staff. She described the situation in nursing homes as 'Dickensian':

Some of the most difficult cases—you have been hearing about dementia today—are managed by the least trained staff: little girls with six weeks training and no concept of real care. Yet it seems that these places are to be the new hospices and the now hospices are to become only acute short-stay facilities. This attempt to save state funds and shift costs onto the Commonwealth should be resisted to the death.⁶³

6.50 Alzheimer's Australia called for mandatory training and support for staff of aged care facilities in relation to artificial nutrition, hydration, antibiotics, pain management, hospitalisation, resuscitation, differences in cultural values and beliefs around dying, advanced care directives and the law.⁶⁴

Training in oncology

6.51 Associate Professor Frances Boyle, Former Executive of the Medical Oncology Group of Australia, told the committee that specialist palliative care doctors and nurses needed to be integrated at every level of cancer care in Australia. This would entail making oncology training positions available which is currently difficult to do:

If we are talking about an expansion of the palliative care workforce, we have got to do our bit to make sure that those training positions are available at our end to pull them in so that, if they are going to be involved earlier in the care of cancer with patients, they need to know more about chemotherapy, more about radiotherapy, and they need to be involved in communication training with our trainees, not just on their own. So we would be certainly very willing to look at methods to increase access to training. For instance, at our hospital, which is a private hospital, we have put in an application for an extended settings job to rotate the palliative care

61 Ms Elizabeth Foley, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 36.

62 Ms Geri Malone, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, p. 36.

63 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 71.

64 Dr Ron Sinclair, Consumer, Alzheimer's Australia, *Committee Hansard*, 24 April 2012, p. 2.

trainees into. Like everybody else, we are waiting to find out what happens about that funding, but certainly there are an increasing number of oncology units in Australia that could be providing some training for palliative care physicians.⁶⁵

The palliative care curriculum

6.52 The committee heard from witnesses that the curriculum studied by those entering the health workforce needs to include education in quality end-of-life care. Ongoing support through continuing professional development is also required.⁶⁶ The committee was pleased to hear about current programs and training modules in palliative care—specifically the Palliative Care Curriculum for Undergraduates and the Program of Experience in the Palliative Approach.

6.53 Palliative Care Australia (PCA) explained to the committee that working in palliative care needed to be made an attractive career choice for doctors, nurses and allied health professionals.⁶⁷ Dr Yvonne Luxford, Chief Executive Officer of PCA, noted that exposure to palliative care in undergraduate training was required to cultivate this interest among health professionals. She explained that the College of Physicians includes practitioners of palliative medicine, but noted that palliative care is not taught across the curriculum.

6.54 Dr Luxford told the committee about a government-sponsored program called PCC4U—Palliative Care Curriculum for Undergraduates⁶⁸—which 'has some reach into the various undergraduate curriculums of health professionals, but not nearly enough'.⁶⁹ Professor Jane Phillips, Professor of Palliative Nursing at the University of Notre Dame, noted that the PCC4U curriculum is embedded within her university's three year nursing degree and that medical schools and allied health school are also able to utilise content from that program, allowing emerging clinicians to be exposed to palliative care.⁷⁰

6.55 The committee also heard about PEPA—the Program of Experience in the Palliative Approach.⁷¹ Offered as postgraduate informal education, PEPA is supported by the Department of Health and Ageing and is aimed at educating health professionals who do not have specialist palliative care expertise but who have an interest in the area.⁷² PEPA is also targeted to Indigenous health workers, with

65 Associate Professor Frances Boyle AM, Former Executive, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 46.

66 See for example Dr Yvonne Luxford, *Committee Hansard*, 24 April 2012, p. 18.

67 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 21.

68 Palliative Care Curriculum for Undergraduates, www.pcc4u.org, (accessed 28 September 2012).

69 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 21.

70 Professor Jane Phillips, *Committee Hansard*, 2 July 2012, p. 59.

71 See Welcome to PEPA, www.pepaeducation.com (accessed 10 October 2012)

72 Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 58.

location-specific resources to account for different palliative care needs around Australia.⁷³

Enhancing knowledge and awareness of palliative care in the health curriculum

6.56 Palliative Care Nurses Australia suggested enhancement of the undergraduate health curriculum by embedding palliative care principles, through programs such as PCC4U. While noting the 'crowdedness' of the undergraduate curriculum, PCNA stated that palliative care should be a basic component of all health professional curricula and also called for the establishment of professional mentor programs.⁷⁴

6.57 When asked how many universities around Australia have a chair of palliative care, the Centre for Palliative Care responded that there were five or six.⁷⁵ Dr Yvonne McMaster told the committee that medical students need to be inspired by 'charismatic palliative care specialists of the highest calibre' in teaching hospitals:

That is what catches the attention of the students and attracts them to the specialty. Universities must teach palliative medicine, and the teachers must be able to inspire young people to go into a specialty where they can really make a difference to people's lives and wellbeing.⁷⁶

6.58 Associate Professor Andrew Cole, Chief Medical Officer for HammondCare, expressed worry about how little of the curriculum for the training of health professionals is devoted to end-of-life care:

All of us are most concerned about the very small amounts of clinical teaching time given to healthcare students—medical, nursing and allied health—as they learn about end-of-life care compared with, for example, the time given to learning about the care of infants and children. In my own university [University of New South Wales], the medical students would spend a term in each of first, second and third years learning about beginnings, growth and development and they would spend about a week learning about palliative care and care at the end of life. At Sydney University, they spend about half a day.⁷⁷

6.59 Associate Professor Mark Boughey explained that the Centre for Palliative Care, an academic research and education centre at the University of Melbourne, encourages early exposure to palliative medicine:

Prof. Boughey:...we are then going into the hospitals and trying to encourage intern placements, junior doctors and early trainees so they get an exposure. They may never go to palliative medicine but they get an

73 Dr Yvonne Luxford, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 23.

74 Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 58.

75 Associate Professor Jennifer Philip, Catholic Health Australia, *Committee Hansard*, 4 July 2012, p. 54.

76 Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, p. 70.

77 Associate Professor Andrew Cole, Chief Medical Officer, HammondCare, *Committee Hansard*, 2 July 2012, p. 17.

exposure about what palliative care and palliative medicine is all about that they can carry into whatever area they go.

Senator FIERRAVANTI-WELLS: Would that be at undergraduate level?

Prof. Boughey: It depends on the priorities of any university. Somewhere like Melbourne University that we are associated with has moved to a postgraduate model. They have about a two-week program built into two separate parts of their four-year course. They have taken a fairly serious approach to palliative care being part of that training.⁷⁸

6.60 In comparison to training offered at other institutions, a two week program may be seen as quite substantial:

Some other universities may only have a few hours or a few lectures in a six-year period. That is not to say that palliative care does not get mentioned in the disease profile of all the training; it is just the specialist area where the people who work in palliative care have access to students. In many ways medicine is more organised than nursing, allied health or other areas of training. I do not think in occupational therapy or physiotherapy it is actually part of the undergraduate training. Once you get away from medicine, it falls off quite precipitously in Australia. There is nothing to say there is a minimum standard in training for students in this area, even though it is so much a part of our work.⁷⁹

6.61 According to Associate Professor Boughey, there are different needs for workforce development depending on the health professional:

At the moment we might have nurses who have had a great deal of experience but that experience is not recognised in a structured way so that, say, a young graduate nurse can be told: 'This is your career. If you want to become a career specialist in palliative care, these are the stepping stones to move towards it.' It is much more organised in the medical field. For a psychologist who wants to work in the area there is not really any training pathway other than being experienced in death and dying, which does not necessarily mean that they have had the training.⁸⁰

6.62 Associate Professor Boughey cited the success of a palliative care training program in Victoria which has encouraged promising workforce developments:

To give an indication: their program was set up five years ago—there was a two-year pilot and then three years into the program—and it has gone from having only five or six trainees in palliative care medicine to about 35 positions and 17 trainees. That is significant growth in a three-year period. It is all because we have centralised, coordinated, brought the trainees

78 Associate Professor Mark Boughey, Centre for Palliative Care, and Senator Concetta Fierravanti-Wells, *Committee Hansard*, 4 July 2012, p. 54.

79 Associate Professor Mark Boughey, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 55.

80 Associate Professor Mark Boughey, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 55.

together and provided value-added education. We are getting people move to Victoria from interstate, whereas before we had to move to other parts of Australia because our training requires us to do certain terms that were not available in Victoria. It is an interesting model. Queensland is taking up a view that they want to develop a similar program and process to keep their trainees in Queensland. So things are happening but it is on a state-by-state basis at the moment.⁸¹

Committee view

6.63 The committee strongly endorses the interdisciplinary and team-based models of care about which it received evidence, and noted the importance of nurse-led teams in providing care in this sector. These multidisciplinary teams need to be effectively resourced and well trained.

6.64 The committee recognises that the palliative care workforce must be properly equipped with the knowledge, skills and experience to provide high quality end-of-life care to people with terminal illnesses, as well as to their families and carers. The committee heard that through enhancements to the health workforce curriculum, in both undergraduate and postgraduate settings, a broader awareness of the principles of palliative care will become more greatly embedded within the health system and not just among specialist palliative care providers. The committee believes it is important that such awareness be developed in the healthcare community, so that health practitioners refer patients to specialist palliative care in a timely manner; patients get the most appropriate care; and the healthcare system is not used inefficiently through patients with palliative care needs being inappropriately placed in acute care settings.

6.65 The committee understands the critical role played by nurses in providing quality palliative care. Greater opportunities for nurses to develop their knowledge and specialise in palliative care nursing through postgraduate education should be pursued. The committee sees merit in the creation of a dedicated scholarship fund to assist nurses aspiring to gain postgraduate qualifications and considers that the Commonwealth Government should establish such a fund.

Recommendation 9

6.66 The committee recommends that medical workforce training include being educated about existing pathways to specialist palliative care, ensuring that this care is applied effectively to best meet patient need.

Recommendation 10

6.67 The committee recommends that the Australian government create an ongoing and dedicated national scholarship fund for postgraduate studies in palliative care nursing.

81 Associate Professor Mark Boughey, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, pp. 55–6.

Chapter 7

Models of service delivery

Introduction

7.1 Funding regimes are not the only aspect of palliative care that vary from state to state, as well as locally. There are different ways that palliative care service delivery can be organised, and different kinds of organisations that are involved. Some care is delivered publicly, some privately. Some is delivered in hospitals, some in residential facilities, some in aged care, and some at home. A range of different professionals can be involved, and the way they are paid can vary too.

7.2 During its inquiry, the committee heard regularly about some particular service models that were highly regarded or were involved in important innovations. It also heard that such innovations could be placed under pressure or cut because of pilot funding or non-ongoing funding being all that was available. This chapter focusses on a small number of service delivery models, to consider what was regarded as positive about these, and what issues arise in implementing them. All of them focus on community-based care, but in each case the setting varies.

Models of service delivery

7.3 Throughout the inquiry, submitters and witnesses repeatedly referred to the model of care provided by Western Australian based Silver Chain¹ as being very effective in providing community based palliative care. In its submission to the committee, Silver Chain outlined and explained what it has identified as a 'best practice model of specialist community palliative care provision', ² the model which it has implemented in Western Australia and is starting to extend to both South Australia and Queensland.

7.4 The best practice model through which Silver Chain operates integrates specialist community provision of palliative care with primary health care infrastructure. The model involves three specific service offerings – a metropolitan community palliative care service; a palliative nurse consultancy service; and a palliative rural telephone advisory service, all guided by the principles of building capacity within families to care for their own; integrated and coordinated services; interdisciplinary/multidisciplinary care planning; and evidence-based, client-centred care:

1 Silver Chain, a Western Australian based not-for-profit organisation that has been providing care to people living in metropolitan, rural and remote areas for over 100 years is one of Australia's largest providers of community, clinical and health care services to the Western Australian and South Australian communities, and a growing entity in Queensland. Silver Chain provides a diverse range of services including palliative care and through its Hospice Care Service in Western Australia provides specialist community palliative care services
Source: Silver Chain, *Submission 80*, p. 2.

2 Silver Chain, *Submission 80*, p. 2.

1. Metropolitan Community Palliative Care Service: Provision of in-home specialist palliative care to clients within the metropolitan area and to all metropolitan care facilities that do not have a registered nurse managing care 24 hours a day.

2. Palliative Nurse Consultancy Service: Provision of a palliative nurse consultancy service to metropolitan public/private hospitals and residential facilities where client care is managed by a registered nurse 24 hours each day. The service provides specialist nursing advice, assessment, procedures, specific staff education and telephone follow up to meet the care needs of a specific client. Referrals are accepted from medical practitioners, registered nurses and allied health staff that are providing care within the facility. Involvement is limited to a period of five days following which the client is separated from the service. The client can be re-referred and there is no charge to the facility or the client.

3. Palliative Rural Telephone Advisory Service: Clinical Nurse Consultants who have specialist skills and knowledge provide telephone advice to rural service providers regarding managing the palliative care needs of a specified client. This service is available via a free call telephone number 24 hours per day, seven days per week.³

7.5 Silver Chain explained that its services are delivered through an interdisciplinary team consisting of specialist nurses, medical consultants, registrars, general practitioners, allied health professionals, care aides, and volunteers.⁴ This model enables Silver Chain to provide a whole of metropolitan service, 24 hours a day seven days a week, engaging general practitioners and providing personal and respite care.⁵

7.6 Silver Chain identified that their service:

...admits approximately 3,000 people annually, with more than 660 people receiving care on any given day, and an average length of stay of 84 days. Sixty per cent of admitted clients are supported to die at home (compared to national average of 25-30%). Recent analysis of Silver Chain data over the last two years demonstrates that the majority of those who died at home had no hospital admissions during their episode of care with the service.⁶

7.7 The services provided by HammondCare in New South Wales were also identified as a very successful and effective model:

HammondCare, a not-for-profit, aged-care provider of good reputation entered the palliative care service provision field in 2009... they opened a palliative care suite ('Bond House') within their own RACF at

3 Silver Chain, *Submission 80*, p. 8.

4 Silver Chain, *Submission 80*, p. 2.

5 Silver Chain, *Submission 80*, pp. 8–9.

6 Silver Chain, *Submission 80*, p. 2.

Hammondville (a suburb of Sydney). This is at HammondCare's own expense and is currently not receiving any extra external funding.⁷

7.8 Dr Yvonne McMaster, a retired palliative care physician, spoke of the palliative care suite provided by HammondCare. Dr McMaster explained that the services provided through HammondCare's suite differ from the usual aged care situation as it provides:

1. Assessment by Specialist Palliative Care Team prior to referral, whether this assessment occurs at home/residential care or in hospital.
2. Support from the specialist palliative care team; including specialist consultation in the palliative care suite, 24 hour telephone advisory service, GP support, pharmacy access, multidisciplinary input and weekly meetings, bereavement support for families and education for nursing staff.
3. GPs with a special interest in palliative care are provided with a specific mentorship and capacity-building programme to support them.
4. In-house pharmacy licence which provides access to emergency palliative medications.
5. Designated Palliative Care Suite nursing staff.
6. All residents and their families will work with staff to plan for future care, in accordance with wishes (regularly reviewed and updated as circumstances change).
7. Tailor made palliative care education plan including the Program of Experience in the Palliative Approach (PEPA), buddy shifts and mentoring. PEPA is available to all disciplines including GPs.
8. Comprehensive education program for all staff.
9. Close links with the in-patient unit.
10. Access to HammondCare's specialist palliative care medical, nursing, allied health, pastoral care and project manager consultative services across Sydney.
11. Refurbished private rooms with ensuites.⁸

7.9 HammondCare further detailed the services they provide through the palliative care suite model and how this model is addressing gaps it has identified in the provision of palliative care:

The difference is firstly and foremost in the training and skill level of the staff. The staffing levels are greater within the palliative care suite. Access to specialist nursing and specialist medical support is there because of our link with Braeside Hospital and the palliative care team. We have set up a partnership where there is a 24-hour on-call telephone advice line which provides the nursing staff immediate advice about what is happening rather than waiting, which is the norm in aged care. It is really about time and

7 Dr Yvonne McMaster, *Submission 92*, p. 22.

8 Dr Yvonne McMaster, *Submission 92*, pp. 22–23.

expertise, the gaps that we face. Time is not just that nurses in aged care are time poor; we all know that. It is more the turnaround time for a person who is deteriorating. As Dr McVey will say, the identification of that is critical in and of itself. A person is deteriorating and then the nursing staff need to call the GP, who may not be available on that particular day and it may take 24 hours before the GP arrives. The GP may write an order for symptom control of some form of medication. That needs to then go to a pharmacy, which is often off-site. That needs to then come back to the aged-care facility and it is not unrealistic to expect that 48 hours have passed from the initial determination that the person is deteriorating.

The facility has two options: either do our best to be kind and caring to a person, which we all know is not enough, or send the person through to the acute system via the accident and emergency department, and we all know that is not ideal either. So what we have tried to develop is a process and expertise level that circumvent that time issue. We have acquired a drug licence for that unit, which means we are able to hold stock within the residential aged care facility of medications that is not the norm. I have to say it was quite an interesting process getting that drug licence because I do not think there are that many requests of that nature anymore. So there was surprise coming from the pharmaceutical branch of 'Do people still do that, actually get drug licences?' That meant we could have medication on site. Specialist support and a dedicated GP that has been working with the specialists to make sure the GP is actually aligned with the treatment plans.⁹

7.10 HammondCare advised the committee that its costing of the program indicated an additional cost of \$50 000 per bed per annum:

At the moment it is being cross-subsidised because we are able to put that in the larger facility, so we have put that into a 124-bed facility and we dedicated nine beds, so there is cross-subsidisation. We do get Commonwealth funding for people, but the additional cost is approximately \$50,000 per bed per annum.¹⁰

7.11 When asked about their model and the inspiration for its establishment, HammondCare representatives explained to the committee:

We have known for a long time that the care of older people, particularly in nursing homes, during the dying phase is not done universally well. A lot of aged care providers will say that they do palliative care really well. That really is based on a lot of good people who care but it is not necessarily technically competent. As I said, being an organisation that had the benefit of schedule 3 hospitals, palliative care hospitals, it was an opportunity to say that the purpose of acquiring those hospitals was to be able to say, 'We want to provide older people with the right care throughout the various stages of their life and we need to make sure we can cross over those areas of expertise. So our aged care services were fabulously expert in dementia

9 Ms Angela Raguz, General Manager, Residential Care, HammondCare, *Committee Hansard*, 2 July 2012, p. 18.

10 Ms Angela Raguz, HammondCare, *Committee Hansard*, 2 July 2012, p. 18.

care and we had hospitals that were expert in palliative care. So how do we bring the two together?...It was only about creative thinking; it was a good idea.¹¹

7.12 HammondCare further explained to the committee that although their applications for funding were declined they decided to 'do it anyway' and have commissioned the unit for the coming year to demonstrate 'not just the cost-effectiveness but the better outcome for the people and families.'¹²

7.13 HammondCare informed the committee that although they had again approached the Commonwealth seeking funding to expand their model, the complexities of providing aged and palliative care prove to be barriers to further future investment:

...it [palliative care] is an area that we do not think can be ignored. I think we need to be looking at innovative models, and there are opportunities through flexible funds programs and whatnot to get these things up and running and off the ground. We just started that before that was actually open—the flexible funds round last year.

...The response [from government] is that absolutely there is a need, but like any response the government is saying, 'We think we are putting enough into aged care so there is not really an option for a lot more top-up'. It costs more than aged care but it costs less than subacute care, and so it is that in-between land. In the state health system there is that very real truth that, even if a person is out of that subacute bed or acute bed and in an aged-care bed, another person very quickly fills that, so there is not a real dollar saving. It is just that the cost of care for this person is less than what it would have been there. So it is hard to actually get people to come on board.¹³

7.14 Another example of a service model delivering effective palliative care was Eastern Palliative Care Association Incorporated. Eastern Palliative Care is the largest community based palliative care service in Victoria. In the 2010-11 year Eastern Palliative Care 'supported over 1260 new clients... 83 per cent of whom has malignant disease and 36 per cent who were under the age of 69.'¹⁴

7.15 Eastern Palliative Care do not have access to hospital beds but rather work with hospices and inpatient palliative care units to support clients to 'die in their place of choice with symptoms well managed'.¹⁵ Representatives of Eastern Palliative Care explained how its services are effectively targeted and delivered:

Every client in the region who gets referred for specialist palliative care comes into our intake team, and our intake team go through an assessment

11 Ms Angela Raguz, HammondCare, *Committee Hansard*, 2 July 2012, p. 22.

12 Ms Angela Raguz, HammondCare, *Committee Hansard*, 2 July 2012, p. 22.

13 Ms Angela Raguz, HammondCare, *Committee Hansard*, 2 July 2012, pp. 22–23.

14 Eastern Palliative Care Association Inc., *Submission 42*, p. 1.

15 Eastern Palliative Care Association Inc., *Submission 42*, p. 1.

process where we look at whether they have generalist needs or specialist needs.¹⁶

7.16 EPC explained that in the case of generalist needs, where the patient is 'relatively stable and has no particular issues; the family is all on board and the aged care facility is on board,' they would not provide ongoing support, rather:

[EPC] would provide advice on the phone to the aged-care facility. They may be referred off for RDNS, the Royal District Nursing Service, in case they need extra support, but we would not keep going with those.¹⁷

7.17 To determine the care that will be provided, Eastern Palliative Care's intake team perform an assessment. Those who have symptom issues that are not being managed are then provided with care services.¹⁸

7.18 Eastern Palliative Care explained that referrals to their service are generally made by doctors although families can make referrals and aged-care facilities are increasingly referring patients for assessment.¹⁹ EPC informed the committee that they do not have a waiting list, rather they have a process in place which enables their intake team to assess the patient's need and see urgent clients within four hours:

Ms Hogan: We do not have a waiting list...our intake team, they triage and so the people who are very urgent get seen within four hours and the people whose needs are not so urgent might have to wait 10 days, but they are still on the books and we are still making contact with them and so there is still that ongoing contact. So that whole concept of the waiting list is something that we do not have at all.

Ms Moody: My board have given directions, if for some reason we cannot see that person within 10 days, that we are to put on extra staff and meet the community's needs. It is the board's responsibility to find funding for that.²⁰

Common issues faced by these models of service provision

7.19 It is clear from the examples provided that levels of funding, and availability of workforce, are hurdles that face service providers in providing effective and efficient care. However, there are also other important factors.

7.20 Palliative Care Australia attributed the success of the Silver Chain model to its nurse-led coordinated multidisciplinary workforce:

16 Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 5.

17 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 5.

18 Ms Jeanette Moody, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 5.

19 Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 5.

20 Ms Louise Hogan, Manager Human Resources and Public Relations; Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 8.

At the moment where it is working well in terms of coordination of care, such as the Silver Chain model that I mentioned before, it is usually a nurse-led model in terms of case coordination. But it really does include an entire multidisciplinary team that sits down and meets. So there is all that back-end work that goes into ensuring somebody receives the best possible care.²¹

7.21 Similarly, Palliative Care Queensland suggested that the success of the Victorian model, as demonstrated by Eastern Palliative Care's service, could be attributed to their governance arrangements where a consortium within a region coordinates service provision:

The Victorian model of having a consortium within a region where you try to pull together the paediatric, adult, disability or whatever other services and get them talking to each other and sorting out the problems... is absolutely vital. If you sat in Brisbane on a hotline you would have no idea what Roma offered or what Cairns had, even though you might have a list of services.²²

7.22 The Victorian Healthcare Association echoed this view and explained that the 'devolved model of governance' in place in Victoria enables innovation in service delivery and the allocation of funds:

...through the devolved model of governance there has been a capacity for local solutions to be put in place. Our funding model here in Victoria is reasonably complex. It has been based loosely on an activity based funding system for 18 or 19 years now, so we are well established in the playground. Activity based funding to hospitals in Victoria still counts for only about 65 per cent of hospital funding. There is a range of other different funding mechanisms as well that come into play. Then each of those hospitals have their own board of governors. Therefore they have their own chief executive and the creation of strategy, while it needs to be consistent with state government policy directions, can still be intuitive to the way in which that policy direction is interpreted at the local level. That creates opportunity for innovation.²³

7.23 Silver Chain in Western Australia informed the committee that it received approximately 95 per cent of its funding from the Western Australian state government:

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- 21 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 25.
 - 22 Professor Rohan Vora, President, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 28.
 - 23 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, pp. 15–16.

...It would probably be 95 per cent or a little bit above. There are donations and bequests we receive, but the majority of funding is through the state government with a small amount of DVA funding.²⁴

7.24 Through Palliative Care Queensland's description of the fragmented provision of services in that state, the barriers that have been overcome by Silver Chain, Eastern Palliative Care and HammondCare become clear:

Obviously, under the new health arrangements—we have talked before about the divide between the Commonwealth and the states—there are also the issues around what happens about out-of-hospital care. Within a state, you get caught up with the systems manager, the 17 health and hospital services and a statewide paediatric service that goes across the state, so it will be interesting to see how that develops and that will hopefully help with some of these issues, but what happens about the other 17?

We come from an area where the services are already really fragmented and vary hugely, even within a metro area, let alone the rest of the state. We are worried that we will have 17 totally different services developing with different priorities on palliative care. People may have to travel from one district to another if they want to have certain services, even in end-of-life care. Firstly, we asked for improved coordination of services across Queensland and the development and implementation of a state-wide service plan. We note the South Australian plan and the strategy in Victoria, and hope that with the new state government—who have, wonderfully, called an inquiry into the whole state of affairs there—we might start getting some traction. We are very hopeful that we can work with the new government on reversing some of the issues.²⁵

7.25 In addition to interdisciplinary teams and effective governance, some inquiry participants were concerned that Australia has a medical model of care, resulting in the use of relatively high-cost, hospital based care, with less use of holistic and home-based care than might be desirable:

The community hospice model of care which is still very prominent in the UK, USA, Canada, New Zealand, Europe and parts of Asia, has in Australia been superseded by very sophisticated Palliative Care based on a strong medical model. While quality Palliative Care is undeniably important, it is of some concern that the hospice model of care, which can support and underpin home care has virtually been abandoned in Australia. With the strong “medicalisation” of palliative care in Australia, the concept of holistic and person centred end-of-life care has at times been compromised and people’s right to choice in place of care and type of care thereby discounted. This fact I would suggest, is in part represented in the low statistics of home deaths in Australia.²⁶

24 Mr Mark Cockayne, General Manager, Health; and Director, Hospice Care Service, Silver Chain, *Committee Hansard*, 5 July 2012, p. 32.

25 Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 24.

26 Anam Cara House Geelong and Colac, *Submission 54*, p. 2.

7.26 The Victorian Healthcare Association raised a similar issue:

International research suggests that up to 90 per cent of people with a life-threatening illness would prefer to die at home, or in a home-like environment. The capacity to meet a person's wish to die at home is important as it allows them to spend time with their families and friends and maintain their own routines and preferences in a safe and familiar environment. Despite this preference however, only 26.5 per cent of Victorians die at home, while 56 per cent died in hospital.²⁷

7.27 Silver Chain (noted above) provide a contrast with this Victorian result: sixty per cent of their clients were able to die at home.

Committee view

7.28 The committee concludes that for service delivery to be both cost-effective and achieve positive outcomes for the dying, their carers and families, there must be a focus on 'dying in place'. The committee is not indicating that dying at home is better than in hospital, and it recognises that choices around the place where palliative care occurs must also depend on carers' availability and capacity (see chapter 5).

7.29 The committee is concerned that people's preferences are not being met. Furthermore, the cost of care in a hospital-centred system is higher than that based around 'dying in place', where appropriate. Thus Australia effectively risks running a system that is relatively expensive, and does not meet people's needs or preferences around death.

7.30 The committee concluded that regardless of where care is delivered, multi-disciplinary teams and good coordination were critical to effectiveness. Regional service delivery organisations were often praised for their work, and it was clear that effectiveness 'on the ground' and at the local level was important. However, what was not clear was the extent to which governance should be devolved to achieve good community service delivery. The committee heard that there was a strong sense that devolved organisation is a feature of success in Victorian palliative care. In contrast however, Silver Chain, one of the most highly regarded services in the field, is a very large organisation that does not appear to operate with a particularly devolved or decentralised organisational structure.

7.31 The committee takes the view that the most important consideration in service delivery reform at present is to increase the capacity to support palliative care in the home (including residential aged care), or specialised hospice facilities where that is the preference, and reduce unnecessary (and often unwanted) transfer into the hospital system. This is likely to have the effect of saving money. Most important however, is that it will provide a better experience to patients and those around them.

27 Victorian Healthcare Association, *Submission 57*, p. 1.

Recommendation 11

7.32 The committee recommends that service delivery models include a greater emphasis on community-based care, 'dying in place', and a reduction in unnecessary hospital admissions.

Chapter 8

Case management

8.1 Throughout the committee's inquiry many stakeholders labelled Australia's palliative care system as fragmented. One recurring theme in responses to this fragmentation has been that a method of case management be introduced to assist families and carers navigate the system at what is a very stressful time.

8.2 The perceived fragmentation of palliative care is consistent with what this committee is often told about fragmentation and coordination problems with the wider health system. In palliative care it results at least in part from the fact that the provision of palliative care services, although jointly funded by the federal government and the state and territory governments, remains the responsibility of the individual state and territory governments. These governments both have and require the flexibility to allocate those funds to meet the needs of their different population and demographic characteristics, meaning there are varying delivery models and organisations. The service providers are generally those providing aged care services, but the service itself is not aged care. Service provision differs radically between rural and urban settings, and despite the fact that life-limiting illnesses do not discriminate based on age, many palliative care services and settings relate in some way to aged care.

The fragmented approach to palliative care provision

8.3 Throughout the committee's inquiry it became clear that there is much variation in the standard of care being delivered. In addition to the variation, the committee consistently heard of difficulty being experienced by carers and families as they sought to access palliative care services through the health care system and spoke of its fragmented nature. SARRAH explained their concern that the provision of palliative care and therefore access to palliative care is currently fragmented:

We are of the view that Australia should be justly proud of its health system, which offers a range of palliative care services. However, these services across the nation are fragmented and not coordinated.¹

8.4 Catholic Health Australia suggested that the current fragmented nature is the result of the fact that palliative care in Australia is still relatively new:

In some respects, specialist palliative care is still in its infancy. Services have grown up very much in an ad hoc fashion across Australia. There is no consistency. What does a specialist palliative care service look like? It varies from location to location and from state to state.²

¹ Mr Rod Wellington, Chief Executive Officer, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, p. 29.

² Professor Katherine Clark, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 39.

8.5 The Medical Oncology Group of Australia (MOGA) explained that the disparity between service provision in rural and regional areas and services provided in metropolitan areas is concerning:

...in that area of traditional end-of-life care there is a great lack of conformity around the country in terms of access to specialised palliative care services, and the heart-wrenching comments that have come to us from our members who work in regional and rural Australia really reflect that devastation of the oncologist trying to manage these patients right to the end, often as the only oncologist in town without the back-up of hospice facilities and community nursing and sometimes even access to basic drugs in local pharmacies that you would need for end-of-life care. So that is one problem. In the city, it is not so bad for that traditional pointy end of palliative care, but in the country it is a big problem.³

8.6 Professor Jane Phillips suggested that the effectiveness of palliative care service delivery could be improved through a more coordinated and focused approach at the federal level:

...we need to enhance the delivery of palliative care, strategically, at the Commonwealth level, either through a lead agency or through an enhanced palliative care division. That is really looking at the ways in which the Commonwealth needs to be able to work across operational boundaries, to focus on improving palliative care. If we look at the many reform documents that have been published, palliative care gets a mention in many of them, but it actually requires reform in primary care, aged care, acute care services and community based programs.⁴

8.7 A solution proffered by many witnesses to the current fragmented approach to palliative care was the introduction of a case manager to assist families and carers through what is an extremely difficult period.

The case management response

8.8 Mrs Fiona Engwirda spoke of the difficulties she encountered when trying to navigate the system to access services and equipment necessary to deliver palliative care to her daughter:

I am an educated and articulate member of the community and I cannot stress enough how difficult this process has been for me. I am concerned that other members of the community who may be isolated, may not speak English as a first language or may be marginalised with various reasons may be lost in the system when they should be supported. I acknowledge the difference that exists between disability and palliative care but also the

³ Association Professor Frances Boyle AM, Former Executive, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 41.

⁴ Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, p. 58.

crossover that is intrinsically linked for many children with complex medical conditions.⁵

8.9 When the views of stakeholders were sought on the idea of a case manager in the palliative care system, there was general support for case management as a key feature in the provision of palliative care given the level of fragmentation and the complexity of navigating the system.

8.10 Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Reference Group spoke of the pain parents encounter when trying to navigate the system and how this could be assisted through the implementation of a case manager:

Dr Hynson: She certainly would not be the first parent to make a comment like that. I had a father say to me that there were two nightmares: one was the illness and the fact that my child was dying, while the other was trying to navigate the system. There is layer upon layer—

Senator MOORE: And every state is different. There seems to be commonality in the fact that it is tough.

Dr Hynson: Yes. I was on the edge of my seat while listening very intently to the occupational therapist, because I am so familiar with the issue of families not being able to get the basic equipment they need and the respite. Parents very willingly take on the task of looking after their child. Home is the centre of care. All they are asking is that they have the information, the support and the infrastructure to do it, and that they can have a bit of a rest from time to time. Most of their requests are very modest. They are not asking for somebody to come and do this. They do not want to be in hospital, which is where they end up because the system is not great.

So, case management is a huge piece of it. In our experience it is patchy. If you get a good case manager everything works superbly. If you get a case manager at all, the experience and knowledge is variable.

Senator MOORE: Where would you get a case manager from?

Dr Hynson: A lot of families with children with conditions like this have packages of care. Some of them are able to—

Senator BOYCE: Through disability funding?

Dr Hynson: Yes, and a case manager may or may not come with that. If one does come, they may or may not have the expertise to know where to access other support for the family. We have a case manager with my team, and a lot of equivalent teams throughout Australia—

Senator MOORE: Based at the children's hospital?

Dr Hynson: Based at the children's hospital. So we would make sure families are linked into all the things that we are aware of and our case manager would work with others in the community to pull that all together. But, of course, not every family gets to us, or they get to us late when the clinical staff decide that the child is in a palliative phase. Because it is often

⁵ Mrs Fiona Engwirda, *Committee Hansard*, 2 July 2012, p. 24.

not acknowledged that that is where it is going, the referrals often do come late, which means families miss out on supports further upstream. I think that trying to put this into the control of families as much as we can would be a great thing, and trying to pull together some sort of one-stop shop that could be internet based is on our list of things to do. I think this is where the reference group could potentially be, because it already exists. I am happy to talk about how we could take it to a better place, but there is already—⁶

8.11 The Australian Nursing Federation informed the committee of their support for case management stating:

...it is absolutely imperative, particularly when there is distance involved, that there is someone who can really pull that together. I am sure you have heard lots of times about the different agencies involved and what a nightmare it is. Often, again, it is about who is in the community. I know that in some instances it might be the allied health person. It is about who has a good, permanent—and I underline the word 'permanent'—relationship with the individual in the community. We go on about fly-in fly-out, but that is another issue.⁷

8.12 Dr Yvonne McMaster, a retired palliative care physician explained how she considers case management could operate to ensure the provision of adequate palliative care:

What is needed now is a palliative care project manager in every Medicare Local, to ensure that palliative care has the right priority for the community. There are many things that that project manager could be doing. The rural nurses are overworked and overstretched, and many are approaching retirement age. They are holding on by their fingernails, doing a magnificent job—trying to teach the GPs, having to do battle with them; most have no office back-up and no relief; the conditions are almost Third World.

We need more social workers throughout rural New South Wales to ensure that the psychological, social and clinical needs are met. There is a big role for case coordinators, and social workers are filling in some of that, but they need Medicare items for end-of-life and palliative care consultations. That may be something the committee can carry forward.

What I am suggesting for rural palliative care is that 11 major towns in New South Wales be strengthened as palliative care hubs. Each should have funding for a palliative care specialist as soon as one can be found. We should be recruiting for palliative care specialists for these towns from the UK and New Zealand. I am told, however, that services are required to have six failed attempts at recruiting within Australia before they are allowed to

⁶ Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 27.

⁷ Ms Geri Malone, Australian Nursing Federation, *Committee Hansard*, 24 April pp. 42–43.

recruit overseas. It seems to me a good way to put off having to spend any money. Can you put a stop to this?⁸

8.13 The ACT branch of the Health Consumers' Association of Australia were also complimentary of the suggestion raised of having a case manager to assist carers navigate the system when trying to access palliative care services:

CHAIR: In the very short time we have got left I would like to ask about one of the issues that came up this morning, that it would be good to have case managers. We had an example of where Ms Jackman was telling us about her experience with her husband and trying to organise care and coordinate the care herself. She has experience in health care and herself did not know where to access particular services. We have subsequently discussed that with a number of witnesses. What are your thoughts? Would that be something useful if a case manager could be identified that can help the consumer access care, identify information and work out what they need when.

Ms Snell: Absolutely. I think that that model is incredibly valuable. We have often heard our members talk about having a navigator, which is a similar kind of model, within the hospital system, particularly for the elderly. It just gets beyond their ability to cope. Those people who have got family able to take time off work continually get by, but I think of those who do not have them, who are not that well-resourced. They are lost in the system.

Dr Stevens: I do think sometimes that the palliative care nurse practitioners in some ways function in that role.⁹

8.14 National Disability Services explained that case management could be particularly helpful in situations where a patient's needs are complex:

Case management is appropriate where the person's needs are complex and there are a number of parties that need to work together well. So in many cases that would be appropriate, I think, when a person reached the end stage of their life. The example we gave in our submission in relation to the NPY Women's Council and the way in which they managed to pull together a lot of relevant parties, some of which may not have been otherwise thought of, was, I think, a good indication of how a case management approach is quite important.¹⁰

The case manager

8.15 There was widespread support for the idea of a case management approach. The committee considered which professionals were well placed to be case managers,

⁸ Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, pp. 71–72.

⁹ Ms Kerry Snell, Consumer Representative Program Coordinator; Dr Adele Stevens, President, Health Care Consumers Association ACT, *Committee Hansard*, 24 April 2012, p. 49.

¹⁰ Dr Ken Baker, Chief Executive Officer, National Disability Services, *Committee Hansard*, 24 April 2012, p. 68.

and how case management can operate without adding additional layers of bureaucracy or complexity.

8.16 Services for Australian Rural and Remote Allied Health (SARRAH) suggested that although general practitioners (GP) were often suggested, in some rural and remote areas that was not practical and an allied health provider would be more appropriate:

Mr Wellington: The issue was raised about who should lead that case management team. We have a view that it does not necessarily need to be the GP. In some rural and remote settings there may not be a GP, it may be an allied health professional.

Mr Bishop: We have an amazing member from Western Australia who is a dietician who has worked in that community for many years and has a really strong rapport with the Aboriginal people in that community. That person, who has the trust and rapport of those people community, would seem to me to be the most appropriate person to be a case coordinator.

Mr Wellington: Another example, just leading on from that, relation to Aboriginal health workers in remote communities, where there are no GPs. Why shouldn't they be deemed as appropriate case coordinators, particularly given that there are a range of cultural issues that need to be acknowledged?¹¹

8.17 Alternatively, Palliative Care Australia suggested that the new Medicare Locals be used as a vehicle for delivering better palliative care to the community:

...we will have dialogue continuing as these Medicare Locals develop and evolve. Because palliative care is not that high profile, if you like, in the healthcare sector, there is a considerable amount of advocacy that needs to be done in this area, through Medicare Locals and through the boards being advised that palliative care is an important issue and that end-of-life care must be considered. It comes down to advising those boards about palliative care, and hopefully the process we are going through now is one measure to do that.

...when you talk about palliative care, it is like: 'No, we haven't really thought about that because we have a list of hundreds of other things that we see as priorities locally.' But, when you start to discuss palliative care in the sense that it is a public health issue and that it is an issue that really needs to be taken on board from a primary healthcare perspective, then they start to think, 'Yes, this is something we need to consider.' This comes back to the notion of Medicare Locals and local hospital networks becoming a bit more involved in it...¹²

¹¹ Mr Rod Wellington; Mr Michael Bishop, Life Member, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, p. 34.

¹² Dr Yvonne Luxford, Chief Executive Officer; Dr Ian White, National Policy and Communications Manager, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 20.

8.18 Catholic Health Australia however expressed some reticence at placing too many expectations and responsibilities on Medicare Locals:

We are in the process of rolling out Medicare Locals that are to be the hubs meant to oversee this coordination of services. I do not want to overburden the Medicare Locals because they have modest operational budgets and [there are] many aspirations for them. It would make sense that the Medicare Locals become the place in which aged-care providers, as the illustration, relate to ensure that there is access to the specialist palliative services within their aged-care facilities. That then triggers the discussion that the aged-care facility is not currently funded via the aged-care funding instrument for a specialist palliative care function. It is one thing to have access through the Medicare Locals to the coordination of it; it then needs to determine that the aged-care funding instrument would need to be expanded to have a specific palliative care capability within it.¹³

8.19 Palliative Care Nurses Australia (PCNA) suggested that GPs may reluctant to take on the workload that would be required of a case manager, and that nurses could effectively fill the role:

Some nurse practitioners are already working with GPs. They are in the GPs' surgeries seeing people and going out to visit them as well. They can take a lot of the load off the GP for the more run-of-the-mill issues that might arise. If somebody's pain management needs changing but nothing is really new apart from a slight increase in pain, then the nurse practitioner is able to just increase the current medication.¹⁴

8.20 The PCNA went on to explain how palliative care nurse practitioners would be effective case managers:

The care of somebody in that situation [community palliative care] is complex, and it can change very quickly. So a big part of the role of the palliative care nurse is being able to anticipate what might happen and talking to the family and saying, 'All right, if your relative deteriorates then these are some of the things we might have to look at—for example, putting the person into respite.' So it is helping the family come to terms with the fact that they may have to do that in the very near future...

...communication skills ... [are] fundamental to what we do in the area of palliative and end-of-life care. A lot of the problems that arise, particularly in the acute hospital setting, are because many health professionals, particularly medical specialists, are just not comfortable having those conversations about end of life and their communication skills are not necessarily excellent, shall we say.¹⁵

¹³ Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 36.

¹⁴ Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 61.

¹⁵ Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 62.

8.21 PCNA consider that palliative care nurse practitioners would be a natural fit for the case manager role:

...Having worked as a clinical palliative care nurse in the community, that is very much part of our role: going out, seeing how the patient and the family are managing and organising extra services for the family. Often they struggle with the amount of care that is required for the person with an end-of-life-stage illness at home... So it is a big ask for families, and as health professionals we recognise that and are very alert to the signs that they need more help.¹⁶

8.22 Professor Jane Phillips, a Professor of Palliative Nursing at the University of Notre Dame and St Vincent's Sacred Heart, echoed the views of PCNA explaining to the committee that nurse practitioners, in conjunction with Medicare Locals, could ensure effective delivery of palliative care services:

...nurse practitioners are an exciting and evolving role, but it is a role in which we really want to make sure that nurses are working in partnership with other members of the interdisciplinary team. It is not necessarily about being an independent practitioner. There is great scope to be thinking about nurse practitioners integrated into Medicare Locals.¹⁷

8.23 In making this point however, Professor Phillips highlighted the importance of ensuring consistency in the nurse practitioner role regardless of location.¹⁸

8.24 Despite hearing general support for the concept of a national case management system, Mrs Julianne Whyte of Amaranth Foundation expressed some reservations identifying the importance of first establishing how case management would actually work:

...in a lot of the Hansard reports and a lot of other submissions people talk about a 'case management' approach. I have really struggled in our research to look at what 'case management' meant and what it was. Even when I was working in care respite as a case manager there were issues around whether it was a professional case management or referral brokerage model—how people interpreted their role of case manager. Our research showed that it really needs a very professional social work type approach to a case management model, similar to what they are doing in mental health—recognising that it needs this comprehensive skill set that perhaps is not being provided at the moment.

...we found from our research that social work perhaps should be and could be the better profession to deliver a lot of the care coordination or supportive care that is not being provided to people in palliative and end-of-life care. Some of the research that we did, especially with the division of

16 Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 61.

17 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, pp. 60–61

18 Professor Jane Phillips, *Committee Hansard*, 2 July 2012, pp. 60–61.

general practice, that looked at how we worked with practice nurses, the linked nurses and the supportive care networks to get GPs to do case conferences, family meetings was a really good project with some fantastic outcomes but probably needs to be seated outside of the GP domain rather than within it, because I think it gets swallowed up by the processes within GP services rather than looking at what are the needs of families and caregivers.¹⁹

8.25 South Australia Health noted the advantages that could be gained through case management:

Absolutely. Yes, in an ideal world, a case management model at the diagnosis of a life-limiting illness would actively support people to navigate what is a very frightening and difficult area of health care, often because of all the factors that you have raised, and especially if you have a medical practitioner that does not believe in palliative care for a start, which is actually a difficulty that we encounter at a service level.²⁰

8.26 Although supportive of the concept of case management, South Australia Health identified that the key to ensuring access to and delivery of effective palliative care relies on the identification and establishment of appropriate clinical pathways, including diagnosis and referral:

It is certainly a challenging area. The work that we have looked at through the clinical network is to try and get pathways nailed that are clear and easy to use for the primary care providers specifically. We have a working party at the moment looking at referral criteria into palliative care, because I think that is the first area where it actually falls apart. We went through a stage many decades ago where palliative care accepted every comer, and now the demand has outstripped the resource and we have got specialist teams. So where is specialist palliative care different from general end-of-life care and how do we actually articulate that? The onus is on specialist palliative care services to make clear statements about what the referral criteria are, to make it clear and simple so that it is well understood and then support that with education.²¹

8.27 South Australia Health further explained that they are currently working on establishing and identifying these pathways and hope that it will ensure people do not fall through the gaps:

We have key clinicians and also the primary healthcare sector, oncology, all our chief referrers sitting around the table nutting out, right down to the language, what is going to make it clear and simple so that they will actually know whether this is a referral that will get into palliative care or whether they need to be going somewhere else. And if they are going somewhere else, palliative care also need to be clear in helping to guide

¹⁹ Mrs Julianne Whyte, Chief Executive Officer, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 28.

²⁰ Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 23.

²¹ Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 23.

them so that it does not become too hard and the gap opens and people fall through it.

The next phase of that work is looking at the patient pathway...We have got to look at that patient journey. That is something that the clinical network has been asked to review and, again, to look at it through the eyes of the consumer and not the eyes of the services. So there have been some directions about moving forward that we hope will start to address some of those concerns about consumers not getting services, or not knowing when to get them or how to get them, or what criteria are required for a referral to go through and be realised...

...of course it comes back to whose responsibility it is and whether specialist palliative care should take leadership, at least in being able to say, 'The referral's come through and we're going to coordinate other services to take care of the end-of-life non-specialist population.' That is going to need a lot of work to nut that out...²²

Committee comment

8.28 Throughout the course of its inquiry the committee has received much evidence suggesting that many people requiring palliative care are unable to access that care given the complexities of the health care system and its fragmented nature. The committee is concerned that the fragmentation of the palliative care system acts as yet another barrier at a time when families are most at need of the support that can be gained through the provision of palliative care services.

8.29 The committee considers that the role of case managers is important. It acknowledges the point made by Amaranth Foundation, that there are different case management models, and there needs to be clarity around what works best in palliative care.

8.30 Case management requires both a person to take on the role, and the allocation of responsibilities to that person. Patients and carers also need to be able to identify who the person is, and where they should go to obtain case management services. All of these things indicate that program funding of some sort would be required: if there is no recognition of the role and no money to pay for it, then it is unlikely to be done, and certainly unlikely to be done consistently, reliably or equitably.

8.31 For this reason a case management model will need recognition at a federal level with the agreement of all of the states and territories. As well as ensuring both funding and consistency, agreement is desirable to ensure that the implementation of such a model did not result in an additional layer of bureaucracy.

8.32 The committee acknowledges the work being undertaken in South Australia to map the palliative pathway in order to understand where general 'end-of-life-care' and specialist palliative care intersect and ensure that the health care providers, whether

²² Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 23.

they be aged care, primary care or palliative care specialists deliver a consistent and complete standard of palliative care for the patient's palliative journey.

Recommendation 12

8.33 The committee recommends that the Council of Australian Governments consider developing and implementing a case management model.

Recommendation 13

8.34 The committee recommends that the Council of Australian Governments develop and implement a uniform national palliative care pathway that clarifies when general palliative care moves into specialist palliative care, and maps the diagnosis and referral process to ensure that a palliative patient's journey involves coordinated access to all necessary services.

Recommendation 14

8.35 The committee recommends that the Council of Australian Governments review the Medicare Locals structure to consider how the provision of palliative care services, both general and specialist, is integrated into primary health care at the local level.

Chapter 9

Research and data

9.1 This chapter looks at research and data collection efforts in relation to palliative care needs in Australia. It outlines the current state of research and areas for improvement, including the need for a more strategic and coordinated national research agenda and priority areas for further research. The chapter examines some current research initiatives and also considers funding arrangements. Data collection is covered, including the need for clinical services to collect evidence in a systematic way in order to inform research and best practice in palliative care. Finally, the chapter will briefly look at issues around the evidence base for palliative care medicines, including complementary medicines.

A nationally coordinated approach to research is needed

9.2 Witnesses told the committee that palliative care needed to be nationally prioritised on Australia's research agenda, with appropriate funds and targeted research programs.¹

9.3 The Clinical Oncology Society of Australia (COSA) and Cancer Voices Australia (CVA) advocated in their submission:

An increased commitment to research implementation to ensure research findings are translated into clinical practice.

Establishing strategies to monitor and record all types of palliative care activity in Australia.

An emphasis on palliative care research in health and medical research funding mechanisms within Australia.²

9.4 Associate Professor Jennifer Philip, Co-Deputy Director of the Centre for Palliative Care, emphasised that a well-coordinated and strategic approach to palliative care research was necessary. She stated it was important that 'good care is underpinned by good-quality evidence and also that we are not wasting resources or, perhaps even worse, wasting people's precious time by giving them either ineffective or futile interventions'.³ She told the committee that a coordination approach, for example, through the Palliative Care Clinical Studies Collaborative (PaCCSC)⁴ was a

1 For example see Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 18.

2 Clinical Oncology Society of Australia and Cancer Voices Australia, *Submission 101*, p. 2.

3 Associate Professor Jennifer Philip, Co-Deputy Director, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 52.

4 Discussed further at the end of this chapter.

good initiative.⁵ Professor Philip also said that Canada and the UK were the countries Australia should be looking at benchmarking itself against in terms of research.⁶

9.5 Professor Patsy Yates, President Elect of Palliative Care Australia (PCA), commented that overall Australia was 'doing pretty well' when compared internationally in terms of palliative care research:

It has really only been in the last decade or so that we have started to see that develop in Australia. Some of that was due to some of the investment that was put in about 10 years ago for some dedicated money to build capacity in the palliative care research sector. I think that has really paid dividends in terms of enabling some really important research to be done.⁷

9.6 However, Professor Yates noted that further development of research evidence was needed in order to better inform areas of practice such as symptom management and models for coordinating patient care at the end of life. She noted that PCA has been engaging with specialist palliative care services to assist them to measure outcomes and use data to drive and improve their practice, stating 'services have taken to that fairly well but they still have a long way to go'.⁸

What is the current state of research?

9.7 The committee heard that there were several palliative care research initiatives underway and other smaller research projects. Information-sharing and networks of clinicians and researchers have also been set up, although fairly informally.

Examples of current work

9.8 The Centre for Palliative Care is an academic research and education centre, which is a collaborative centre of the University of Melbourne, based at St Vincent's Hospital. Associate Professor Mark Boughey, Co-Deputy Director of the Centre, told the committee that it had played 'a fairly significant role in the development of research activity' in the field of palliative care.⁹ Its submission stated:

The Centre has a state-wide role in palliative care education and research in Victoria, with networks and collaborative projects extending nationally and internationally. The Centre plays a pivotal role in the development and implementation of training and education programs for health professionals from a variety of disciplines, while undertaking cutting-edge research to set benchmarks and improve practices in palliative care.¹⁰

5 Professor Jennifer Philip, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 53.

6 Professor Jennifer Philip, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 56.

7 Professor Patsy Yates, President Elect, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 12.

8 Professor Patsy Yates, Palliative Care Australia, *Committee Hansard*, 10 July 2012, p. 12.

9 Associate Professor Mark Boughey, Co-Deputy Director, Centre for Palliative Care, *Committee Hansard*, 4 July 2012, p. 52.

10 Centre for Palliative Care, *Submission 110*, p. 1.

9.9 The Amaranth Foundation, which offers support and information to carers and families dealing with terminal illness and promotes a model of care that emphasises the psychosocial aspects of palliative care, said that the research it had published had attracted some attention:

We have had people come to us and say that when they were doing some research and literature searches—because we have just started publishing—that we are the only ones doing this type of work. We have had difficulty with—and respect to people who might be here in the audience—acceptance by the area health service. I have actually been drilled to within an inch of my life as to my professional competencies, my motivation and why we do what we do.¹¹

9.10 Mrs Julianne Whyte, Chief Executive Officer of the Amaranth Foundation, described to the committee some of the research projects she had undertaken, how some of the findings differed from existing healthcare literature, and how this had informed the Foundation's approach to palliative care:

...I was really lucky and fell into some amazing research positions that looked at care-planning needs of patients in rural and remote communities requiring palliative care. These were research opportunities funded under the Department of Health and Ageing Local Palliative Care Grants rounds 4, 5 and 6. I worked with the Commonwealth carer respite centres and the Riverina Division of General Practice, which is now the Murrumbidgee Medicare Local, and also in a private capacity as a social worker in that time. In that time we did quite a lot of research, literature and qualitative and quantitative assessment of what people really wanted in palliative and end-of-life care in the community. We really did not go into the acute care setting, but looked at what was happening in the community in rural and remote New South Wales.

From the work that we did back then, it has been over six years and we have worked with over 400 families. We really felt that we had a good grip on what people were saying were the problems and the issues that they had. What we found, too, was that a lot of stuff is out there about the delivering of bad news, how to communicate with people and what is needed by people; but what I found in my personal experience was that there was not a lot of translation from the research into the practical skills on the ground. There were no people doing what the research said people wanted. That was a bit of a struggle. Our final research project was the round 5, which was looking at mental health, dementia and palliative care. We took a mental health approach to that and looked at how people with a mental illness, whether pre-existing or as a result of their diagnosis, fitted in and managed the palliative care and end-of-life care journey.

We found quite an amazing mismatch between what the research said and people's personal lived experience—the whole aspect of distress, despair, demoralisation, suicidal ideation and how people responded to that within

11 Mrs Julianne Whyte, Chief Executive Officer, Amaranth Foundation, *Committee Hansard*, 12 July 2012, p. 35.

the healthcare system. Within the existing medical healthcare system but also from the mental health perspective. We found that the mental health and the acute care system rarely talk to each other. There was a real mismatch between what people were given on what people really wanted.¹²

9.11 Mrs Whyte is currently undertaking her PhD on the competency standards of social workers within end-of-life care. She has also started lecturing social workers and psychologist on psychological responses to palliative care at Charles Sturt University.¹³

9.12 Other organisations such as the Pharmacy Guild of Australia are currently undertaking research into the extended role of pharmacy in the palliative care setting.¹⁴

Networks and information sharing

9.13 When asked about what information-sharing networks were present in the palliative care community, Professor Jennifer Philip acknowledged that there was no formal network, but 'an informal network in terms of people [who] are mates and at the same time competitive' for research dollars. She spoke about a network in Victoria which has received funding from the Victorian Cancer Agency to enable greater information-sharing, although this is still in its infancy.¹⁵

9.14 Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Reference Group told the committee that the group she represented had 'self-organised':

Dr Hynson:...essentially we are a group of individuals who try to get together when we can, call each other when we can and do things by email. We have been the point of contact for the National Standards Program, NSP. We have also put together a blue booklet for general practitioners on palliative care for children with cancer and we are hoping to do the same for non-malignant conditions. If we had a small amount of funding to meet once a year, to have a few teleconferences and perhaps a project officer to help us with some of those things, we could really leap up exponentially and leverage that goodwill that is already there. It is a great group.

Senator SMITH: It strikes me that it is quite a representative group across the country.

Dr Hynson: We have all had to work very closely because we are all fairly isolated in our own states. Older members of the group have nurtured the younger ones, so there is a real spirit of bringing through the next

12 Mrs Julianne Whyte, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 27.

13 Mrs Julianne Whyte, Amaranth Foundation, *Committee Hansard*, 12 July 2012, p. 27.

14 Mr Harvey Cuthill, National Councillor, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, p. 4.

15 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 53.

generation and sharing. There is not a spirit of competition at all; it is very much about collaboration.¹⁶

What are some future research priorities?

9.15 Witnesses told the committee that research needed to continue in areas such as drug interventions and symptom interventions. Although these are probably the most well-researched aspects of palliative care, there are still evidence gaps.¹⁷ For example, Professor David Currow, Professor of Palliative and Supportive Services at Flinders University, spoke about evidence gaps around delirium and the risks and benefits of anti-psychotic medications:

...which are prescribed thousands of times each day for people who are acutely confused. We do not have any evidence that their benefit over and above good nursing care is there and, in fact, for some people they may be detrimental. We need to answer those questions and that may have important consequences for other parts of health care, particularly aged care, the acutely unwell as people come in from trauma or people in the post-operative setting.¹⁸

9.16 Psychosocial interventions were identified as a particular area needing further investigation:

...what really are effective ways of helping someone to look after someone at home, what is the most effective way to manage a person who develops a delirium at home when we know that is often a time when families will find it too difficult and bail out and take that person to hospital, even though it may well be in the very last period of time of life. I think some of those psychosocial interventions are a particular area. In Australia we have quite a lot of expertise in those but it has not been in a coordinated way, it has been around a couple of key people who have tried to do things bit by bit.¹⁹

9.17 Dr Hynson told the committee that further research on children receiving palliative care was needed. At the moment, she and her colleagues in paediatric care seek advice on symptom and pain management from those providing palliative care to adults. She noted the limitations of this approach, given the dearth of evidence in this area: 'A lot of the medications we use are not approved for use in children. We are doing it because we are having to push the boundaries in terms of extrapolating practice from adult practice into the paediatric world'.²⁰

16 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, and Senator Dean Smith, *Committee Hansard*, 4 July 2012, p. 30.

17 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 54.

18 Professor David Currow, Professor of Palliative and Supportive Services, Flinders University, *Committee Hansard*, 2 July 2012, p. 66.

19 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 54.

20 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 30.

9.18 Another area identified for research related to the information needs of parents who have a child diagnosed with a terminal illness. According to Mrs Fiona Engwirda, State Council Member and Consumer Representative for Palliative Care Queensland, the best pathway to enable swift referral and access to appropriate services should be the subject of further research.²¹ The role of families in palliative care was another suggestion for further research.²²

9.19 The Medical Oncology Group of Australia told the committee about a project it hoped to have funded, involving the delivery of care using telemedicine:

At its most basic, if you have a little Skype camera sitting on your laptop at home, you can interview a patient. From a regional cancer centre a specialised nurse, for instance, would be able to interview a patient and a carer, look at what pain levels they have, look at the medications they are taking, make suggestions about altering those and then check back in with that patient 24 hours later to see what has happened. A group of us in Australia are working on some national guidelines for cancer pain management and trying to pull together all the evidence and turn that into a program—if this, do that; if that, do that.²³

Recommendation 15

9.20 The committee recommends that the Commonwealth government increase its support for paediatric palliative care research.

Funding for palliative care research

9.21 The committee heard that grant funding for palliative care research largely came from the Commonwealth Government.²⁴

9.22 Professor Jennifer Philip emphasised that sustained funding was required in an area still in 'relative infancy' so that research programs could be built and more postgraduate positions could be created to be able to compete for grants.

It does take a little bit of time to get to that level, to evolve those centres of experience and excellence in order to be able to do that. So I think the notion of having some sustained funding for a period of time is important.

Having said that too little of the cancer dollar is going to palliative care, it is also true that the major area where palliative care research funding comes from is from cancer. Yet we know that people with heart disease et cetera also have requirements for palliative care. Those bodies probably need some encouragement for them to start considering directing some of the

21 Mrs Fiona Engwirda, *Committee Hansard*, 2 July 2012, p. 28.

22 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 53. See also Centre for Palliative Care, *Submission 110*, p. 2.

23 Associate Professor Frances Boyle AM, Former Executive, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 42.

24 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 25.

research dollars towards palliative care research, because it is important for that group of patients as well.²⁵

9.23 She noted a Canadian research model around palliative care which has been aimed at developing key research areas through five-year periods of funding:

...thereafter they have been able to create ongoing funding streams themselves, getting competitive grants. It has attracted a number of postdocs and has built capacity and world excellence in those areas. So it is an interesting model that may be of interest to the committee.²⁶

Cancer research funding and palliative care

9.24 The committee heard calls for palliative care to be integrated as a fundamental part of cancer care, including from a research perspective.²⁷ Professor Philip observed that not enough of the cancer research budget was currently being directed to palliative care:

We know that in other countries, particularly the US and the UK, palliative care research takes up less than one per cent of the cancer research budget. We do not have the figures for Australia, but we do know that between a quarter to a third—and, in some places, even higher—of people who are diagnosed with non-skin cancers will die from cancer. So, currently, an incommensurate amount of the research dollar is going to palliative care. Cancer Australia have agreed that they will audit their research output with respect to palliative care, so I think that is going to be done in the next round.²⁸

9.25 She said that in terms of National Health and Medical Research Council funding, she could recall at least two specifically targeted rounds in the last 12 years with palliative care as a priority. (From one of those funding rounds, Professor Philip had received a PhD scholarship.)²⁹

9.26 The committee notes that Cancer Australia collaborates with the NHMRC in administering the Priority-driven Collaborative Cancer Research Scheme. The Scheme is an 'annual national research project grants funding scheme which brings together government and other funders of cancer research to collaboratively fund cancer research in Australia'.³⁰ Funding bodies set priorities each year for that round of grants.³¹

25 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, pp. 52–3.

26 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 53.

27 Clinical Oncology Society of Australia and Cancer Voices Australia, *Submission 101*, p. 2.

28 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, p. 52.

29 Professor Jennifer Philip, *Committee Hansard*, 4 July 2012, pp. 53–4.

30 Cancer Australia, Priority-driven research <http://www.canceraustralia.gov.au/research-data/research/priority-driven-research> (accessed 2 October 2012).

31 Cancer Australia, Research priorities for 2012 <http://www.canceraustralia.gov.au/research-data/research/priority-driven-research/research-priorities-2012> (accessed 2 October 2012).

9.27 Ms Kate Swetenham from SA Health commented that grant funding is inherently unstable and that in an ideal world it would be good 'to have some positions bolted to the floor with some ongoing funding so that you can retain that research culture'. She added:

I think it is unsettling and nerve wracking for people who take on contract positions to near the end of their contract. Then they start to look elsewhere even though there might be a degree of comfort that this is likely to continue or develop into something else. Then you lose that critical mass that you have through their involvement and have to retrain someone else into it. So you are constantly experiencing downtime which impacts negatively on your ability to get things done in a timely fashion.³²

Data collection

9.28 Evidence from submitters and witnesses pointed to the need for consistent data collection practices to become embedded in the clinical environment and for systems to be set up to enable the accurate measurement of this data. The committee heard about the significant gaps in data collection and the consequences of this in terms of quality of care and services.

Lack of good data

9.29 Mr Peter Cleasby, President of Palliative Care New South Wales, commented that in New South Wales, palliative care data is not good and is 'contaminated by a range of different artefacts within the hospital system in particular'.³³

9.30 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre for Blue Care, expressed frustration that it was 'almost impossible to get good figures about how many people transfer from a residential aged-care facility into a hospital and actually die in the hospital; or do they come back?' She said that determining the advantages and disadvantages of transferring patients was constrained by this lack of data:

There is often a myth about the enormous volume of people being transferred from residential aged care into public hospitals to die, but we do not know the figures. We know how many people get transferred, but we do not know what happens to them once they are transferred—whether they come back. It is often appropriate to transfer somebody from residential care into a hospital—I am not saying that you should never do that—but until we really have a handle on the volume of that work and why those people are transferred and do not come back, it is hard to solve that problem.³⁴

32 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 27.

33 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, p. 48.

34 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre, Blue Care, *Committee Hansard*, 2 July 2012, p. 4.

9.31 Mr Trevor Carr, Chief Executive of the Victorian Healthcare Association, advocated the development of industry benchmarks and the strengthening of compliance with the 13 standards set by Palliative Care Australia. However, he acknowledged that a lack of good data available for external analysis made this task difficult.³⁵

9.32 The Clinical Oncology Society of Australia and Cancer Voices Australia suggested establishing a web portal for palliative care data and a mechanism for the collection of this data.³⁶

The role of the Commonwealth in supporting data collection

9.33 The Department of Health and Ageing appeared before the committee and outlined what funding had gone towards improving data collection in palliative care:

As part of the National Palliative Care Strategy we fund projects to improve data collection and, indeed, we have funded AIHW, the Australian Institute of Health and Welfare, over a number of years to improve national data on palliative care provision. We currently have a project over the years 2011-12 to 2013-14 which is focusing on developing performance indicators for the National Palliative Care Strategy, publication of annual compendium reports on palliative care data and associated work, and supporting a data subcommittee of the palliative care working group, which is the group of all Commonwealth, state and territory officials. Nevertheless, this is an iterative process and data in these areas is improving...Certainly the goal is to progressively improve the comprehensiveness, quality, comparability and consistency of palliative care data more broadly.³⁷

The role of clinical services in contributing to the evidence base

9.34 Several witnesses told the committee that it was crucial that clinical services delivering palliative care should build in measurement, data collection and evaluation of outcomes in order to contribute to growing the evidence base for the best interventions and management approaches.

9.35 For example, Professor David Currow, Professor of Palliative and Supportive Services at Flinders University, acknowledged it was 'very tempting' for specialist services to focus only on clinical matters, but he stressed that:

...if we do that we do not progress the research evidence base that will improve the models of care and the clinical care we offer, and we will not progress the education that needs to be provided to colleagues who are currently in practice and for whom this was not part of their training.³⁸

35 Mr Trevor Carr, Chief Executive, Victorian Healthcare Association, *Committee Hansard*, 4 July 2012, p. 11.

36 Clinical Oncology Society of Australia and Cancer Voices Australia, *Submission 101*, p. 1.

37 Ms Alice Creelman, Assistant Secretary, Cancer and Palliative Care Branch, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, p. 44.

38 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 63.

9.36 In South Australia, full tertiary palliative care services (designated as 'level 6 services') are required to provide research evidence and input into education programs across the undergraduate and postgraduate curricula.³⁹

9.37 Associate Professor Rohan Vora, President of Palliative Care Queensland, was a strong advocate for mandatory data collection and measurement of patient outcomes:

This is absolutely vital and we need to be funded to be able to do that to get some meaningful data. At the moment, each service has to try to find somewhere within it, along with service provision, someone who is actually going to collect this data and down clinical time to do it.⁴⁰

Current data collection work

9.38 While noting the real need for better palliative care data collection, the committee was pleased to hear about some existing initiatives to drive improvement in this area.

Palliative Care Outcomes Collaboration

9.39 The committee heard about the Palliative Care Outcomes Collaboration (PCOC). Its submission outlined its role:

Palliative Care Outcomes Collaboration (PCOC) is an excellent example of a national and voluntary programme using benchmarking to measure outcomes in palliative care. PCOC assists palliative care providers to improve patient outcomes by enabling their clinicians to accurately assess the quantity of care they provide to their patients.

PCOC obtains and reports on information regarding patient care and symptom management. This information supports clinicians in their treatment decisions, assists managers in their service planning and informs policy makers in funding and planning services.

Participating palliative care services submit their data sets biannually to PCOC, enabling PCOC to develop state and national data sets. These datasets are analysed and reported to services, providing them with feedback of their performance, recognition of their achievements and opportunities for quality improvement in their delivery of patient care.

With the primary aim of enhancing palliative care delivery in Australia, PCOC works to support palliative care services by providing education, report analysis and participation in research and quality improvement activities.⁴¹

9.40 Blue Care appeared before the committee and stated that the work of the PCOC had been compromised to some extent by a lack of willingness from large

39 Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 22.

40 Associate Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, pp. 24–5.

41 Palliative Care Outcomes Collaboration, *Submission 111*, p. 1.

organisations to participate in data collection for PCOC. They described the 'extra administrative burden' felt by some organisations in Queensland which hampered good data collection.⁴²

9.41 Professor David Currow responded to these observations, acknowledging that embedding data collection practices into clinical care would naturally take time:

...we are asking for a data naive clinical community to very rapidly collect data at point of care and start to compare with each other in a benchmarking process. That is a difficult issue for any community. If we look across clinical care, we can look to emergency medicine, intensive care, some of the surgical subspecialties, neonatal care and, to a lesser extent, maternal and child health as the only other areas that are really taking on data collection at this sort of level of granularity.

It is not particularly onerous and we have seen small, relatively poorly resourced teams not only come on board; most importantly, their key success factor has been embedding this into their day-to-day clinical work. This is not esoterica out here; it is actually practical stuff. It is stuff that we say to the community we do well—things like, 'What is the pain control like for this person today?'⁴³

9.42 Professor Currow described how the PCOC had succeeded in getting the palliative care sector engaged in reporting of data:

Within a very short space of time, 2006 to 2012, to have this up and running, where we estimate that 80 per cent of all people referred to specialist palliative care services are covered, is a tremendous engagement of the sector.

We have seen lots of services who can now say, 'We've collected the data for the first time systematically. We've seen a problem. We've put a program in place to address that problem and we've seen our outcomes improve.' There were lots of people who said, 'You can't measure outcomes in palliative care.' Clearly we can and they are patient centred outcomes: 'What is your symptom control like? What are we doing to better maintain your level of function in the face of inexorable decline?' And, yes, there are a couple of very notable services across the country that are not participating, but they are the exceptions now.⁴⁴

9.43 He acknowledged the reticence of some services to participate fully in the work of the PCOC, noting that some groups within the Collaborative 'have really been challenged by some of their results':

Prof. Currow:...This is not a comfortable place for every service to be. If we look at a median, half the services are going to be below the [median]. So the investment has been to work alongside services to look at how the

42 Associate Professor Deborah Parker, Blue Care, *Committee Hansard*, 2 July 2012, p. 4.

43 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 65.

44 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 65.

quality of that care can be improved, and that is what we are starting to see now.

...

Senator MOORE: Has there been any attempt to link this data to funding? Would you be afraid that, if you gave data and it did not look good, you might not get funding?

Prof. Currow: It is a voluntary program at the moment and it has been deliberately voluntary for a couple of reasons. You have absolutely identified the major one. There is another large service provider that is participating in yet another state, and they were already collecting much of this data and their funding was contingent on it. They have had to look at how they collect their data so that they are actually reflecting patient centred responses.⁴⁵

Mortality reviews

9.44 Associate Professor Rohan Vora described to the committee a process developed on the Gold Coast known as a mortality review for expected deaths. These reviews are normally done for unexpected deaths, but not usually for expected deaths. Mortality reviews examine the 'quality of death'.⁴⁶ Associate Professor Vora explained:

Mortality reviews are usually there to see whether you should have informed the coroner or done something different to avoid death. We have introduced a different type of mortality review and continue to do that. Mortality reviews, we believe, should also include expected deaths—that should be audited for quality of care, carer support and bereavement follow-up plans.⁴⁷

Committee view

9.45 The committee considers that building the research and evidence base for palliative care in Australia is crucial to improving service delivery and quality of care. There is a need for a more strategic and coordinated research agenda, underpinned by adequate funding. In this regard, the Committee notes that the government in 2011 commissioned the Strategic Review of Health and Medical Research in Australia, chaired by Simon McKeon AO. This review has a number of terms of reference relevant to the preceding discussion, including 'current expenditure on, and support for, health and medical research in Australia by governments at all levels', 'ways in which the broader health reform process can be leveraged to improve research and translation opportunities in preventative health and in the primary, aged and acute care sectors', and 'the degree of alignment between Australia's health and medical research

45 Professor David Currow and Senator Claire Moore, *Committee Hansard*, 2 July 2012, p. 65.

46 Associate Professor Rohan Vora, Palliative Care Queensland, *Committee Hansard*, 2 July 2012, p. 32.

47 Associate Professor Rohan Vora, President-Elect, Australasian Chapter of Palliative Medicine, *Committee Hansard*, 2 July 2012, p. 10.

activities and the determinants of good health'.⁴⁸ The committee notes that the NHMRC and Centre for Palliative Care were submitters to this process, which is ongoing.

Recommendation 16

9.46 The committee recommends that Cancer Australia, in reviewing the distribution of research funding, discuss with funding bodies the capacity to ensure that appropriate levels of funding are being provided to palliative care research.

9.47 The committee also supports a systematic approach to data collection and measurement. It acknowledges the good work of the Palliative Care Outcomes Collaboration and considers that improvements in data collection and evaluation would not only lead to better translation of clinical evidence into best practice evidence, guidelines and standards, but increased efficiencies in terms of resource allocation and costs to the health system through better knowledge of what works well in palliative care.

Recommendation 17

9.48 The committee recommends that governments encourage care providers to provide data to the Palliative Care Outcomes Collaboration and consider making the reporting of this data a condition of public funding.

9.49 The committee notes the recommendation of the Centre for Palliative Care:

Develop a nationally funded framework for palliative care research that:

1. Provides funding for the development of research programs specifically addressing symptom management, psychosocial support (including family carers and bereavement), and health service evaluation.
2. Invests in capacity building by developing a critical mass of palliative care researchers.
3. Creates a “whole of health” approach to palliative care research that incorporates cancer care and non-malignant diseases.
4. Focuses on strategies to translate research into practice in specialist and generalist settings.⁴⁹

Recommendation 18

9.50 The committee recommends that the Australian government develop a nationally funded framework for palliative care research, as outlined by the Centre for Palliative Care.

48 Strategic Review of Health and Medical Research in Australia, Terms of Reference, http://www.mckeeonreview.org.au/9937/Terms_of_Reference/ (accessed 2 October 2012).

49 Centre for Palliative Care, *Submission 110*, p. 3.

Evidence base for medicines

Palliative Care Clinical Studies Collaborative

9.51 The Palliative Care Clinical Studies Collaborative (PaCCSC) was first funded in 2002–03.⁵⁰ Administered by Flinders University⁵¹ and led by Professor David Currow, the Collaborative's focus is multi-site clinical drug trials to gather evidence to register palliative care medicines on the Australian Register of Therapeutic Goods and possible listings on the Pharmaceutical Benefits Scheme (PBS).⁵²

9.52 Professor David Currow explained to the committee that the PaCCSC's funding from the Commonwealth currently runs until mid-2014. He said there had been 'a fantastic return on investment' from this collaborative work—for example:

We were delighted last year, for example, to have three sites where the Australian Council on Healthcare Standards—and these were not sites that were just palliative care; they were across the range of clinical care—singled out the palliative care units for the quality of the work that they were doing as the most highly commended on site, and that was because of the Palliative Care Clinical Studies Collaborative. So there are direct collateral benefits that patients, their families and staff will experience because of that investment by the Commonwealth.⁵³

9.53 The committee heard from Professor Currow about the work that had been done over the last decade by the PaCCSC on the evidence base for medicines used in palliative care. In 2000 from a national survey, a number of medications were identified as critical to community based palliative care. Work was done to have some of these medicines listed for subsidy on the PBS in 2004. However, for other medications in widespread use, not enough evidence for their effectiveness had been identified:

The Commonwealth then put out a tender for an organisation to lead national, collaborative, multisite research for clinical trials at a level of quality that would inform both registration with the Therapeutic Goods Administration and importantly subsequent subsidy, were they to be positive studies with the Pharmaceutical Benefits Advisory Committee [PBAC].

I want to go on record as saying that, as those studies were developed, the TGA [Therapeutic Goods Administration] and the PBAC offered to every

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

51 The PaCCSC comprises Flinders University/Southern Adelaide Palliative Services, Sydney Cancer Centre, Sydney South West Area Palliative Care Service – Liverpool Palliative Care Services, WA Centre for Cancer and Palliative Care, Centre for Palliative Care Research and Education/Queensland University of Technology/Mater Health Service and the Peter MacCallum Cancer Institute.

52 'Increased access to palliative medicines in the community', Department of Health and Ageing, <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program-prio2> (accessed 14 September 2012).

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

company, every new triallist, the opportunity to talk about the design. We have done that ahead of these ever going to ethics committees and their input has been absolutely invaluable in refining that process. At the moment, there are 12 sites across Australia who are participating in these studies. They cannot be done in other populations. We cannot take information from a population of people who are relatively well and extrapolate it into [these] populations who are frail, on many medications and need to have evidence developed for them. Two of those studies have already been completed and are being reported at the moment. Importantly, some of these findings will be able to be extrapolated to other areas of health care.⁵⁴

Complementary medicine

9.54 In discussion with the Medical Oncology Group of Australia, the committee heard that complementary medicines are widely used in palliative care and that there was a lack of research around the evidence for these substances, such as herbs and vitamins, which have sometimes been recommended to patients by general practitioners. Associate Professor Frances Boyle, Former Executive of the Medical Oncology Group of Australia, told the committee of the risks involved in mixing these therapies with chemotherapy drugs:

It is almost impossible then to work out what the interactions might be with chemotherapy drugs. Many chemotherapy drugs are made from plants and for that reason they have the potential, in the liver, to interact and change each other's metabolism. We have the greatest respect for medicinal plants. We cure a lot of cancer with them—but by knowing what the active ingredient is and purifying it rather than by having something that you are taking orally, with poor labelling. The other thing, of course, is that there is increasing evidence that things like meditation, relaxation and so forth are beneficial to cancer patients. I do not think that the herbs and spices really fall into the same category as many of the other mind-body type things where there is clear evidence of benefit. We encourage patients with advanced cancer to become involved in those things.⁵⁵

9.55 Ms Kay Francis, Executive Officer, added that the Medical Oncology Group of Australia held significant concerns about the lack of regulation of complementary medicines:

Ms Francis:...The media are constantly hyping up all of these quite often bogus treatments and recipes for a 'solution' to cancer or any number of diseases. But we have a totally unregulated market. It is absolutely extraordinary, when we have such an effective health system and controls in place in all other areas of drug access in this country.

Senator FIERRAVANTI-WELLS: Your comments do not appear to deny that there should be complementary medicines—

54 Professor David Currow, *Committee Hansard*, 2 July 2012, p. 66.

55 Associate Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 44.

Ms Francis: No, not at all.

Senator FIERRAVANTI-WELLS: There is a role for them but it is part of a more holistic and a more—

Ms Francis: Exactly. We need to have, whether it is the Therapeutic Goods Administration or some other new body that needs to be established in the Department of Health and Ageing, I think it is time at a federal level that we address this.

Senator FIERRAVANTI-WELLS: I think there is now quite a high usage of complementary medicines in Australia.

Ms Francis: I think that something like 75 per cent of patients across the board in Australia use some form of complementary medicine, regardless of their condition.⁵⁶

9.56 Professor Boyle noted that the National Health and Medical Research Council (NHMRC) is now looking more closely at complementary medicines and that 'there are a number of groups around the country who would have the appropriate scientific rationale and background to do appropriate research in that area'.⁵⁷

Committee view

9.57 The committee notes that complementary medicines are in widespread use around Australia. It acknowledges the concerns of expert clinicians from the field of cancer care regarding the lack of evidence and regulation of these alternative therapies. The committee welcomes the work being done by the NHMRC⁵⁸ into examining 'alternative therapy claims' and supports further research being conducted into the interactions of complementary medicines with evidence-based drugs used specifically for cancer care and palliative care.

Recommendation 19

9.58 The committee recommends that the NHMRC publicly report the results of its work on alternative therapy claims in relation to palliative care.

56 Ms Kay Francis, Executive Officer, Medical Oncology Group of Australia, and Senator Concetta Fierravanti-Wells, *Committee Hansard*, 2 July 2012, p. 44.

57 Associate Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 44.

58 See 'Complementary medicines', National Health and Medical Research Council, <http://www.nhmrc.gov.au/your-health/complementary-medicines> (accessed 14 September 2012).

Chapter 10

Accessing equipment

Background

10.1 This chapter examines the evidence which the committee received concerning the difficulties faced by palliative care recipients in accessing equipment. As the majority of patients with life limiting illnesses desire to be cared for and pass away in the community or home setting, aids and equipment are necessary to help achieve that goal.

10.2 In the course of the committee's inquiry, much reference was made to the Home and Community Care (HACC) program and its important role in assisting palliative care recipients.¹ Although the HACC program is broader than equipment provision, the evidence the committee received highlighted the important role equipment plays in supporting those patients with life limiting illnesses who are not being cared for in a hospital setting.

The HACC program

What is the HACC program?

10.3 The Commonwealth HACC Program provides services that support older people to be more independent at home and in the community. HACC services include:

- nursing care;
- allied health services like podiatry, physiotherapy and speech pathology;
- domestic assistance, including help with cleaning, washing and shopping;
- personal care, such as help with bathing, dressing, grooming and eating;
- social support;
- home maintenance;
- home modifications;
- assistance with food preparation in the home;
- delivery of meals;

1 The HACC program, which was previously jointly funded by the federal and state and territory governments, became a federal government program from 1 July 2012. HACC services can be accessed by people aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people), who are at risk of premature or inappropriate admission to long term residential care, and carers of older Australians eligible for services under the Commonwealth HACC Program. Source: <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> (accessed 26 September 2012).

- transport;
- assessment, client care coordination and case management;
- counselling, information and advocacy services;
- centre-based day care; and
- support for carers including respite services.²

10.4 The eligibility requirements to enable access to the Commonwealth HACC program require that a person be:

- aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people); and
- at risk of premature or inappropriate admission to long term residential care; or
- a carer of older Australians eligible for services under the Commonwealth HACC Program.³

Recent changes

10.5 The Department of Health and Ageing (DoHA/the department) explained the recent changes that were made to the HACC program and which took effect from 1 July 2012:

From 1 July 2012 the Commonwealth HACC Program will provide funding for basic community care services which support frail older people and their carers, who live in the community and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long term residential care. The target population for the Commonwealth HACC Program are frail older people with functional limitations as a result of moderate, severe and profound disabilities and the unpaid carers of these frail older people. Older people are people aged 65 years and over and Aboriginal and Torres Strait Islander people aged 50 years and over.⁴

10.6 DoHA explained that as a result of the changes the responsibility for the provision of such services to younger people will remain with the state and territory

2 Department of Health and Ageing, Commonwealth Home and Community Care (HACC) Program, <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> (accessed 28 September 2012).

3 Department of Health and Ageing, Commonwealth Home and Community Care (HACC) Program, <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> (accessed 28 September 2012).

4 Department of Health and Ageing, answers to questions on notice (question 7) received 23 May 2012.

governments.⁵ The department also informed the committee that the HACC program is not designed to provide specialist palliative care services although those receiving HACC services may in fact be palliative care patients:

The Commonwealth HACC Program does not provide specialist palliative care services as these services continue to be outside the scope of the Program. However, people who are receiving palliative care services may also be part of the Commonwealth HACC target population and therefore may be eligible to receive basic maintenance, support and care services. Commonwealth HACC services may be provided to people receiving palliative care services as long as these services are not expected to be provided as part of the general suite of specialist palliative care services.

People that are in the target population will be assessed to establish the type and extent of their support needs. Services will be provided based on this assessment, the priority of need of the person and the capacity of the service provider to deliver support within existing resources. Support through the Commonwealth HACC Program is also available to carers of eligible people.⁶

10.7 The committee acknowledges that as the recent changes to HACC only took effect from 1 July 2012, it is too soon to tell whether or not they have improved access to services and equipment for the majority of palliative care recipients. However, stakeholders identified a number of areas which at times presented barriers or limitations to the HACC and state run equipment programs. Among these barriers were the need to improve access to equipment, particularly for younger patients including children, and the need for greater regulation of equipment.

10.8 Services for Australian Rural and Remote Allied Health (SARRAH) explained these difficulties succinctly:

In Australia we have a very fragmented and hopeless group of systems in terms of equipment provision across the states... each state has a totally different way of providing equipment to support people in palliative care, in disability and in the acute health system. How people can access equipment depends on the way the states run those. So there is money provided by the Commonwealth to support palliative care equipment but that is usually a

5 State and Territory governments will continue to fund and administer basic community care services for people under 65 years and Aboriginal and Torres Strait Islander people aged under 50 years. This change in responsibility applies to all states and territories except Western Australia and Victoria who are not participating in the reforms to HACC. Basic community care services for frail older people and younger people with disability in Victoria and Western Australia will continue to be delivered under the Home and Community Care Program as a joint Commonwealth-State funded program, until otherwise agreed. Source: Department of Health and Ageing, answers to questions on notice (question 7) received 23 May 2012.

6 Department of Health and Ageing, answers to questions on notice (question 7) received 23 May 2012.

separate pool of equipment that is managed by the states or by the disability sector. It really is a dog's breakfast.⁷

Better access

10.9 The Victorian Palliative Care Special Interest Group of Occupational Therapy Australia (OTA) provided the committee with an example of the practical difficulties patients requiring palliative care have experienced when trying to access equipment either through the HACC program or other state-funded/based programs. They explained that in Victoria, hospitals are required to provide equipment for a 28 day period following a patient's discharge even though the patient may clearly require equipment for a longer period of time:

Hospitals are required to provide equipment for 28 days post discharge... Sometimes that works in palliative care because people can get re-admitted within the 28 days. But it is also dependent very much on service to service.⁸

10.10 OTA further explained that access to equipment may also be affected by the associated hire costs, which are often prohibitive and vary considerably despite the fact that the costs that would be associated with caring for those patients in hospital would be many times more.⁹

10.11 OTA explained that given the prohibitive costs families often incur when hiring equipment, some service providers seek to assist at a financial cost to themselves:

...I do not charge any of my patients for any equipment for palliative care that I have; other hospitals do. I think it is a bit rough being asked to fork out money when there is enough other stuff going on, but other services do. And you have to manage that financially as well. We have a high turnover so it keeps coming back and that is how we manage that. The other patients are charged. If somebody needs something longer, say, an electric hoist at home, we will pay for that for the month. We have no budget to pay for that. We have to but we have no budget. Then the family pick up the cost after that or sometimes they can access money through unassigned bed funds.¹⁰

10.12 The financial barriers to accessing equipment were also raised by Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Reference Group. Dr Hynson explained:

7 Mr Michael Bishop, Life Member, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, pp. 32–33.

8 Ms Deidre Morgan, Senior Occupational Therapist, Palliative Care, Peninsula Health, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 23.

9 Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

10 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 23.

...we have exactly the same issues [as OTA] with families of young children trying to obtain equipment. We have state based organisations and, on the surface, it looks as though you can get equipment but the subsidies have not changed in 15... to 20 years. The total cost for a motorised wheelchair might be \$12,000 to \$15,000, but the contribution from the state might be \$3,000. Then the family has to find the gap. The wheelchair cannot be ordered until the gap is found. So you find families fundraising and having parties to try to get the rest of the money. A good case manager will be trying to source things.¹¹

10.13 Dr Hynson informed the committee that although the hospital program she runs has flexible funds attached to it which enable the hospital to pay the gap for families, the fund was only established after a couple of instances where children died waiting:

A couple of children died waiting for equipment or for handrails to be put in their house so they could get around and, by the time the handrails got there, they had lost the ability to walk. The family was left with this constant reminder. So a couple of bad things happened that ended up with us holding that flexible fund. We have to manage that very tightly.¹²

10.14 Dr Hynson explained the optimism some have in the introduction of the National Disability Insurance Scheme; they see it as a way of ensuring such circumstances do not arise by providing basic services including equipment and supplies for children suffering life limiting illnesses:

We are hoping that perhaps a disability insurance scheme will mean that families do not have to fight for basic supplies. The very disabled kids do not just need a wheelchair, as the OTs were saying; they need a whole lot of other stuff as well. So it [the cost] adds up.¹³

10.15 In addition to long waiting times, the committee also heard of time limits being imposed on the provision of equipment and services. According to SARRAH this is occurring in Queensland:

...access to equipment in some instances is capped at three months but other states have various arrangements. To reinforce what Michael said, it is all over the shop. There is no standardisation: the provision of equipment in some states is insufficient, whilst in others there is no cap.

...Just an example: if you drive around Tweed Heads, outside nearly every second house there is for sale a motor scooter that has been provided by the government or that has been purchased and that they cannot get rid of, yet

11 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 31.

12 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 31.

13 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 31.

there are all these other people who cannot access these. So it is really very fragmented.¹⁴

10.16 Dr Ken Baker, Chief Executive Officer of National Disability Services (NDS) also explained to the committee that access to equipment and aids in rural areas, due to the scarcity of resources, often requires care providers to take an 'ad hoc' approach when determining what services can be provided:

...in rural services there is often quite an ad hoc approach to constructing whatever package of supports is available from wherever it can be drawn. It is probably not a usual function of HACC to provide this, but in rural areas organisations often have to be very innovative as to how they put together support for people.¹⁵

10.17 Dr Baker also spoke of difficulties of palliative care recipients in group homes accessing equipment under the HACC program in a timely manner:

There has been a longstanding barrier to people in group homes accessing any HACC support whatsoever. There is a commitment in the National Disability Agreement to resolve that barrier and perhaps the National Healthcare Agreement may assist in doing that. This is an example of where there are a range of HACC services that are available to the people in the general community that are not available to people in group homes. The assumption is that people in group homes can get everything they need through the specialist disability service system. It is not true and it disadvantages people with disability.¹⁶

National inconsistencies

10.18 In addition to identifying the need for better access to HACC and HACC-like programs, concerns were consistently raised that patients who do not qualify for HACC are falling through the cracks as the state equipment programs are not adequate.

10.19 Eastern Palliative Care (EPC) explained that the inability of patients, particularly those who do not fall into the aged care criteria, to access HACC services or equipment, is having a negative impact on the quality of care. EPC explained:

Ms Pedley: The difficulty we have for the under-64s is that they do not come under the HACC funding, so they are often denied community based services through local governments.

CHAIR: So they do not qualify for HACC because they do not have a disability—

Ms Moody: That is right.

14 Mr Michael Bishop, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, pp. 32–33.

15 Dr Ken Baker, Chief Executive Officer, National Disability Service, *Committee Hansard*, 24 April 2012, p. 67.

16 Dr Ken Baker, National Disability Service, *Committee Hansard*, 24 April 2012, p. 67.

CHAIR: or they are under 65. Okay.

Ms Moody: That is a real problem with all of the government programs: it is a capsule. If you fall outside that capsule, you miss out on very good support services.¹⁷

10.20 The issue of people under the age of 65 not being able to access HACC services was raised again by the OTA as a major concern:

My concern...is that there are a lot of people on that palliative care or non-curative pathway who do not fall into that aged-care bracket. That is one of the limits. We get a lot of people in their 40s and 50s who do not meet those ACAT criteria or HACC funding criteria. There are a lot of ways that that particular age group falls through many gaps...Certainly in haematology the age groups are huge. I know Olivia's specialty is in adolescent and young adult care. So there is a raft of people and a lot of age groups that just miss out altogether if we just go down the aged-care/ACAT pathway.¹⁸

10.21 Ms Deidre Morgan, an occupational therapist and member of OTA, explained how access to occupational therapy and other services through a HACC like system for younger people is fundamental. Ms Morgan identified that often younger palliative patients do not receive rehabilitation funding as they do not show improvement and therefore separate and additional funding for them is required:

Often rehab funding is based on improvement. If you are not improving then you are discharged. The terminology that is often used is that they have 'failed'. We struggle to get younger people. Yesterday I visited the home of a 39-year-old who nearly fell down the steps while we were there. His goal is to go down the steps every night so that he can lie in bed with his two daughters and read them stories.

...And there is that pressure of funding, so I think we need to be looking at an alternative funding model for rehab for people at the end of life. It is not just cancer; it is the chronic neuros, MND, MS, Parkinson's. These groups of people do not consistently improve and they dip out—they do not access HACC funding.¹⁹

10.22 OTA identified that in these instances, where these younger palliative patients cannot access support services in the community environment, for example through HACC and HACC-like programs, they end up in hospital:

Quite often they will be taking up an acute bed for enormous amounts of time because there is a big black hole there; they cannot be supported in the community with their level of decreased capacity.²⁰

17 Ms Christine Pedley, Manager, Allied Health, Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, pp. 6–7.

18 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 22.

19 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 22.

20 Mr Andrew Smith, Registered Occupational Therapist, Leukaemia Foundation, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 22.

10.23 Professor Jane Phillips, a professor of nursing at Notre Dame University and St Vincent's Sacred Heart, also explained the importance of immediate access to HACC or equivalent services – explaining that it is a requirement not only for the patient with the life-limiting illness but also for the carer and/or family who require support:

The thing is that for palliative care there cannot be a waiting list. When we think about HACC services, they are not only for the patient; equally importantly, they are quite often there to support carers to be able to manage. I think one of the things that is not necessarily clearly articulated in a lot of palliative care policy is that people can only stay at home with an invisible network of people supporting them to remain there. That is unpaid carers, augmented with paid carers.²¹

10.24 Professor Phillips also called for the HACC program to be reviewed as a matter of priority given that palliative care recipients will not always be aged care recipients able to access services on account of their age:

Reviewing the way in which HACC is made available to people with palliative care needs is a really important priority. There is great variability, as you have no doubt heard as you have travelled around Australia, in the way in which people can access HACC services. Sometimes for palliative care patients they are not necessarily available, and that may be because an area has exceeded its available funding and there is a waiting list.²²

10.25 Given the evidence it received identifying that different approaches to the administration of equipment and aid programs, the committee sought to understand whether there were national standards and guidelines that applied to the administration of the HACC program:

Senator MOORE: So we have got tomes of guidelines—and they are big; I have seen them, pages and pages—we have the core standard for aged care, and the Commonwealth now has the ownership of HACC. Are there any standards within the HACC Program looking at palliative care?

Ms Balmanno: HACC providers, prior to 1 July and continuing after 1 July, need to comply with the Community Care Common Standards, which are the same standards that are applied to community care providers under the Aged Care Act—so for package care providers.

Senator MOORE: So it is a standard two lines in terms of the standard, and then the big guidelines.

Ms Balmanno: The standards themselves are quite short. The review process against the standards, in terms of what is considered in assessing compliance with the standards and whether people are meeting the standards, is much more involved, which is causing us some challenges with the transfer of HACC providers to the Commonwealth, because

21 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, p. 60.

22 Professor Jane Phillips, *Committee Hansard*, 2 July 2012, p. 60.

obviously some of them are quite small services through to quite big services who would be performing palliative care-type arrangements in the community and things like that. We also have the very small Meals on Wheels team and others who are operating in a different way. But it is the same standards that apply.²³

Is there a better approach?

Is better regulation required?

10.26 When providing evidence to the committee, OTA explained that community service providers and district nurses no longer own equipment due to the storage problems and maintenance costs. However as the hospitals hold the equipment it is they that now grapple with these issues, but generally handle them differently.²⁴

10.27 OTA also commented on a new problem – the incorrect prescription of equipment – and the importance of prescribing the appropriate equipment:

...you do not want to prescribe something that is going to make somebody more dependent and more physically unable to care for themselves and be at home for as long as possible.²⁵

10.28 OTA informed the committee of instances in which case a person who has had their drivers' license revoked can purchase a motorised scooter:

You can go into an equipment shop and buy a scooter, which is another dodgy issue when you have had your car licence taken away... Somebody can have their licence removed, because they are unsafe to drive because they have a visual defect with hemiparesis, and go to a shop that sells medical health equipment—and they are popping up everywhere—and be sold a scooter for several thousand dollars and pop off down the road with a little orange flag. I know there has been at least one death or even two deaths while crossing four-lane roads.²⁶

An equipment library?

10.29 In the course of the committee's inquiry, reference was made to the Motor Neurone Disease (MND) equipment library that operates in Victoria. The committee sought more information in relation to this program:

MND is obviously a relatively small diagnostic group and it has a relatively predictable and enormous decline in function from walking to only being able to... It has an enormous functional decline that is very predictable. The MND Society has, through fundraising over many years, created an

23 Ms Rachel Balmanno, Acting First Assistant Commissioner, Ageing and Aged Care Division, Department of Health and Ageing, *Committee Hansard*, p. 39.

24 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

25 Mr Andrew Smith, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

26 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

enormous equipment library with things like hoists, hospital beds, air mattresses, wheelchairs.²⁷

10.30 The committee heard that the main benefit of the MND library was the speed in which people could access equipment:

One of the main points about the MND library is that it is usually very quick to access these things, so you are not waiting like you are with the main equipment provider, which is SWEP. You can be on a waiting list for 18 months, which is not much use for someone who might be dead in 12 months.²⁸

10.31 The committee understood that the MND library was established to overcome delays patients had been experienced when accessing aids and equipment through the state government run programs.

Committee comment

10.32 The committee is concerned that support and treatment for people with a life-limiting illness during the later stages of their disease may be difficult to access, and is also concerned by the inconsistency across jurisdictions in relation to accessing aids and equipment. The committee was impressed however by the MND Equipment Library and, while the committee acknowledges that not all life-limiting illnesses have the same predictability in the decline of a patient's function, it considers that the implementation of an equipment library on a national basis should be considered. A national 'equipment library' may limit delays in both accessing equipment and having equipment collected or removed following the passing of a palliative care patient.

10.33 The committee notes that since 1 July 2012 the Commonwealth HACC Program is providing funding for basic community care services which support frail older people and their carers. Those eligible include people aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people); and those at risk of premature or inappropriate admission to long term residential care, or a carer of older Australians eligible for services under the Commonwealth HACC Program. While it is too soon to tell whether those changes will be effective, the committee takes the view that the implementation of those changes should be closely monitored to ensure that the issues which were identified during the course of the committee's inquiry are addressed. To ensure that younger people requiring HACC-equivalent services and equipment do not fall through the gaps, the committee would like to see the state and territory governments, through COAG, look at establishing a consistent approach to the provision of equipment and services for those younger people. Alternatively, the government could consider including 'palliative care' as an eligibility criteria for access to the HACC program – ie a person with a life limiting illness would qualify for HACC services and equipment regardless of age.

10.34 The committee was also troubled to hear of the incorrect prescribing of equipment. Although it did not receive much evidence on this particular point, the

27 Mr Andrew Smith, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

28 Mr Andrew Smith, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

committee suggests that the government examine this issue and whether current regulatory structures and prescribing guidelines are sufficient to address these concerns.

Recommendation 20

10.35 The committee recommends that the Council of Australian Governments examine the viability of introducing a national equipment library for palliative care patient needs, examining whether such an approach would allow more efficient and timely provision of available equipment and funds.

Recommendation 21

10.36 To prevent the mis-prescribing of equipment, the committee recommends that the Australian government investigate current regulation and consider improving regulation of both private and public palliative care equipment providers.

Recommendation 22

10.37 The committee recommends that the Australian government closely monitor implementation of the recent changes to the Home and Community Care program to ensure that the program is meeting the needs of those over 65, and that palliative care recipients who do not fall into the aged care bracket are receiving adequate support.

Recommendation 23

10.38 The committee recommends that the Australian government consider changing the eligibility to Home and Community Care (HACC) to include palliative care patients or carers of such patients, regardless of their age. The committee notes that as the HACC program is linked to funding and funding agreements, the Australian government consider this recommendation in the context of considering changes to the funding model for palliative care.

Recommendation 24

10.39 The committee recommends that the Australian government analyse and identify potential gaps in the provision of palliative care and palliative care funding for people with disabilities, especially in supported accommodation.

Chapter 11

Palliative care for special needs groups

11.1 Palliative care services need to be sufficient flexible to meet the needs of groups that may have different values or needs around death and dying. A range of witnesses expressed concern about the accessibility of palliative services for particularly Indigenous Australians, and children and adolescents.

Indigenous Australians

11.2 Palliative care for Aboriginal and Torres Strait Islanders (ATSI) was raised by numerous submitters and witnesses, with most of these identifying both the availability and appropriateness of care as key concerns. Greater engagement with Indigenous communities and health services, as well as more funding and specific training for people engaged in palliative care delivery were offered as possible solutions to help overcome these barriers.

Cultural appropriateness of care

11.3 The cultural appropriateness of care was an issue that was raised repeatedly in the context of the delivery of palliative care in Aboriginal communities. Many contributors attributed the relatively poor engagement by Aboriginal Australians with palliative care services to health professionals' lack of cultural knowledge around death and dying.

11.4 Carers NSW specifically discussed the issue in terms of the spiritual and cultural rituals associated with dying:

Aboriginal people often have different cultural understandings and values which influence the types of services they are willing to access. This includes different understandings of concepts such as kinship and family relationships, caring, place, healing, communication styles and death and dying. These differences are particularly significant in the context of palliative care, when a loved one is dying and spiritual and cultural rituals can be particularly important...¹

11.5 Ms Sarah Brown, Chief Executive Officer of Western Desert Aboriginal Corporation and Manager of the Purple House, provided the committee with an example of the cultural and spiritual rituals that palliative care service providers in Aboriginal communities must take into consideration:

We were talking about cultural considerations before. Culture is not static. There is an issue of payback for some communities, and that is that traditionally no death is ever blameless; every death is the result of somebody doing something wrong or the wrong way. That can have implications for palliative care. If a person really wants to go home, their

1 Carers NSW, *Submission 61*, pp. 5–6.

partner, their wife may suffer payback from the deceased person's family after the death, and that is really difficult to deal with. In our experience, it can be used as an excuse not to provide palliative care and for that person to die in hospital. Then the person who is going to pass away is always the one who is really keen to be back on country, and often it is a matter of them being able to persuade their family to provide that support.

But it varies. It could easily be used as an excuse not to do palliative care on community, because it is too hard. The family might get payback or the nurses might get payback for that death. This is a topic that the directors of our committee have had to deal with and talk about a lot over the years because there will be a time when someone we take home for dialysis dies either on a dialysis machine or in the community while they are home. A lot of it is about communication. It is about all the family and the extended family understanding that that person is very sick, that this is their wish to be on country and that their death is not going to be anybody's fault and everyone is doing the best they can for them.

So sorry business and the cultural issues can have an impact on what care is provided. We have had families where the person is desperate to go home but the family is scared of what will happen after the death, scared of payback. In some cases it has been a matter of the palliative care revolving around getting the person home for a few days to say goodbye and then back to hospital to die. But it is great if people have got those choices and the professionals have the skills to be able to have those conversations with people.²

11.6 The Australian Nursing Federation (ANF) emphasised the general importance of respecting the 'cultural, spiritual and community needs' of Aboriginal and Torres Strait Islander peoples in mainstream health care:

Health care professionals from all disciplines involved in palliative and end of life care must learn to be respectful, mindful and dedicated to providing care within the cultural and spiritual beliefs of the individuals they care for. Such health professionals do not need to know the culture and spiritual beliefs and knowledge – they need to respectfully follow the guidance of those community members who are experts.³

11.7 KinCare concurred, highlighting the need for better training in understanding the cultural preferences of Aboriginal groups:

Mainstream services may not provide culturally appropriate care due to a lack of understanding of Indigenous culture, rigidity in systems, and a lack of training of staff in cultural competencies and person centred care. Cultural preferences relating to death are particularly important.⁴

2 Ms Sarah Brown, Chief Executive Officer of Western Desert Aboriginal Corporation and Manager of the Purple House, *Committee Hansard*, 25 July 2012, pp. 11–12.

3 Australian Nursing Federation, *Submission 85*, pp. 5–6.

4 KinCare, *Submission 25*, p. 5.

11.8 More broadly, it was widely recognised by submitters that '[i]mproving the cultural appropriateness and sensitivity of mainstream organisations',⁵ as well as better engagement with and utilisation of ATSI community and health services, would help to improve palliative care for Indigenous Australians.⁶

11.9 Carers NSW discussed the 'Practice Principles' developed by the National Palliative Care Program as a 'useful guide' and highlighted the 'concept of cultural safety, which emphasises respecting and empowering the cultural identity and wellbeing of an individual'.⁷

11.10 Similarly, Palliative Care Australia (PCA) argued a case for 'all policies, procedures and processes of health care' to 'respect and reflect different cultural and ethnic values, beliefs and practices that surround death, dying and end of life care'. A key element in their argument is that commitment is made to education and training that includes:

- significant investment by government to increase the number, qualification levels and professional registration of Indigenous peoples in the health workforce;
- appropriate training and education about cultural perspectives relating to palliative and end of life care issues, in core curricula for all health workers and health practitioners providing services to Indigenous people; and
- inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV continuation of PEPA to build on or develop cultural appropriate education for Indigenous health workers.⁸

11.11 The Commonwealth currently has a significant number of initiatives targeted at increasing Indigenous participation in the health workforce.⁹

11.12 In addition to the commitment to education and training, PCA emphasised the need to work with Indigenous organisations themselves to develop models of care that meet the needs of the community. Concrete measures would include:

5 Carers NSW, *Submission 61*, p. 5.

6 See for example Carers NSW, *Submission 61*, pp. 5–6; Palliative Care Australia (PCA), *Submission 98*, p. 13; Australian General Practice Network (AGPN), *Submission 107*, pp. 9–10; Australian and New Zealand Society of Palliative Medicine (ANZSPM), *Submission 33*, pp. 8–9; Mercy Health, *Submission 58*, p. 4; BlueCare, *Submission 28*, p. 15.

7 Carers NSW, *Submission 61*, pp. 5–6.

8 Palliative Care Australia, *Submission 98*, pp. 13–15.

9 Department of Health and Ageing, Department of Health and Ageing (DoHA) and Department of Education, Employment and Workplace Relations (DEEWR) - Aboriginal and Torres Strait Islander Health Workforce Projects
<http://www.health.gov.au/internet/main/publishing.nsf/Content/work-atsihwp> (accessed 3 October 2012).

- support and funding of an increase in the availability and accreditation level of interpreters to communicate with indigenous Australians;
- support and funding for culturally specific research on the nature of grief and bereavement in indigenous communities and the implications for this in the development of appropriate support services; and
- the development of strong linkages between community controlled health services and specialist palliative care services.¹⁰

11.13 The Australian General Practice Network (AGPN) similarly offered specific recommendations intended to improve the cultural appropriateness and accessibility of palliative care that also included fully funded and supported training and education programmes for health care professionals to address the specific needs of Indigenous communities.¹¹

Accessibility of palliative care

11.14 According to many submitters there are specific barriers to the accessibility of palliative care to ATSI people. In addition to concerns relating to the cultural appropriateness of care, there are other specific barriers ranging from mistrust of mainstream services, there being no services available, or that treatment is not available close to hand, and people do not want to leave their homes or communities to receive treatment. KinCare and Carers NSW both raised mistrust as an issue:

Many Aboriginal people mistrust mainstream services and medicine, preferring to access services delivered by Aboriginal organisations or individuals. This reduces their access to diagnostic and treatment services, delays identification of the need for palliative care, and may result in a decision not to take up services available.¹²

...

Many Aboriginal people are reluctant to access mainstream health services. This is often linked to past experiences of discriminatory policies and practices directed towards Aboriginal people, such as removal of children and a lack of rights and choices, the impacts of which continue to shape the lives of Aboriginal people today. Mainstream services may also be perceived as culturally inappropriate, as they may be unfamiliar with the values and traditions of the local Aboriginal communities or engage in practices which appear insensitive. For these reasons, Aboriginal people often prefer to use specific Aboriginal community services, although in the case of palliative care this is often not available.¹³

10 Palliative Care Australia, *Submission 98*, pp. 13–15.

11 Australian General Practice Network, *Submission 107*, pp. 9–10.

12 KinCare, *Submission 25*, p. 5.

13 Carers NSW, *Submission 61*, pp. 5–6.

11.15 The ANF provided an example that demonstrated some of the challenges facing indigenous Australians who require palliative care and service providers who deliver that care:

One example was that they have come to an arrangement for one of these women that she goes to Alice Springs for three weeks and comes back out to the community for one week. That is the cycle. That involves a road trip every time she does that. That seems in some ways to be working, but in terms of being able to do that better in the community they just do not have the resources to support them in their homes. It comes back on the remote area staff, who are remote area nurses and Aboriginal health workers. Whilst they might say it is certainly within their remit to provide all sorts of care for people, they are not resourced well enough, as you would know, to provide that for someone in their home. End-of-life care requires a lot of resources, time and commitment. That was just an example of how when people have to go and access things there is a distance factor. Things like HACC services and those other things that have been talked about are just not available in those communities and it comes down to a very small amount of health resources to provide that additional care. It just seems that people are then disadvantaged because they cannot die in their own home as they would choose to.¹⁴

11.16 Ms Sarah Brown gave examples of the practical difficulties of providing palliative care, particularly for renal dialysis patients in remote communities, where resources are scarce:

I was a remote area nurse for a long time, and the times when people palliating in communities worked really well were when there were enough resources for the primary healthcare service to dedicate a nurse to be a support person for the family for the period of that palliation. It works better in bigger communities where you have a big team. I managed a palliative clinic for a couple of years and had a fellow with end-stage renal failure who opted not to start dialysis in the first place. He went home to die, and I was able to provide that family with a nurse 24 hours a day when they needed him. To know that family really well and to take over pain management a whole lot was fantastic. So that is about resources and remote communities.

Certainly at the moment people by default will often end up in hospital for a long time. There is a big gap in Alice between hostel accommodation and nursing home accommodation, and there is nothing in between. In hostels you have to be incredibly independent to stay there. There are few resources supporting people in hostels. Nursing homes are full of old people, which is not necessarily our client group, and there are not many beds. So we are in the situation where people can be in the continuous care ward for 12

14 Ms Geri Malone, National Professional Officer, CRANaplus, Australian Nursing Federation, *Committee Hansard*, 24 April 2012, pp. 38–39.

months or 18 months, in the hostel, going across for dialysis, coming back—that is their life, and it is no life.¹⁵

11.17 Ms Brown explained that the resources required by Aboriginal people and their communities may not be typical and as such are not funded by the government:

In terms of issues, it is all about resource provision and about the difference between what a government service thinks should be provided and what Aboriginal people and their families think should be provided. For example, often we will have trouble sourcing the resources for travel, for a bed that is off the ground, for blankets, for extra food for the family while they are looking after the person. The government may support the process of discharging someone from hospital. It may provide travel for that person to get home, but, in terms of paying carers in community to provide extra support, the only organisation that I know that has some resources for that is NPY Women's Council.¹⁶

11.18 A personal account of the challenges facing Indigenous Australians was given by Ms Cherie Waight, Victorian Aboriginal Care Project Coordinator for the Victorian Aboriginal Community Controlled Health Organisation. Ms Waight explained:

Palliative care is not a word for us in the Aboriginal community. It is very foreign to us...Traditionally in our culture—and, I am aware, also in many other cultures; though I am here to talk about our people—we just took care of our own people. We did not know that there were other services available, and we did not know that we could have assistance. Many of our people managed and struggled within their own home environment.¹⁷

11.19 Ms Waight's story described the lack of understanding between palliative care providers and Indigenous people, specifically around communication and information sharing, as well as the cultural barriers she faced while caring for her terminally ill husband. Her full account is included to reflect the issues that arose in the relations with the service providers, but also to illustrate the expectations of her extended family around her husband's death:

I want to share my personal experience with you. I am a 49-year-old woman. Going back 23 years, I lost my husband. My husband had cancer. He had a brain tumour. There were two different cultures at play. My late husband was a non-Aboriginal man, but I was an Aboriginal woman. I was only very young and would not have known what the word 'palliative' meant. I came from a little country town, as it was at that time—it is very big now—called Shepparton. I came to Melbourne and I met my late husband. Within a short time we found out that he had cancer. He was 24 and I was 21. During that time my late husband went through chemotherapy

15 Ms Sarah Brown, Chief Executive Officer, Western Desert Aboriginal Corporation, and Manager, Purple House, *Committee Hansard*, 25 July 2012, p. 11.

16 Ms Sarah Brown, Western Desert Aboriginal Corporation, and Manager, Purple House, *Committee Hansard*, 25 July 2012, p. 14.

17 Ms Cherie Waight, Victorian Aboriginal Care Project Coordinator, Victorian Aboriginal Community Controlled Health Organisation, *Committee Hansard*, 4 July 2012, p. 45.

and radiation, and I had no understanding about chemotherapy. I had no understanding of what that did. I had no understanding of what radiation was all about.

...

I would take my husband to treatment, I would take my husband to hospital, I would go to work—however I fitted work in—and I would take my 12-month-old baby between home and my place and my work and my mother-in-law's. Then I would bath and feed my husband, because he had come to a stage where he could not bath himself and he could not feed himself—and we are talking about a 30-year-old man. I did not know about, and I was never offered, palliative care. I was never told that I could have my husband cared for, other than "Ms Waight, you need to bring your husband in because we've got to give him some morphine. You cannot administer that." That is all I knew. So, okay, Alex would go in for a couple of days and then I would have to pick him up and I would take him home, I would bath him and I would feed him. He had been a very strong man who had been totally independent.

He became a little bit more permanent in the Heidelberg Repatriation Hospital and I thought: "If he's okay why can't I bring him home?" — because that is what I did; I always brought him home. But when I walked in there they said to me, "We're going to transfer him to Caritas Christi. That is in Kew, Ms Waight. We have to as we can no longer care for him." I wondered what Caritas Christi was, as I did not know. I challenged that. I was 24 years of age and I never ever challenged anything. I had always shown nothing but respect, because that is what I was taught by my elders and my grandparents and my community: "You listen and you hear. You respect everything that you hear from a non-Aboriginal person." But I decided to say, "Well, what does that mean? I don't understand. I don't know what that means." My late husband used to always say to me, "The last thing I want to do is to be put into somewhere where I am just going to die." So I would often say to them, "No, I need to bring him home." The choice was taken out of my hands. I would say, "No, as Aboriginal people we take care of our own." That is all I know. We did that with my grandfather when I did not even know what a palliative approach was. In the end, they said to me, "You just need to go and have a look at Caritas Christi in Kew and tell us what you think. This is the address." I dropped Nerita, my daughter, off to her grandparents and said, "This is what they have decided to do. This is what I am going to do. I am going to go over and have a look."

I went over to Caritas Christi, had a look and walked out in tears. I was traumatised, absolutely traumatised. As soon as I walked in, I saw two elders come out of there who had passed away. I asked the nurse to tell me what this place was about. She told me, 'This is where you come and have your last breath really. We take people beforehand so they can die here.' I said, 'What?'

There were cultural differences. I went home to the in-laws and explained to them I want him to come home. What you call palliative care was called hospice care at the time. I challenged the situation and they said, 'He must

stay here. You cannot take care of him.' I said, 'How do you know I cannot take care of him? I have been washing and cleaning him, feeding him, dressing him and getting him to his parents, who were also totally incapacitated and unable to assist in things because they had no transport and were a low-income family. The father had very serious chronic illnesses too. I wanted to talk to them about some cultural issues, which went in one ear and out the other. They did not want to know about it.

Anyway, my husband stayed in Caritas Christi. I respected what the doctors had chosen. I respected that they knew best what had to be done. I asked for some culturally appropriate things for me. I explained to them that I have a very big family and am going to have family coming here because my husband was accepted into this very big Aboriginal family. They said, "No, you cannot have that. You are only allowed a couple of people in and out." Often my family would travel down from Shepparton to visit my husband and myself. Alex was in Caritas Christi only for two weeks. My spirits came and told me that my husband would not last more than two weeks in Caritas Christi because it was a place where he did not want to be.

I asked for some things to be done so that, culturally, my daughter and I could be protected, and so I would know my husband's journey would be okay. Those things were not allowed to happen. In the last few days of my husband, I had a lot of family come to visit him. Alex came from a very small direct-sibling family. I used to hear the nurses say, "There are too many black people in here. What are we going to do about it? You need to go and tell her." They did not know that I was listening. "You know she smells. She needs to go home and have a shower. Are you going to tell her?" Of course I am not going to leave my husband. I was newly married. You knew it was all about the differences of colour. And no, my husband did not last more than two weeks in there. The last two nights of my husband's life my family was in and out and nurses would come to me and say, "You have too many people here." I would say, "I come from a very big Aboriginal family. Somewhere along the line you have to accept that." "No, you can only have one or two." I understand it can be uncomfortable for other people going through that journey. I understand there are families who like to do their journey very quietly. I get all that but it is about making a difference and making palliative care services understand. I am going back 23 years because my daughter was one. She turned 1½ when her dad died. That was my experience.¹⁸

11.20 Palliative Care Australia (PCA) outlined some examples of 'positive activity' with regard to palliative care for Aboriginal and Torres Strait Islander peoples in some parts of Australia:

We are certainly linked in and very aware of the delivery of palliative care in certain areas that predominantly have an Aboriginal clientele, such as in Alice Springs, where it is quite a different model of care, and it is usually a different disease model also. It is predominantly end-stage renal as opposed

18 Ms Cherie Waight, Victorian Aboriginal Care Project Coordinator, Victorian Aboriginal Community Controlled Health Organisation, *Committee Hansard*, 4 July 2012, pp. 46–47.

to cancer, which is what you see in most of the rest of the country. Efforts have gone in there to ensure that people can die on country and, as you were also saying, that they do not have to leave country. There is a lot of effort made to achieve that, but there is not necessarily the funding and support to make sure that that happens. I think, as you mentioned earlier about the potential for Closing the Gap funding to be used in that area, that is a great opportunity.

...and there are different locations where there has been lot of very positive activity. I would speak to Victoria as being an area where they are really trying to address Aboriginal issues as well in the delivery of palliative care. They have very active groups there. Also, in some areas some of the Indigenous health workers have taken on additional training in palliative care. I am aware of people on the Torres Strait Islands and up around the Cairns area who have certainly done that.¹⁹

11.21 The desire of many indigenous Australians to return to country at the time of their death was consistently raised during the inquiry.²⁰ The Purple House explained the importance of helping Aboriginal people with a limited lifespan to return to country and how their 'purple truck' was assisting:

The emphasis is all about getting people with a limited lifespan back to country, to spend time with their families, to pass on the cultural knowledge and to contribute to community for as long as possible.²¹

11.22 The AGPN recognised that the desire to remain at home during end-of-life care was not unique to Indigenous Australians but presented more challenges for Aboriginal and Torres Strait Islander peoples:

...whilst Indigenous Australians, like non-Indigenous Australians, overwhelmingly prefer to die in the familiar surroundings of home, in some communities there can be added complexity to providing effective, quality care associated with the poor standard of/limited access to basic services in these communities.²²

11.23 Aged and Community Services Australia (ACSA) shared this view:

There is a general preference in Indigenous communities to remain in the family unit, often with the involvement of traditional healers. Caring for older Indigenous people who are dying in these circumstances can be challenging due to the often poor standard of accommodation and basic services in many communities, and the crossover of western and traditional approaches to medicine. These circumstances call for considerable

19 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 23.

20 See for example SA Government, *Submission 27*, p. 4; National Disability Service (NDS), *Submission 49*, p. 4; Mercy Health, *Submission 58*, p. 4; PCA, *Submission 98*, p. 13.

21 Ms Sarah Brown, Western Desert Aboriginal Corporation and Purple House, *Committee Hansard*, 25 July 2012, p. 10.

22 Australian General Practice Network, *Submission 107*, p. 9.

flexibility in service delivery, preferably in partnership with the informal carers. Training and employment of more Indigenous people to deliver aged care would assist.²³

11.24 National Disability Services provided a case study where the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council facilitated the return of an indigenous woman ("BL") to her country just prior to her death:

NPY received a referral from NT Palliative Care team and Purple House Renal Dialysis Unit requesting assistance to return BL to her remote community to pass away. After being on dialysis for 15 years doctors had decided she could receive no more treatment. She had only a short time to live.

BL had lived in a hostel in Alice Springs during this time and had had little contact with family and had only been out on the lands once for a visit. To return her home, there were many things to put in place:

Locate family: Because BL had been in Alice Springs for so long she had lost touch with most of her family...

Liaise with remote clinic staff: Because of shortage of staff, the remote clinic was dubious about having BL back in community to "finish up"...

Discharge Planning: Royal Flying Doctor Service was notified...

Family Support:

Organised for new bedding and mattress to be sent out for BL.

Spoke with remote Centrelink team and set up carer payment immediately for main carer.

Gave purchase orders for fuel to family members from other communities so they could drive over to visit BL.

Contacted prison in Perth so BL's son could have phone link up with his mother.

Gave purchase order for community store so family could buy extra food.

Final Days: When BL flew into community there many family members present to meet the plane. BL was happy and aware of her surroundings...

BL spent 8 days in her community and died peacefully surrounded by family.²⁴

11.25 The option to return to country was also endorsed and recommended by PCA who suggested that 'clear policies, procedures and mechanisms are established to

23 Aged and Community Services Australia, *Submission 122*, p. 8.

24 National Disability Services, *Submission 49*, p. 5.

support "return to country" for Indigenous Australians who are approaching the end of their life'.²⁵

11.26 With respect to a collaborative approach to palliative care for Indigenous Australians, the Australian and New Zealand Society of Palliative Medicine (ANZSPM) recommended that the Commonwealth government 'support doctors working in Aboriginal Medical Services throughout the country in all practical ways'.²⁶ The ANZSPM continued:

The development of a palliative approach for Indigenous patients with non-malignant conditions requires active collaboration between Aboriginal health providers, primary care providers servicing Aboriginal communities and specialist physician groups. The Commonwealth through the various peak bodies could facilitate the development of such models of care. Pilot programs have already been developed in some jurisdictions e.g. The Northern Territory Renal Palliative Care Program.²⁷

11.27 Mercy Health also suggested that a collaborative, inclusive approach was required and that there is a need for health professionals to actively engage with the communities in designing those services:

There is a need for palliative care health care professionals to engage with Aboriginal Health workers and Aboriginal Health Centres. Together they should meet with community Elders to develop relationships and an understanding of palliative care and support services available. This would further enhance the care staff's understanding of the spiritual and cultural traditions of the Indigenous community, which has been demonstrated through previous endeavours.²⁸

11.28 The Victorian Aboriginal Community Controlled Health Organisation emphasised the important work of the Program of Experience in the Palliative Approach (PEPA) with Indigenous communities. Ms Waight stated:

One of the most important factors that we have found is to provide education and training to our Aboriginal health workers. One of the things that has been a success—that is what I would call it—over the last four years is having the opportunity to continue to train our Aboriginal health workers. We have done that through the PEPA training. That PEPA training has been designed to be culturally appropriate. One of the most important things is making our Aboriginal health workers and our Aboriginal hospital liaison officers that work within hospitals comfortable with dealing with what you call 'palliative care'. With that, we have had the opportunity to develop specifically culturally appropriate Aboriginal health worker PEPA

25 Palliative Care Australia, *Submission 98*, p. 13.

26 Australian and New Zealand Society of Palliative Medicine, *Submission 33*, pp. 8–9.

27 Australian and New Zealand Society of Palliative Medicine, *Submission 33*, pp. 8–9.

28 Mercy Health, *Submission 58*, p. 4.

training. In saying that, the importance of that is that we have been able to train 135 Aboriginal health workers across the whole of Victoria.²⁹

11.29 Other witnesses were equally positive about the work of PEPA with indigenous communities;³⁰ however, several submitters argued that further government support and an expanded role for PEPA were needed. For example, the Cancer Council NSW and LifeCircle recommended that the Commonwealth government continue to enhance PEPA's 'focus on Aboriginal and Torres Strait Islander palliative care, incorporating Aboriginal and Torres Strait Islander cultural awareness for specialist palliative care providers and generalist health workers involved in palliative care'.³¹ The Little Company of Mary Health Care was concerned that 'Current funding levels for PEPA are inadequate to meet existing demand and as more people require care in non-specialist setting this demand will only increase'.³²

11.30 The Department of Health and Ageing submissions discusses palliative care services for Indigenous Australians at a number of levels. The department stated that palliative care service is included in the *National Strategic Framework for Aboriginal and Torres Strait Islander Health (NSFATSIH) 2003-2013* which includes, as one of its key principles, 'activities to improve the access to, and quality of service delivery (including palliative care where appropriate) for all Aboriginal and Torres Strait Islander people'.³³

11.31 The Department also submitted that '[t]he palliative care needs of Aboriginal and Torres Strait Islander people with a life-limiting illness are considered and addressed in all the work progressed under the National Palliative Care Program (NPCP)'.³⁴

11.32 This program includes support for numerous projects including funding the Wodonga Institute of TAFE to develop of an Aboriginal and Torres Strait Islander palliative care resource kit.³⁵ The kit included:

- Practice principles for staff at all levels who provide care to terminally ill Aboriginal and Torres Strait Islander people in mainstream palliative care services or hospices;

29 Ms Cherie Waight, Victorian Aboriginal Care Project Coordinator, Victorian Aboriginal Community Controlled Health Organisation, *Committee Hansard*, 4 July 2012, p. 46.

30 See for example Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, pp. 22 and 23; Mercy Health, *Submission 58*, pp. 7–8; Cancer Council NSW and LifeCircle, *Submission 83*, p. 13; Department of Health and Ageing, *Submission 96*, p. 4.

31 Cancer Council NSW and LifeCircle, *Submission 83*, p. 13.

32 Little Company of Mary Health Care, *Submission 81*, p. 14.

33 Department of Health and Ageing, *Submission 96*, p. 3.

34 Department of Health and Ageing, *Submission 96*, p. 3.

35 Department of Health and Ageing, *Submission 96*, p. 8.

- Education and training resources to support the Practice Principles; and
- A discussion paper on the existing literature relating to Aboriginal and Torres Strait Islander peoples' perspectives on death and dying.³⁶

Committee View

11.33 The committee understands that there are important cultural considerations around death and dying that must be considered in the provision of palliative care to Aboriginal and Torres Strait Islander Australians. The committee takes the view that every effort should be made to ensure that the appropriate needs and wishes of the person requiring such care in these communities are met and that Indigenous Australians should have access to the same standard of palliative care as non-Indigenous Australians.

11.34 The committee acknowledges the evidence it received during the inquiry that specifically cited the importance of supporting Indigenous people to 'return to country' in their palliative care journey and spend their final days with family. In view of that evidence the committee strongly supports efforts to ensure this is possible.

Recommendation 25

11.35 The committee endorses the recommendations of Palliative Care Australia that, in relation to Commonwealth funded programs, it support:

- **appropriate training and education about cultural perspectives relating to palliative and end of life care issues, in core curricula for all health workers and health practitioners providing services to Indigenous people; and**
- **inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV continuation of PEPA to build on or develop cultural appropriate education for Indigenous health workers.**

Recommendation 26

11.36 The committee recommends that the Australian government increase funding to palliative care programs for Indigenous communities in rural and remote areas, with a particular emphasis on return to country.

Children and adolescents

11.37 The palliative care needs of children and adolescents were the subject of discussion during the course of the inquiry. In particular, the need for and availability of specialist palliative care services for babies (both perinatal and neonatal) and children and adolescents, as well as the transition from services for children to those available for adults, were raised.

36 Department of Health and Ageing, *Submission 96*, pp. 8–9.

Perinatal and neonatal palliative care

11.38 A number of submitters were concerned about a lack of specialist perinatal and neonatal palliative care in Australia. The committee heard several case studies demonstrating the need for perinatal palliative care, including one in which a woman and her family received appropriate care and support and another instance where a woman and her family experienced 'misunderstanding, miscommunication, suspicion and [...] neglect from medical professions'.³⁷

11.39 Associate Professor Dominic Wilkinson of the University of Adelaide argued:

There is an urgent need for more research into neonatal and perinatal palliative care in Australia. Attention needs to be paid to ensuring that palliative care is available in all major perinatal centres and neonatal intensive care units, and that women and infants are referred appropriately.

Palliative care in Australia currently provides very valuable support to many children and adults with life-limiting conditions.

Dying newborn infants and their families need support too.³⁸

11.40 Associate Professor Wilkinson also identified what he believed to be the barriers to perinatal palliative care in Australia:

I would like to suggest that there are at least four barriers to the provision of good neonatal and peri-natal palliative care. These include, first, a simple lack of awareness of the problem and of the needs of these infants and their families; second, negative attitudes, including implicit and sometimes explicit criticism of women who choose to continue their pregnancy in the face of a serious malformation; third, ethical concerns and misunderstandings, particularly discomfort or fear associated with the care of dying newborn infants; and, fourth, a lack of necessary resources.

11.41 Palliative care for foetuses and newborn infants is just as important as it is for people with life-limiting diseases at any other age. Associate Professor Wilkinson emphasised the need for education to inform parents and families of the best support available and a need for research in this particular area. He finally stressed that parents and families of newborn infants with palliative needs are able to access the appropriate services:

...there is a need to acknowledge that palliative care is important for foetuses and newborn infants with life-limiting illnesses, just as it is at any other age[...] Second, there is a need for research into the needs of families of dying infants in Australia and into how best to support them. Third, there is a need for education in palliative care for those involved in the care of dying infants. Finally, and most importantly, we need to make sure that pregnant women and newborn infants, wherever they are cared for in Australia, are able to access palliative care if required and if appropriate.³⁹

37 Associate Professor Dominic Wilkinson, *Committee Hansard*, 13 August 2012, p. 2.

38 Associate Professor Dominic Wilkinson, *Submission 53*, p. 2.

39 Associate Professor Dominic Wilkinson, *Committee Hansard*, 13 August 2012, pp. 2–3.

Recommendation 27

11.42 The committee recommends that the Australian government give increased attention to the need for improved research, education and services to support the perinatal and neonatal palliative care needs of health professionals, pregnant women and their families and newborn infants.

Children and young people

11.43 Palliative care for children and young people in Australia was also discussed during the course of the inquiry. Again there were examples provided of excellent palliative care for children and young people, and their families, as well as evidence that access to care was disparate and difficult to access.

11.44 The Paediatric Palliative Care Australian and New Zealand Reference Group (PPCANZRG) discussed the level of palliative care currently required for children in Australia and whether it is currently being provided:

[I]t is estimated that 5300 children require palliative care each year. The numbers may be relatively small in comparison to the adult population but the needs are great. These children require specialist care and although efforts are underway to improve the care of this patient group, they continue to "fall through the cracks". They often find themselves unsupported by a local community that is fearful of and ill-equipped to deal with the death of a child. They may not be able to access specialist care. And they are often unable to access basic supports such as respite, equipment and financial assistance. There are also 'cracks' in the evidence base due to a lack of basic research.⁴⁰

11.45 Palliative Care Australia supported the view that the palliative care needs for children and adults are very different:

There is a need to recognise that palliative care for children and adolescents is different from palliative care provided to adults. The provision of paediatric palliative care varies widely across Australia, with some states and territories not having dedicated paediatric services. There is a need to ensure that families know what services are available, care is well coordinated, high quality and supported by the best available research and evidence.⁴¹

11.46 The PPCANZRG also highlighted the need for better support to be provided to the families of those children:

The trauma experienced by parents, siblings and the wider family from the death of a child is also profound with increased potential for complicated grief reactions, impaired long-term adjustment and even increased mortality. The provision of effective palliative care can be expected to directly benefit the child but also has the potential to be a preventive health

40 Paediatric Palliative Care Australian and New Zealand Reference Group, *Submission 63*, p. 1.

41 Palliative Care Australia, *Submission 98*, p. 10.

intervention for the family, with long term implications for family functioning, mental health, education and employment.⁴²

11.47 The reality for children with a life-limiting illness and their families was discussed by the families in evidence to the committee. Mr Burnet has two terminally ill sons, Sebastian and Charlie, and described some of the challenges he and his wife have faced in their endeavours to find suitable care and support in Victoria:

In term of the resources available to help, in what has been one of the most complicated and confusing systems ever, we have really struggled trying to understand what organisations do what, what funding is available to help us with purchasing disability equipment or to help with specialist care and who to call for all the issues that we have. I am sure many families in our situation would have given up in frustration. We have really had to treat looking after our boys like a semi-permanent job. Thankfully, though, through a lot of persistence and with a lot of help from the [Royal Children's Hospital] palliative team, we have been able to source special disability strollers, bedding, baby equipment, car seats et cetera, et cetera—the list goes on—and this help has been invaluable.

[T]here are so many areas of support parents of dying kids need that general medical facilities are unable to provide. Whether it is struggling with nights on the weekend like the one we have just had, or the much tougher times we have ahead, we will be incredibly reliant on and thankful for the palliative support we have found.⁴³

11.48 Mrs Fiona Engwirda shared her family's experience in Queensland:

Due to Kate's complex medical requirements she required intensive 24 hour care, which was provided by my husband and I, with no outside nursing help and minimal respite funding... These care requirements had a profound and devastating impact on our family.

The precarious balance between home life and hospital management of a baby so complex was extremely difficult... In order to manage life at home for Kate's siblings, (James and Harrison) my husband (who has runs a small business in Building Design) relocated his office to home so he could provide continuity of care to our boys whilst I managed Kate, including her admissions and 24 hour nursing requirements. This move (coupled with the GFC) has had a profound impact on the business' ability to continue to earn income, and we suffered significant financial hardship.

The hospital system did not distribute information about respite or make an attempt to link us with any service until Kate was 6 months of age – we were granted emergency funding by DSQ as I presented (in tears) to a local DSQ office, obviously stressed, exhausted and overwhelmed with the situation we found ourselves in.

It was through my own research and talking to other parents that I became aware of HACC (Home and Community Care) funding and located a

42 Paediatric Palliative Care Australian and New Zealand Reference Group, *Submission 63*, p. 1.

43 Mr Richard Burnet, *Committee Hansard*, 4 July 2012, pp. 35–36.

service directory (after many hours of internet searching) online. I proceeded to ring every service provider in our local area, in order to see if they could provide us with funding for respite – after days of phone calls. I had 3 service providers lined up for interviews, after a lengthy and exhaustive process, these interviews translated into a total of 16 hours of in-home assistance per week. Not even 1 night per week. I proceeded to fill in the 70 page application form for Centrelink's disability funding in my spare time. The paperwork and process driven system of obtaining funding on top of the emotional and physical demands of caring were relentless.

...

In a bid to provide our family with respite options, [Royal Children's Hospital] Paediatric Palliative Care Service referred us to a facility in Sydney that provides end of life care to children at no cost to families. Funds were sourced (approx \$600) via *Xavier Children's Support Network* as part of their *HACC funding* for family "breakaway packages" to contribute towards our airfares.

In 2010 we travelled interstate to NSW to visit Bear Cottage a purpose built facility that could provide appropriate paediatric care for children like Kate who were required specialist palliative care -while our family enjoyed some much needed respite. We valued this experience and the full nights of sleep that came with it.⁴⁴

11.49 To assist families to navigate paediatric palliative care services, Mr Burnet recommended a 'single point of accountability':

If there was one thing I had to say, that is it: the last thing you need when you get this sort of news is having to struggle. As we would call it at work, it is a SPA—a single point of accountability where we will be able to point you in the right direction for everything rather than having to either do it all yourself or use organisations that may have part of a puzzle but not have a complete puzzle...My wife often says that she dreams, if she ever had the time, once the boys pass away, of getting a simple website that has everything you need that you can go to, work out what your steps should be and how you should follow some sort of a process to work out who is going to help and when.⁴⁵

11.50 Bear Cottage and Very Special Kids were praised in evidence to the committee, and witnesses expressed a desire to see a similar model adopted in other states.⁴⁶ Bear Cottage is the only children's hospice in NSW and offers respite and palliative care to children and young people:

In addition to providing palliative care facilities for children, Bear Cottage contains the amenities of a comfortable home, with 10 children's bedrooms, family accommodation and a quiet room. There are also areas for recreation

44 Mrs Fiona Engwirda, *Submission 124*, pp. 7–8 and 9.

45 Mr Richard Burnet, *Committee Hansard*, 4 July 2012, p. 36.

46 Mrs Fiona Engwirda, *Submission 124*, pp. 9-10.

including a spa room, multi-sensory room and teens' room. Families do not pay to stay at Bear Cottage.

The location of Bear Cottage at Manly ensures children and families can rest in quiet surroundings or enjoy the attractions and amenities nearby of one of Sydney's traditional beach holiday destinations.

Most families staying at Bear Cottage come here for respite with the length of stays up to two weeks. Families using Bear Cottage for end of life care may stay as long as necessary.

Bear Cottage was established entirely by the community and continues to rely on the community for funding.⁴⁷

11.51 Very Special Kids provides similar services in Victoria:

Very Special Kids provides counselling and support services to families caring for a child diagnosed with a life-threatening illness. Following the death of a child families are supported through the bereavement support program.

[Very Special Kids] also operate Very Special Kids House an eight bed children's hospice, providing planned and emergency respite and end-of-life care.

Very Special Kids was established in 1985 after two families recognised there was a need to support other families experiencing the loss and grief associated with having a child diagnosed with a life-threatening illness.

Very Special Kids depends on the community and our fundraising activities for more than \$3.3 million of our annual income. All services are offered free-of-charge to families.⁴⁸

11.52 The transition from paediatric to adult palliative care services was identified as another challenge for young people. Palliative Care Victoria outlined several case studies, including Giulia's story which raised some of the difficulties experienced when transitioning to adult palliative care services:

Giulia is an 18 year old young woman with Rett Syndrome who lives at home with her mother, Ursula, and her sister. Rett syndrome is a neurodevelopmental disorder that affects girls almost exclusively...

While Giulia was under 18 she attended the Glenallen Special School and she and her family received support and services through Very Special Kids and a state government program called Family Choices. Turning 18 meant that she had to transition from the paediatric system to the adult service system and she and her family could no longer access the respite they had been receiving through Very Special Kids, the special school which had

47 Bear Cottage, *What is Bear Cottage?*, available: http://www.bearcottage.chw.edu.au/about/what_is.html (accessed 29 August 2012).

48 Very Special Kids, *About us*, available: <http://www.vsk.org.au/about-us> (accessed 29 August 2012).

been her daily activity for 13 years or the services through the Family Choices program.

When Giulia was 16 her mother began the search for comparable respite in the adult system and placed her name on a waiting list; she also looked for an adult day activity centre; she had to apply for an Individual Support Package (ISP) to replace the Family Choices program and there was no guarantee that there would be a package available when Giulia turned 18. Ursula wonders how people who are not as familiar with the system cope.⁴⁹

11.53 Problems with funding different aspects of care were highlighted by the Centre for Cerebral Palsy in WA who explained in their submission that the delivery of palliative care funding in WA is highly complex:

The Centre's residential adult clients are funded by the State's Disability Services Commission (DSC) on an individual basis. Each year there are two opportunities for The Centre to assist clients requiring additional funds to apply for increased funding. This option for increased funding is available for clients receiving palliative care. On the other hand, block funding rather than individual funding is provided by DSC for clients requiring therapy and health services. All of The Centre's services for children are located in the therapy and health services program. Increases in funding to this program are through growth funding, based on 'blocks', which means there is currently no option for receiving more funding assistance for children in palliative care, even though there is a recognition that they require additional and extended support and services.⁵⁰

Advance care planning and children

11.54 Dr Jenny Hynson from the Australia and New Zealand Paediatric Palliative Care Reference Group spoke of the difficulties of discussing both palliative care and the subject of death in the cases of children:

This is where, really, it becomes specialist territory. There is probably a whole half an hour conversation, but to put the barebones around it the natural instinct of parents is to protect their child from knowledge about scary things. But the evidence and the experience we have would suggest that children are very clever and very sharp and often work things out for themselves...The other evidence that we are aware of is that children who are in that situation who feel that they cannot communicate with others and cannot share their concerns do feel very isolated and often develop anxiety as result of that.

11.55 Dr Hynson expanded on the importance of communication and the sharing of information on both the child and their family:

If we take symptoms management, which is the piece I know best, there are still a lot of children who are not having simple things like pain managed because they are not able to access specialist input. If they have a difficult

49 Palliative Care Victoria, *Submission 106*, Appendix 5, pp. 20–21.

50 The Centre for Cerebral Palsy, *Submission 24*, pp. 4–5.

moment of death, that haunts their parents for years into the future. We know that from the literature. That has an impact on the parents' grief, mental health—it has all these ramifications. You try to achieve the best possible life, a peaceful moment of death, support for the family and good communication.⁵¹

11.56 The ANF provided the committee with their policy on nursing care of children and young people with a terminal illness which includes specific reference to the communication of information:

Children and young people with a terminal illness should be informed and consulted and their wishes considered in any decisions made regarding their care and treatment. These decisions should be regularly reviewed together with the child or young person with the terminal illness and their selected family members.⁵²

11.57 The ANF's policy also highlights the importance of including the parents and families in the overall palliative care process, and that the care is provided in an appropriate setting:

The availability of a parent or significant other to support the provision of care and to support the child or adolescent requiring palliative care services is paramount. Parents and families should be supported to keep children and adolescents at home for palliative and end of life care wherever possible. Being in their own environment with their family, friends and pets nearby, reduces the stresses associated with palliation and facilitates dying with dignity...

Where it is not possible for children and younger adolescents to remain at home, a dedicated paediatric hospice should be available in all states and territories. We consider that it is not appropriate for children/adolescents to be cared for in an adult hospice environment.⁵³

11.58 Palliative Care Australia echoed these points through requests that funding is provided to ensure that appropriate care is available, and that a National Paediatric Palliative Care Strategy is developed:

That funding is provided to ensure that children with life threatening conditions and their families have equitable access to quality information and responsive and appropriate palliative care services...

That the Australasian Paediatric Palliative Care Reference Group be funded to develop and implement a National Paediatric Palliative Care Strategy.⁵⁴

51 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 29.

52 Australian Nursing Federation, *Submission 85*, p. 8.

53 Australian Nursing Federation, *Submission 85*, p. 8.

54 Palliative Care Australia, *Submission 98*, pp. 15–16.

11.59 The Clinical Oncological Society of Australia and Cancer Voices Australia submitted that paediatric palliative care had been reviewed in 2002 but the findings have not been implemented:

In 2002 the Department of Health and Aging funded a review of Australian paediatric palliative care (the Paediatric Palliative Care Service Model Review) which found that the needs of dying children had not been addressed within the palliative care system. It is unclear if these needs have been considered in current palliative care service arrangements. We recommend that the senate committee revisit this review to compare its findings with palliative care services currently available to young people.⁵⁵

11.60 Palliative Care Victoria (PCV) pointed out that many children requiring palliative care suffer from multiple disabilities compounding their care needs:

Many children and young people with palliative care needs also have multiple disabilities. The risk, or certainty, of death in childhood or young adulthood and their changing and often complex care needs add a degree of complexity and urgency to their care and associated family support. The disability service system is not equipped to meet all their needs.⁵⁶

11.61 PCV also discussed the review into paediatric palliative care, saying that resourcing and funding are required to fully implement the recommendations:

One of the key findings of the Commonwealth's Paediatric Palliative Care Service Model Review 2004 was a proposal to establish a Paediatric Palliative Care Reference Group to "develop the evidence based national, definitions, standards and policies that are required to implement integrated paediatric palliative care models, including developing information, education and research strategies aimed at improving delivery." Those in the field took up the challenge and formed the reference group without any resources or Government support. Resourcing is needed so that further progress can be made on outstanding work particularly in the areas of neonatal and ante natal palliative care, services for young adults and data collection.⁵⁷

11.62 Questions were put to DoHA specifically on how the department funds and resources palliative care needs of children and young people. DoHA responded that they had provided funding for a number of projects that focussed on the palliative care needs of young people:

The Australian Government has also developed a valuable resource that assists families, carers, clinicians and health workers to better prepare and equip for the many situations they may face as they live with a child's illness. The paediatric palliative care resource *Journeys – Palliative care for children and teenagers* was updated by Palliative Care Australia in 2010-11

55 COSA and CVA, *Submission 56*, p. 3.

56 Palliative Care Victoria, *Submission 108*, p. 11.

57 Palliative Care Victoria, *Submission 108*, p. 11.

with funding from the Department of Health and Ageing for the Australian Government.⁵⁸

11.63 DoHA also submitted that they provide specific funding for children and young people with cancer:

The Youth Cancer Networks (YCN) program is a 2008 Federal Budget Measure providing \$15 million to CanTeen for the establishment of Youth Cancer Networks, from 2008-09 to 2011-12, to improve services, support and care for adolescents and young adults (aged between 15 years to 24 years) with cancer.⁵⁹

Committee View

11.64 The committee agrees that the palliative care needs of babies, children and young people are distinctive from the needs of adults. The types of conditions involved, as well as the communication and support needs of the children and their families make this a highly complex area. The committee is of the view that the first step that should be taken is that the recommendations of the Paediatric Palliative Care Service Model Review that was conducted around 10 years be revisited to investigate whether they were fully implemented and evaluated.

11.65 The committee is also strongly of the view that palliative care should be delivered in appropriate care settings specific to young people and the needs of their families.

Recommendation 28

11.66 The committee recommends that, within twelve months, the Australian government review the implementation and evaluation of the recommendations of the Paediatric Palliative Care Service Model Review, and publish the findings of that process.

Recommendation 29

11.67 The committee recommends that there be appropriate formal recognition of the Australian and New Zealand Paediatric Palliative Care Reference Group, and that the Australian government work with the organisation on the development of a paediatric addendum to the National Framework for Advance Care Directives 2011.

Recommendation 30

11.68 The committee recommends that the Commonwealth, state and territory governments consult with palliative care organisations, and existing children's palliative care support services Bear Cottage and Very Special Kids, about the

58 Department of Health and Ageing, Answer to a question on notice, 24 April 2012 (received 25 July 2012).

59 Department of Health and Ageing, Answer to a question on notice, 24 April 2012 (received 25 July 2012).

feasibility of, and funding required for, establishing similar facilities in other jurisdictions.

CALD communities

11.69 People of linguistically and culturally diverse backgrounds can face additional barriers in accessing care. These can be due to lower levels of awareness of services, linguistic barriers, cultural differences, and lack of appropriate services. CALD communities themselves are diverse, including relatively recent migrants, established migrant families and communities, and groups that have arrived under humanitarian programs.⁶⁰ Palliative Care Australia (PCA) outlined some of the key issues involved in considering the provision of care for people of CALD background:

The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for the patient, family, carers and community. As Australia's cultural diversity increases, cultural misunderstandings resulting in the provision of inappropriate end of life care to people from CALD backgrounds has the potential to grow. There can be issues with translators and medical interpreters where they do not feel able to honestly relay information due to their own cultural beliefs.

Respecting and being sensitive to people from CALD backgrounds and their community ties is integral to the delivery of quality care at the end of life. Cultural practices are not the sole determinants of patient preferences and there may be significant individual differences within communities.

The needs of older people from CALD communities, and new and emerging communities, raise broad equity and access issues. The cultural implications of patient autonomy in regard to decision making, acceptance and use of advance care directives, and truth telling must be understood and respected on a case by case basis.⁶¹

11.70 The committee asked PCA about its work with culturally and linguistically diverse communities. PCA stated:

We have different organisations represented on the steering committees of our different programs that we run. We translate some of our consumer resources into 21 different community languages in order to ensure that the message is getting out there. One of the things that we are aware is problematic with different community groups is that the tools that are used, what we call audit tools, to ensure that the best possible care is being given are not always validated for different cultural groups. This is something that we are quite aware of that is a concern. For instance, we have a patient and family carers audit tool where we check back that people really received high-quality care. It is validated for your Anglo population but not validated for all other community groups. So there really needs to be some time, effort and money put into extending testing and validation of these kinds of

60 See, eg, The Friends of Northern Hospice and Palliative Care Foundation, *Submission 82*.

61 Palliative Care Australia, *Submission 98*, p. 61.

tools and ensuring that they best meet the needs of the entire community and not just the quite narrow field that they do now.

Senator FIERRAVANTI-WELLS: In terms of reaching out to organisations, we do have in our ethnic communities whole myriad groups and different associations, many of which have been welfare based, that had their origins in welfare and then expanded to education in other areas but still retained their welfare base. Most of the main communities certainly have those. How have you worked with those, and do you see scope with greater flexibility in the system for you to do a lot more with those groups and to tap into them?

Dr Luxford: Yes.

Senator FIERRAVANTI-WELLS: Because one of the things that concerns me is the inflexibility of the system. To what extent would you like to see greater flexibility in the system to enable you to be a lot more creative in terms of outreaching that work?

Dr Luxford: Thus far we have predominantly worked with those groups through the translations of the different resources.

Senator FIERRAVANTI-WELLS: It has really been a basic exercise.

Dr Luxford: But also in getting their input into the reference committees of the National Standards Assessment Program, so ensuring that we have representatives there from different community groups. But it is certainly an area that we would love to expand as well.⁶²

11.71 Palliative Care Victoria noted that the number of people accessing palliative care services from CALD communities was lower than for the community as a whole. When Victoria's *Strengthening Palliative Care Policy 2004-2009* was evaluated, it was concluded that 'there was a need for more specific engagement with them to improve their awareness of and utilization of palliative care services'.⁶³

11.72 Like PCA, KinCare and other submitters identified the availability of translators as an ongoing limitation in service provision,⁶⁴ and increasing these services was an explicit recommendation by PCA.⁶⁵ The government indicated that additional money had been put into translation services in the aged care sector, but that 'we acknowledge in this package that we need to do more to support the very diverse demographic that will be coming forward'.⁶⁶

62 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, pp. 25–26.

63 Palliative Care Victoria, *Submission 108*, p. 10.

64 KinCare, *Submission 25*, p. 5; Australian Association of Social Workers NSW Palliative Care Social Work Practice Group, *Submission 70*, p. 1.

65 Palliative Care Australia, *Submission 98*, p. 64.

66 Ms Carolyn Smith, First Assistant Secretary, Ageing and Aged Care Division, Department of Health and Ageing, *Committee Hansard*, 24 April 2012, p. 16.

11.73 The Centre for Cerebral Palsy identified that problems can arise where there is a tension between clinical and cultural priorities:

Hospitals are often unable to balance clinical practice with cultural need, with the former always getting an undue prominence in service provision, even where the cultural element may be of great importance to the receiver of services. It might also be the case that mechanisms for making an individual 'comfortable' in a clinical sense might contradict being comfortable in a cultural sense. This type of contradiction can cause irreparable harm to the emotional and psychological wellbeing of an individual and needs to be avoided as far as possible.⁶⁷

11.74 There were a range of proposals for addressing the diverse needs of CALD communities, beyond provision of translation services. The Australian and New Zealand School of Palliative Medicine recommended that 'a CALD (Culturally and Linguistically Diverse) training module for registrars training in Palliative Care Medicine' be developed.⁶⁸ The Palliative Care Nurses Australia recommended that consideration be given to acknowledging CALD community needs in palliative care standards.⁶⁹ The committee notes that the Australian government recently 'provided funding to the South Australian Partners in Culturally Appropriate Care (PICAC) provider to develop a CALD palliative care training package'.⁷⁰

GLBTI

11.75 As the submission from GLBTI Retirement Association Incorporated (GRAI) pointed out, gay, lesbian, bisexual, transgender and intersex (GLBTI) individuals face some particular challenges in both aged and palliative care. GRAI noted:

GLBTI elders have grown up in an era when homosexuality was criminalised or regarded as a mental illness. Consequently, GLBTI elders tend to have deeply internalised fears of homophobia, be profoundly concerned about exposure and are often very adept at identity concealment. The ramifications of these patterns are an increased incidence of stress, depression and social isolation. Of special relevance to this inquiry is that GLBTI elders are also less likely to access health care and other services as a result of their fears regarding institutions.⁷¹

11.76 Identity concealment and ignorance amongst service providers can be a part of a vicious cycle of invisibility. Dr Jo Harrison observed that 'consumers who are GLBTI remain largely invisible and are therefore assumed by service providers to not exist'.⁷² When GRAI surveyed aged care facilities in Western Australia, the overwhelming majority of centres said they were unaware of GLBTI people in their

67 Centre for Cerebral Palsy, *Submission 24*, p. 5.

68 Australian and New Zealand School of Palliative Medicine, *Submission 33*, p. 15.

69 Palliative Care Nurses Australia, *Submission 45*, p. 9.

70 Department of Health and Ageing, *Submission 96*, p. 4.

71 GLBTI Retirement Association Incorporated, *Submission 67*, pp. 1–2.

72 Dr Jo Harrison, *Submission 77*, p. 2.

facility, with the typical response being "We don't have any of those people here".⁷³ However, most facilities almost certainly do: GRAI suggested that between 8 and 10 per cent of the 900 000 people in aged care will have non-heterosexual identities.⁷⁴

11.77 The palliative care needs of GLBTI people are not homogenous, any more than for other large groups of palliative care clients.⁷⁵ However, Lesbian and Gay Solidarity, and GRAI, both indicated that palliative care providers need to show recognition and acceptance of GLBTI clients. GRAI indicated that it had worked with residential aged care providers to produce a set of best practice guidelines. These included providing a safe and inclusive environment; open communication; GLBTI-sensitive practices; staff education and training; and GLBTI-inclusive organisational policies and procedures.⁷⁶ The committee also notes that the *Guidelines for a Palliative Approach for Aged Care in the Community Setting* consider the needs of GLBTI people.⁷⁷

11.78 Dr Harrison indicated that the Australian government is funding some 'GLBTI cultural awareness in aged care training, and... GLBTI targeted aged care packages to provide services to people living at home'.⁷⁸

11.79 Several submitters pointed out that faith-based organisations are significant providers of both aged care and palliative care services. They expressed concern about the possibility that such services could be exempted from anti-discrimination laws in respect of GLBTI staff or clients, and that this should be prevented.⁷⁹ Dr Harrison pointed out the importance of a:

member of staff who is openly GLBTI or GLBTI-friendly in approach. Often this provides a lifeline from complete isolation, withdrawal and depression. It can also prove to be critically important when end-of-life situations arise.⁸⁰

11.80 There is also little understanding of the needs of carers for LGBTI people. Carers NSW noted that '[t]here is also a lack of information about the needs of carers of persons with a life limiting illness who identify as [GLBTI]'.⁸¹

73 GRAI, *Submission 67*, p. 3.

74 GRAI, *Submission 67*, p. 3.

75 Lesbian and Gay Solidarity, *Submission 48*, p. 1.

76 GRAI, *Submission 67*, pp. 3–4.

77 Department of Health and Ageing, *Submission 96*, p. 9.

78 Dr Jo Harrison, *Submission 77*, p. 5.

79 Lesbian and Gay Solidarity, *Submission 48*, GRAI, *Submission 67*, Dr Jo Harrison, *Submission 77*.

80 Dr Jo Harrison, *Submission 77*, p. 5.

81 Carers NSW, *Submission 61*, p. 9.

Committee view

11.81 People from CALD communities and with GLBTI identities represent significant numbers of palliative care service users, both as patients and as carers. The committee notes that the Australian government is involved in ensuring recognition of the identities and needs of both these groups, through for example guidelines that identify specific needs, translator services, and targeted awareness training. The committee notes the government's acceptance that more will need to be done to provide for the diversity of people coming into aged and palliative care. It is important that the government ensure that the needs of all palliative care service recipients are addressed sensitively and equitably.

Chapter 12

Other matters

12.1 This chapter looks briefly at other important issues that arose throughout the committee's inquiry yet which did not fall specifically within the terms of reference.

International comparisons

12.2 Throughout the inquiry the committee received evidence suggesting that palliative care service provision could indeed be improved if Australia were to consider implementing approaches to palliative care that had proven effective in international jurisdictions.

Gold Standards Framework

12.3 One approach to care that was raised throughout the inquiry by numerous stakeholders was the Gold Standards Framework (GSF) developed and used in the United Kingdom.

12.4 Palliative Care New South Wales informed the committee that the GSF, which was designed to support advanced cancer patients in the community, focuses on community care rather than hospital based care. PCNSW however suggested that its translation to the Australian context may be difficult as the relationship between the government and general practitioners (GPs) in the UK is different to that in Australia. PCNSW told the committee however that in their opinion the 'GSF has some good tools and processes.'¹

12.5 Palliative Care Australia (PCA) informed the committee that they too advocated for the adoption of the GSF by GPs:

We were certainly part of their consultation process around setting up the Medicare Locals and we are certainly advocating with them at the moment for a national program for GPs that is modelled after the Gold Standards Framework in Britain.²

12.6 However, the committee heard that some care providers in Australia are in fact already applying the framework. Alzheimer's Australia informed the committee of a pilot being trialled by Tasmania's Cradle Coast Council.³ Representatives from Tasmania further explained the pilot to the committee:

The project is really based on the United Kingdom Gold Standards Framework, which has been adapted to Australian conditions. It is used in the UK in over 1,000 care homes, and has been since 2004. There is a lot of

1 Mr Peter Cleasby, President, Palliative Care New South Wales, *Committee Hansard*, 2 July 2012, pp. 55–56.

2 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 20.

3 Alzheimer's Australia, *Submission 44*, p. 19.

evidence showing that it gives better end-of-life care and better assessment and management of symptoms. There is more attention to those parts outside of physical medicine, such as the psycho-social, cultural and spiritual aspects. One of the important things is that it reduces avoidable hospitalisation. In fact, it promotes communication. We get better communication between the residents, all of the staff members within the institutions and the carers outside of the institutions.⁴

12.7 As well as Cradle Coast Council in Tasmania, Amaranth Foundation informed the committee that they too use the GSF in the provision of care:

We actually use the gold standards. The NHS in the UK use that prognostication question—just the basic one, that no-surprise question: 'Would you be surprised if this person were to die sometime in the next 12 months?'

We applied that basic question across all the people with advanced chronic illnesses who attended a GP practice. We then identified those people and, within that 12-month period, we brought them in for their usual chronic disease screening process. The nurse would take their blood pressure or do their diabetes, spirometry or whatever check they were doing and I would sit down and have a chat with them. I would ask: 'How do you feel about what is happening to you? What are some of the issues in your life?'⁵

Nursing Home Doctors

12.8 Another model that was suggested be looked into for adoption in the Australian context was that of the Nursing Home Doctor model used in the Netherlands. BlueCare suggested that the committee:

...look at the model used in the Netherlands, which is a nursing home doctor model [and] ...think about a feasibility study of the introduction of a medical specialty in aged-care medicine in residential aged-care, which is different to our current geriatricians. These specialists would be specifically trained and employed in residential aged care. I recently had the privilege of visiting the Department of Nursing Home Medicine, at VU University in Amsterdam. There they use a teaching nursing home model and they provide two-year training, which has been offered in the Netherlands since 1990, when they realised that reliance on GPs for care of their elderly was not adequate. So whilst it is a more expensive model, compared to using GPs, they find that cost savings are realised, with an almost 95 per cent death rate, in the nursing home setting, as opposed to transferring people to acute care, which is what often happens in Australia.⁶

12.9 BlueCare explained that in addition to helping achieve the outcome of deaths in the community setting rather than hospital, the model used in the Netherlands is:

4 Dr Alan Rouse, Tasmanian Health Organisation, *Committee Hansard*, 5 July 2012, p. 1.

5 Mrs Julianne Whyte, Chief Executive Officer, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 29.

6 Associate Professor Deborah Parker, Director, University of Queensland/Blue Care Research and Practice Development Centre, Blue Care, *Committee Hansard*, 2 July 2012, p. 2.

...also about quality of life and promoting residential aged-care facilities as homes where people can maintain quality of life and be well until they die—which is the palliative care philosophy. You need to have personnel who can not only do good assessments, order the right medications or stop the wrong medications, and look to the future to make sure the care people receive is the best that it can be but also support the family through that. So it is partly about stopping people inappropriately going to hospital. We also do not have any data comparing the outcomes for quality of life between that system and others. It is such a unique system that they do not tend to match it with that of other countries.⁷

12.10 BlueCare did however explain that at present the model used in the Netherlands could not be implemented in Australia given the Australian system's requirement that a patient choose their general practitioner:

At the moment, legislatively we cannot oppose somebody having a particular doctor. I have done research in organisations where I have had to write 40 letters to 40 GPs to tell them that we were doing some research in a particular facility and could they participate. If one or two registered nurses have to deal with 40 GPs, administratively that is a major challenge.⁸

Committee comment

12.11 The committee considers that the ongoing development of the provision of palliative care service and models of service delivery in Australia should be informed by international best practice. The committee however considers that this is occurring largely as a result of the dedicated practitioners and academics who work in this field to achieve these outcomes.

12.12 In view of the evidence the committee received concerning the effectiveness of service delivery models that focus on 'dying in place' (covered in Chapter 7), the committee would like to see further research on the appropriateness of introducing a Netherlands-style 'nursing home doctor' model in Australia.

Access to and use of schedule 8 drugs

12.13 Throughout its inquiry stakeholders discussed the importance of ensuring access to schedule 8 drugs for palliative care patients. Schedule 8 drugs are controlled drugs:

Schedule 8 (Controlled Drug) – Drugs of addiction. This category is for substances that should be available for use but require restriction of manufacture, supply, distribution, possession and use to reduce abuse, misuse and physical or psychological dependence.⁹

7 Associate Professor Deborah Parker, Blue Care, *Committee Hansard*, 2 July 2012, p. 7.

8 Professor Deborah Parker, Blue Care, *Committee Hansard*, 2 July 2012, p. 8.

9 Pharmacy Guild of Australia, Australia's unique medication scheduling system http://www.guild.org.au/iwov-resources/documents/The_Guild/PDFs/News%20and%20Events/Publications/Fact%20Sheets/scheduling_system.pdf (accessed 4 October 2012).

12.14 The committee heard that the use of schedule 8 drugs is common in palliative care:

The use of morphine and other opioid medications is common in palliative care, as well as in the management of pain more generally, for example for people with chronic pain of all types. These 'drugs of dependence' are listed on Schedule 8 of the Poisons Standard published by the National Drugs and Poisons Schedule Committee and are thus commonly known as Schedule 8 (or S8) drugs.¹⁰

12.15 Although the use of schedule 8 drugs is common and necessary for pain management in palliative care, the committee consistently heard that access to these drugs is at times problematic.

12.16 The South Australia Advanced Practice Palliative Care Pharmacists (SAAPPCP) stated in their submission that although the addition of pharmaceutical benefits for palliative care had improved access to a small number of listed medications for some patients:

...there is an evidence base for a number of medications for patients with some symptoms, such as neuropathic pain and bowel obstruction that are difficult or even impossible to access by many patients. The use of these medications is often endorsed by national and international professional organisations in clinical guidelines; however, health professionals can have difficulties using the guidelines as the medicines concerned are not always available to the patient.¹¹

12.17 The SAAPPCP went on to explain that:

An additional problem associated with the non-PBS listing of many relevant palliative care medications has implications for pharmacists and medication safety. The standard consumer information provided does not include non-PBS medicine use. Pharmacists have to ensure that patients and carers are provided information about medication options, benefits and associated risks in a format that meets the patients/carers needs. Where evidence is available for additional use of medicines, inclusion of expanded indications on the PBS would facilitate improved information provision.¹²

12.18 They suggested to the committee that what was required was a 'full review of the medications available on pharmaceutical benefits for palliative care' given that a 'lack of standardisation in prescribing practices across Australia has significant flow on effects to other aspects of the patient management, including supply and administration of medicines in a timely way.'¹³

12.19 In addition to these concerns, Aged and Community Services of Western Australia spoke of the jurisdictional inconsistencies that also led to access issues:

10 Aged Care Association of Australia, *Submission 93*, p. 5.

11 South Australia Advanced Practice Palliative Care Pharmacists, *Submission 13*, pp. 2–3.

12 South Australia Advanced Practice Palliative Care Pharmacists, *Submission 13*, pp. 2–3.

13 South Australia Advanced Practice Palliative Care Pharmacists, *Submission 13*, pp. 2–3.

Legislative jurisdictions also impact on a nationally consistent approach to providing health care because of differences in regulations relating to who is able to administer medicines (such as Schedule 8 drugs) and the use of syringe drivers to manage pain, and indeed, access to certain drugs that are funded under the Pharmaceutical Benefits Scheme and public hospital system.¹⁴

12.20 The Pharmacy Guild of Australia (the Guild) also raised these concerns:

...there are differences that apply across jurisdictions that can hinder the access of palliative care patients to medicines. This is particularly problematical in communities on the border or across territories where patients may travel across jurisdictions to access appropriate care ... If you are going to have a national monitoring scheme for opioids, you should have regulations in a standard format in place before you start. ... To have this legislation in common across jurisdictions would facilitate the care of patients.¹⁵

12.21 The Guild suggested that having a safe disposal system in place could assist in the control of schedule 8 medications:

The disposal of controlled drugs in a proper manner could be achieved by having a safe disposal system put in place. Safe disposal is essential to avoid accidental poisoning of household members, particularly children, medicine abuse and toxic release into the environment. As such, the guild would recommend that a return system be considered. That would assist in removing high-risk medicine such as schedule 8 medicines and cytotoxic medicines from households where they are no longer required.¹⁶

12.22 When asked who they consider should address this problem, the Guild explained that action was required at the federal level as the federal government could ask the states to introduce 'uniform regulation for the supply of schedule 8s:'

It is a common-sense approach and a lot of other things under COAG have been established to deliver a uniform set of rules. Providing the Commonwealth were putting a strong case that this was needed for a universal control system as well as for other more humane and medically based conditions, that argument should certainly win the day. I think the Commonwealth would need to take the lead role.¹⁷

12.23 The Guild went on to explain that in their opinion there should be no arguments against such a reform although the states may resist any such changes:

There is no argument against it, except the states like to control what goes on. The argument the states could run is that, even though there would be a centrally based scheme of approval, if something went wrong they would

14 Aged and Community Services WA, *Submission 66*, p. 5.

15 Mr Denis Leahy, Committee Member, New South Wales Branch, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, pp. 1–2.

16 Mr Denis Leahy, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, pp. 1–2.

17 Mr Denis Leahy, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, pp. 7–8.

have to clean it up. They would like to have control within their own states to make sure nothing goes wrong that would be adverse to the patient. So you have an issue there of the cost to the state if there is a misadventure, as opposed to an argument about the universality of availability. You would probably need to address those questions about what the funding mechanisms are to monitor at a state level, as opposed to having regulations that are all-encompassing across state borders.¹⁸

12.24 They informed the committee however that steps were being taken to improve standardisation and national consistency:

...the first step in the process has been put into place. We now have national registration of health professionals. We all have a number, whether we like it or not, and that is already in place. There are linkages in our dispensing systems and our recording in Tasmania and narcotics are recorded live to the state health department. It is a model that is going to be rolled out around the rest of the country as a government initiative.¹⁹

12.25 The Pharmacy Guild explained their 'hope for global palliative care funding being made available to include such things as wound care, compound medicine and nutritional assistance:'

We believe that this could be achieved by the expansion of the palliative care schedule that already exists. Any controlled drug monitoring system should take into account that there will be high use of opioids by this particular group of people during the palliative care phase.²⁰

12.26 The committee also heard that difficulty accessing medication is an issue in rural areas, particularly where medical practitioners are few and nurses do not have access to the necessary drugs:

...where populations tend to be fairly small...the local doctor, the GP, is usually the first port of call. There are towns that do not have a GP and where specialist nursing staff may be of assistance. A lot of palliative care problems can be relatively quickly sorted out by nurses who are properly trained, but they still need access to prescribers. You basically cannot run a non-prescribing service in palliative care and you also need pharmacy back-up... your little kit of drugs, for instance, that you might need to manage someone dying at home is mostly tightly regulated as schedule 8 drugs. So they are not the sorts of things that your community pharmacy is going to be happy to supply without appropriate authority and in the kinds of amounts and volumes that might be needed. Specialist nursing staff can do a lot but they cannot do that without prescribers. We think that some of the newer technologies might be able to assist.²¹

18 Mr Denis Leahy, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, pp. 7–8.

19 Mr Harvey Cuthill, National Councillor, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, pp. 7–8.

20 Mr Denis Leahy, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, pp. 1–2.

21 Associate Professor Frances Boyle AM, Former Executive, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, pp.41–42

12.27 Professor Boyle went on to explain that new technologies may assist in the delivery of palliative care, including pain management, to rural and remote areas. He cited a possible role for the national broadband network:

We have a project with the National Broadband Network, for instance, which has called for research projects to look at delivery of care using telemedicine, and things like managing people's pain using the broadband network in rural areas might well be feasible. We do not know whether that will get funding, of course.²²

12.28 Although these problems of access are greater in rural areas, the committee heard that they also extend to residential aged care facilities where problems accessing medication often arise as a result of a limited workforce:

Where we have difficulty is if that aged-care facility does not have a registered nurse and we are requiring morphine or some schedule 8 medications. If there are untrained staff—and I am talking about PCAs—then we will not train them on that.

What we will often do is train a family member, just like in the home. Just like when you are in your own home, we will train a family member. We find that facilities will not allow a family member to give medications because that confuses their regulations, but we will actually educate a family.²³

12.29 Professor Jane Phillips spoke of this problem and suggested that the concept of nurse practitioners who can dispense controlled drugs could assist in both rural and regional areas and residential aged care facilities:

...it is really important to make sure that we do not make regional differences with nurse practitioners being in only rural communities and not necessarily in metropolitan communities. It should be based on where their skills would be best utilised. Yes, some of the issues around prescribing items are really quite important because you do not actually want to penalise patients by not being able to access their medication because they are seeing a nurse practitioner.²⁴

12.30 Palliative Care Australia went further and suggested that registered nurses be authorised to provide the 'full range of symptom and end-of life support including:'

...symptom assessment, the ordering and administration of medications, particularly schedule 8's and to be able to provide p.r.n. medication administration.²⁵

22 Associate Professor Frances Boyle AM, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, pp.41–42.

23 Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, p. 4.

24 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, pp. 60–61.

25 Palliative Care Australia, *Submission 98*, p. 9.

12.31 PCA suggested that this may assist with limiting the:

...many occasions staffing shortages lead to unrelieved pain and admission into an acute care facility, often through Emergency Departments with unnecessary trauma for both the patient and family. Rural RACFs can only manage patients with complex palliative care needs if they are able to access support, consultation and medications from specialist palliative care teams. This requires more staffing of specialist palliative care teams.²⁶

12.32 When these matters were raised with the department, DoHA explained that:

Each state and territory has its own legislative requirements on the matters that must be included on a valid prescription for a Controlled Drug (Schedule 8) medicine which differ between states and territories. the Therapeutic Goods Administration (TGA) does not regulate prescriptions. Note that the technical requirements for prescription validity is a small aspect of regulation of Schedule 8 medicines by states and territories, which have differing approaches to the public health management of Schedule 8 medicines in drugs and alcohol treatment programs, attention deficit hyperactivity disorder, and longer-term use.

The TGA is aware that states and territories have given priority to assisting the delivering of the Electronic Recording and Reporting of Controlled Drugs (ERRCD) initiative. This initiative is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement between the Commonwealth and The Pharmacy Guild of Australia. A move from manual to electronic recording and real-time reporting will improve the ability to efficiently monitor the prescribing and dispensing of Controlled Drugs to ensure appropriate access to these medicines. Real-time access to accurate dispensing information will improve the efficiency by which state and territory regulators, prescribers and pharmacists identify problems of forgery, abuse and doctor shopping and improve public health outcomes.²⁷

12.33 Another matter raised with the committee was the issue of 'off-label' use of drugs which stakeholders suggested occurs frequently in palliative care. According to the Pharmacy Guild of Australia, between 30 and 45 per cent of prescriptions are used 'off-label':

I would respectfully suggest you could be looking at between 30 and 45 per cent of prescriptions that are dispensed in this space could well be for off-label use. For example, the hypnotics and benzodiazepines that are used have often been approved for sleeplessness or anxiety but in fact in this space are used for delirium, tremors and something similar, and on and on it goes. Quite a substantive volume of the drugs that are used in this space are used for so-called off-label use.

26 Palliative Care Australia, *Submission 98*, p. 9.

27 Department of Health and Ageing, answers to questions taken on notice, question 4, received 23 August 2012.

12.34 The Guild explained that although the use of drugs 'off-label' is not illegal it requires additional work for prescribers:

It is quite a legitimate use. There are some connotations out there that it is illegal. It requires extra work on behalf of the prescribers to provide adequate patient information and that is that you need, as I understand the law, to have an informed patient in this instance. In the case of palliation, that is sometimes quite a difficult space to go into—to have a patient who is informed, if you are using an end-of-life drug for something like delirium, is an extraordinarily challenging circumstance; good luck.²⁸

12.35 When questioned about these matters the department explained:

...there is a project that we are funding that is looking at a number of different off-label drugs for use in palliative care. I think at present there are 26 drugs on the PBS in 50 different forms that are available for palliative care services. They are under the PBS, but obviously the decision to place a drug on the PBS requires a recommendation by PBAC before the government takes action.²⁹

12.36 The department further explained that:

The practice of prescribing registered drugs outside of their approved indications is not regulated or controlled by the Therapeutic Goods Administration (TGA), as it is at the discretion of the prescribing physician. In these circumstances, the TGA is unable to vouch for the safety and efficacy of this use for an unapproved indication and its use is therefore regarded as experimental. It should also be realised that the Australian Government, the Secretary or a delegate of the Secretary cannot be rendered liable to a person in respect of loss, damage or injury suffered by the person as a result of, or arising out of the use of a therapeutic good for a non-approved indication.³⁰

Committee comment

12.37 The committee was concerned by the evidence it received suggesting that palliative care practitioners often encounter barriers when trying to prescribe medications for their patients. The committee considers that these barriers to access are the result of a number of factors and therefore to overcome the problems a multifaceted response is required.

12.38 The committee acknowledges the importance of controlling the use and disposal of schedule 8 drugs, however considers that the need to control these drugs must be balanced with recognition of the important role they play in providing relief to both patients and families, where a loved one is passing through the latter stages of life. The committee takes the view that this cohort of patients has unique needs that

28 Mr Harvey Cuthill, Pharmacy Guild of Australia, *Committee Hansard*, 10 July 2012, p. 8.

29 Mr Nathan Smyth, First Assistant Secretary, Population Health Division, Department of Health and Ageing, *Committee Hansard*, 10 July 2012, pp. 42–43.

30 Department of Health and Ageing, answer to questions on notice, question 5, received 23 August 2012

require flexibility. Impeding access in these cases may in fact cause more pain for both the patient and their family.

12.39 The committee also takes the view that the current mechanisms in place to control schedule 8 drugs is resulting in greater off-label use of medications. The committee considers that as off-label use is not regulated by the TGA, steps should be taken to look at improving access to schedule 8 drugs so that off-label use is minimised.

Recommendation 31

12.40 The committee recommends that the federal government initiate a full review of the medications available on the pharmaceutical benefits scheme for palliative care, particularly schedule 8 drugs.

Recommendation 32

12.41 The committee recommends that through the Council of Australian Governments the federal government expedite the introduction of uniform regulations for the supply of schedule 8 drugs.

Recommendation 33

12.42 The committee recommends that the federal government review the role of nurse practitioners and registered allied health professionals in prescribing palliative care medications to remove barriers to accessing such medications in settings of care where these professionals have a central role in care.

The role of private health insurers

12.43 Throughout its inquiry the committee heard that there are limited private health funds that cover the provision of palliative care in Australia. Palliative Care Australia (PCA) explained that this was the result of it (palliative care) being seen as a 'bottomless pit' rather than a 'prudent investment' not because of any legislative barriers:

There is no legislative barrier to the private sector providing palliative care and the patients claiming for these services through their health insurance. However, insurance funds do not see why they should place it on their schedules. It is seen as a 'bottomless pit' rather than a prudent investment where they could save on inpatient and drug costs.³¹

12.44 PCA went on to explain to the committee that although some private palliative care service providers had managed to receive funding from private health insurers, federal government leadership was necessary to encourage greater participation by private health funds in the funding of palliative care:

...the general lack of willingness of private health insurers to fund more cost-effective palliative care reduces the overall efficiency of the health system and inhibits equity of access. This is an area where national leadership by the Australian Government in relation to demonstrating the

31 Palliative Care Australia, *Submission 98*, pp. 86–87.

business case and negotiating greater participation by private health funds in the funding of palliative care, could be very helpful and productive.³²

12.45 PCA informed the committee that the National Hospital Morbidity Database (NHMD), which provides information about the main funding sources for health care in terms of admitted patients separations, identified that:

In 2008-2009, 77% of palliative care was for public patients; 16% of these cases were funded by private health insurance and 7% by the Department of Veterans' Affairs.

There are marked differences in funding sources for palliative care in public hospitals across jurisdictions ranging from 68% public funding in New South Wales to 96% public funding in the Northern Territory. The proportion funded by private health insurance ranges from less than 1% in the Northern Territory to 23% in New South Wales.

The main funding source for palliative care in private hospitals is significantly different from that in public hospitals. Private health insurance pays for 54% of palliative care in private hospitals of which 31% is for public patients, and the Department of Veterans' Affairs funds 12%. There are also clear differences in the main funding source by jurisdiction in private hospitals. For example, the proportion of palliative care which is designated for public patients and provided in private hospitals ranges from less than 1% in Victoria to 61% in Western Australia.³³

12.46 Cabrini Health,³⁴ the only 'specialist palliative care service in Australia delivering care to patients and families who have private health insurance' also noted the reluctance of private health insurers to participate in the provision of palliative care are:

...resulting in patients needing palliative care being transferred into the public sector at end of life, or the needs of patients and families not being met at this time.³⁵

12.47 They went on to explain that:

This gap in services means that the privately insured patient who receives active treatment for their cancer or other chronic illness from a private specialist and private hospital, is not able to readily access palliative care through the private sector. It is reasonable to assume that privately insured

32 Palliative Care Australia, *Submission 98*, pp. 86–87.

33 Palliative Care Australia, *Submission 98*, p. 42.

34 Cabrini Health is a large Catholic private sector health service providing acute, sub-acute, and aged care services both within the hospital sector and the community, to the people of Melbourne. Within its services portfolio, Cabrini is proud to provide a significant specialist palliative care service through a 22 bed specialist inpatient unit at Cabrini Prahran, a Community Home Care Program to some 160 patients and families, and a Consultative service to improve symptom management and end of life care in our acute hospitals at Malvern and Brighton. Source: Cabrini Health, *Submission 115*, p. 1.

35 Cabrini Health, *Submission 115*, p. 1.

patients generally have an expectation that their private insurance will cover them through all aspects of their illness journey, and not end when curative treatment is no longer appropriate. Some privately insured patients may be able to access private inpatient palliative care, but are missing out on opportunities for comprehensive palliative care in the home because the current funding arrangements favour in-hospital care.³⁶

12.48 As a result, Cabrini recommended that the role of the private health sector in providing comprehensive palliative care to privately insured patients and families be the subject of further inquiry.³⁷

12.49 In its submission PCA went on to explain that '[w]ith appropriate arrangements in place the private sector could play a useful role in providing more choice and access, as well as diversifying the funding sources' for palliative care. It suggested that the main impediments to the greater participation of private health insurers in the provision of palliative care are:

- A fear of cost shifting where the public purse may have funded these services.
- Defining end stage palliative care.
- Assessing patient functionality and the capacity of carers.
- Allocating a budget.
- Managing the private-public mix of services and subsequent funding.
- Locating the required services.³⁸

Committee comment

12.50 The committee acknowledges that in the future demand for palliative care services will increase as the population ages. As more Australians invest in private health insurance, the committee calls on the private health sector and private health insurers to contemplate the role they might play in helping meet the growing demand for comprehensive palliative care.

12.51 The committee considers that further research into the potential role of the private health care sector, including private health insurers, in providing palliative care services is required and suggests that the federal government initiate such a review.

36 Cabrini Palliative Care Service, *Submission 115*, pp. 1–2.

37 Cabrini Health, *Submission 115*, p. 1.

38 Palliative Care Australia, *Submission 98*, pp. 86–87.

Chapter 13

Advance Care Planning

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

Cultural reluctance to discuss death and dying

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

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

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

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

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

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

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

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

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

Increase public awareness

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

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

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

Mrs Waanders: Absolutely!

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

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

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

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

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

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

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

13.8 Palliative Care Australia emphasised that engaging in such discussions is not the sole responsibility of the health system but is also the responsibility of the community and the individual⁷ and also recommended:

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

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

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

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

Increase education

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Committee view

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

13.18 The 'DonateLife' campaign¹⁸ is an example of raising awareness around the issue of organ and tissue donation. It highlights the importance of having discussions with family and others. The committee believes that a national campaign run along similar lines covering advance care planning and advance care directives could address the reluctance to engage in conversations about death and dying, promote the benefits of advance care planning and explain the process which may contribute to a greater uptake. While processes currently differ across jurisdictions, and this is discussed in greater detail below, the committee considers that a national campaign to raise awareness and encourage conversations around future care would be of benefit. This would need to be followed up by campaigns in each jurisdiction to ensure clarity around processes in each jurisdiction of how to put plans and directives in place.

Advance Care Planning

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

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

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

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

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

What is it?

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

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

13.21 An advance care plan may include:

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

How does it occur?

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

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

Advantages

13.23 Advantages of ACP include:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

What is an advance care directive?

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

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

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

The need for national consistency

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

A national framework for advance care

13.39 In 2008, the Australian Health Minister's Conference (AHMC) commissioned work to progress the development of nationally consistent guidelines for advance care directives and related issues. This framework consists of a code for ethical practice and best practice standards for advance care directives which are underpinned by nationally agreed terminology. The National Framework for Advance Care Directives was published in September 2011.⁵⁰ An objective was the mutual recognition of ACD across jurisdictions to be facilitated through harmonisation of formats and terminology.⁵¹

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

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

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

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

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

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

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

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

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

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

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

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

Respecting Patient Choices and other support programs

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Committee view

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

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

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

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

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

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

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

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

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

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

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

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

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

Recommendation 34

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

Recommendation 35

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

Recommendation 36

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

Recommendation 37

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

Potential for the PCEHR and technology in the provision of healthcare

13.64 The committee explored whether the Personally Controlled Electronic Health Record (PCEHR) system could be a vehicle to address the issues raised about jurisdictional differences. PCEHR is a secure, electronic record of a patient's medical history, stored and shared in a network of connected systems. Information will be able to be accessed by the patient and their authorised healthcare providers. Over time patients will be able to contribute to their own information and add to the recorded information stored in their PCEHR.⁷² The establishment of PCEHR was examined by the Community Affairs Legislation Committee which tabled a report on the relevant provisions in March 2012.⁷³

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Committee view

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

Recommendation 38

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

Senator Rachel Siewert

Chair

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

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

APPENDIX 1

Submissions and Additional Information received by the Committee

- 1** Dr Chris Moy
- 2** Ballina Breast Cancer Support Group
- 3** Palliative Care Research Team, School of Midwifery, Monash University
- 4** Medical Oncology Group of Australia
- 5** Karuna Hospice Services
- 6** Hunter New England Local Health District
- 7** South Australian Cancer Clinical Network
- 8** Ms Orysia (Trisha) Ellis
- 9** Mr Denis Colbourn
- 10** Home Instead Senior Care
- 11** Dr Jean Murray
- 12** Stanhope Healthcare Services Pty Ltd
- 13** South Australia Advanced Practice Palliative Care Pharmacists
- 14** Ms Louise McManus
- 15** Dr Bruce Stafford
- 16** Dr John Gillett
- 17** Management Advisory Committee of the NSW Palliative Care Clinical Trials Collaborative ImPaCCT
- 18** Services for Australian rural and Remote Allied Health SARRAH
- 19** Cancer Voices NSW
- 20** Health Care Consumers' Association Inc

- 21** The Returned and Services League of Australia Limited
- 22** Tasmanian Department of Health and Human Services
- 23** Mr Nev Wells
- 24** The Centre for Cerebral Palsy
- 25** Kincare
- 26** Knights of the Southern Cross
- 27** South Australian Government
- 28** Blue Care
- 29** The Royal Australasian College of Physicians
- 30** Ms and Mr Kim McCartney and Gary Coleman
- 31** Mrs Fran Deakin
- 32** Barwon Health
- 33** ANZSPM
- 34** Ms Julie Roberts
- 35** Name Withheld
- 36** Dr Jennifer Tieman
- 37** Working Together Group and Palliative Care Victoria Quality Improvement
- 38** A/Prof Ben White
- 39** Ms Jenny Rowe, Palliative Care Advocacy Support Group (PCASG) - Roma
- 40** Ms Deidre Morgan
- 41** HammondCare
- 42** Eastern Palliative Care Association Incorporated
- 43** MND Australia
- 44** Alzheimer's Australia

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- 45** Palliative Care Nurses Australia Inc
 - 46** Ad Hoc Interfaith Committee
 - 47** Ms Kath Woolf
 - 48** Lesbian and Gay Solidarity (Melbourne)
 - 49** National Disability Services
 - 50** ECH Inc, Resthaven Inc, Eldercare Inc
 - 51** The Pharmacy Guild of Australia
 - 52** MS Australia
 - 53** A/Prof Dominic Wilkinson
 - 54** Anam Cara House Geelong and Colac
 - 55** Ms Michele Wiese
 - 56** Cancer Voices South Australia Inc.
 - 57** Victorian Healthcare Association
 - 58** Mercy Health
 - 59** Occupational Therapy Australia, Victoria Division Oncology and Palliative Care Services in Australia
 - 60** SANT Youth Cancer Service
 - 61** Carers NSW
 - 62** Australian Family Association
 - 63** The Australian and New Zealand Paediatric Palliative Care Reference Group
 - 64** Senator John Madigan, Democratic Labor Party Senator for Victoria
 - 65** Australian Medical Association
 - 66** Aged and Community Services WA (ACSWA)
 - 67** GLBTI Retirement Association Inc.
 - 68** Hon. Christine Campbell MP, Member for Pascoe Vale

- 69** Pharmaceutical Society of Australia
- 70** AASW NSW Palliative Care Social Work Practice Group
- 71** NSW Health
- 72** Catholic Women's League Australia Inc.
- 73** Royal District Nursing Service
- 74** Futures Alliance
- 75** Mr Peter Cleasby
- 76** St Vincent's Health Network
- 77** Dr Jo Harrison, School of Health Sciences, University of South Australia
- 78** Sir James Gobbo AC CVO
- 79** Catholic Health Australia
- 80** Silver Chain
- 81** Little Company of Mary Health Care
- 82** The Friends of Northern Hospice and Palliative Care Foundation
- 83** Cancer Council NSW and LifeCircle
- 84** Mr Bernard Bartsch
- 85** Australian Nursing Federation (ANF)
- 86** Consumers Health Forum of Australia
- 87** Baptistcare
- 88** National LGBTI Health Alliance
- 89** Catholic Archdiocese of Sydney
- 90** Ms Janet Broadstock
- 91** COTA Australia
- 92** Dr Yvonne McMaster
- 93** Aged Care Association Australia (ACAA)

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- 94** Oncology Social Work Australia (OSWA)
- 95** Ballarat Hospice Care Inc.
- 96** Department of Health and Ageing
- 97** UQ/Blue Care Research and Practice Development Centre
- 98** Palliative Care Australia
- 99** Capital Region Cancer Service ACT Health Directorate
- 100** Australian Catholic Bishops Conference
- 101** Clinical Oncological Society of Australia
- 102** Respecting Patient Choices
- 103** Ms Bernadette Tobin
- 104** Mr Denis Strangman
- 105** Amaranth Foundation Ltd
- 106** FamilyVoice Australia
- 107** Australian General Practice Network (AGPN)
- 108** Palliative Care Victoria
- 109** Dental Health Services Victoria
- 110** Centre for Palliative Care c/o St Vincent's Hospital and The University of Melbourne
- 111** Palliative Care Outcomes Collaboration
- 112** ACH Group
- 113** Name Withheld
- 114** Haematology Society of Australia and New Zealand
- 115** Cabrini Health
- 116** Tasmanian Association for Hospice and Palliative Care
- 117** Name Withheld

- 118** National Stroke Foundation
- 119** Mr The Hon. Greg Donnelly MLC
- 120** Bega Valley Community Health Services
- 121** Name Withheld
- 122** Aged and Community Services Australia
- 123** Prof. David Currow
- 124** Mrs Fiona Engwirda
- 125** Dying with Dignity ACT
- 126** National Aged Care Alliance
- 127** Respect Life Group Gunnedah
- 128** South Australian Voluntary Euthanasia Society (SAVES)
- 129** Mr Stan Malicki
- 130** Palliative Care Queensland
- 131** National Rural Health Alliance Inc.
- 132** Name Withheld
- 133** Cradle Coast Connected Care
- 134** YourLastRight.com
- 135** Palliative Care New South Wales
- 136** Name Withheld
- 137** Dr Kathryn Antioch
- 138** Avner Nahmani Pancreatic Cancer Foundation Ltd

Additional Information Received

- 1** Opening Statement of Joan Jackman, tabled 24 April 2012
- 2** Opening Statement of Australian Nursing Federation, tabled 24 April 2012
- 3** Palliative Care Nurses Australia Senate briefing paper, received 24 April 2012
- 4** Additional Information from LifeCircle, received 23 May 2012
- 5** Additional Information from Palliative Care New South Wales, received 2 July 2012
- 6** Additional Information from Medical Oncology Group of Australia, received 2 July 2012
- 7** Tabled documents from Resthaven Inc, received 5 July 2012
- 8** Tabled documents from Amaranth Foundation Inc, received 10 July 2012
- 9** Additional Information from Associate Professor Rohan Vora, received 12 July 2012
- 10** Additional Information from The Minister for Health and Ageing, received 7 August 2012

Answers to Questions on Notice

- 1** Answer to question on notice from Dr Yvonne McMaster, received 18 May 2012
- 2** Answer to question on notice from the Australian Nursing Federation, received 22 May 2012
- 3** Answers to questions on notice from the Department of Health and Ageing, received 23 May 2012
- 4** Answer to question on notice from Services for Australian Rural and Remote Allied Health, received 24 May 2012
- 5** Answer to question on notice from Palliative Care Australia, received 25 May 2012
- 6** Answer to question on notice from Professor David Currow, received 20 July 2012
- 7** Answer to question on notice from Cancer Voices South Australia Inc, received 24 July 2012
- 8** Answer to question on notice, comparison concerning the adoption of consistent palliative care standards from Resthaven Inc, received 24 July 2012
- 9** Answer to question on notice from Occupational Therapy Australia, Victoria Division Oncology and Palliative Services Australia, received 24 July 2012
- 10** Answer to question on notice from Blue Care, received 27 July 2012
- 11** Answer to question on notice from The Pharmacy Guild of Australia, received 30 July 2012
- 12** Answer to question on notice from The Minister for Health and Ageing, received 7 August 2012
- 13** Answer to question on notice from LifeCircle Australia and Cancer Council NSW, received 14 August 2012
- 14** Answers to questions on notice from The Department of Health and Ageing, received 23 August 2012

APPENDIX 2

Public Hearings

Tuesday, 24 April 2012

Parliament House, Canberra

Witnesses

Department of Health and Ageing

ANDERSON, Ms Janet, First Assistant Secretary, Acute Care Division

BUTT, Mr David, Deputy Secretary

CREELMAN, Ms Alice, Assistant Secretary, Cancer and Palliative Care Branch, Population Health Division

DE BURGH, Mr Russell, Assistant Secretary, Office for an Ageing Australia, Ageing and Aged Care Division

PARAS, Mr Andy, Director, Cancer and Palliative Care Branch, Population Health Division

SMITH, Ms Ann, Assistant Secretary, National Partnership Agreement Branch, Acute Care Division

SMITH, Ms Carolyn, First Assistant Secretary, Ageing and Aged Care Division

National Disability Services

ANGLEY, Ms Philippa, National Policy Manager

BAKER, Dr Ken, Chief Executive

Cancer Council NSW

BATT, Ms Gillian Mary, Director, Cancer Information and Support Services

LifeCircle Australia Ltd

BATT, Ms Gillian Mary, Director

GOODWILL, Ms Brynnie, Chief Executive Officer

Services for Australian Rural and Remote Allied Health

BISHOP, Mr Michael, Life Member

WELLINGTON, Mr Rod, Chief Executive Officer

Australian Nursing Federation

BRYCE, Ms Julianne, Senior Federal Professional Officer

COULTHARD, Ms Robyn, Member

FOLEY, Ms Elizabeth, Federal Professional Officer

PIGOTT, Ms Catherine, Member

Palliative Care Australia

WHITE, Dr Ian, National Policy and Communications Manager

LUXFORD, Dr Yvonne, Chief Executive Officer

Palliative Care Nurses Australia

HABERECHT, Mr John, President

MILLS, Mr Jason, National Committee Secretary

CRANaplus

MALONE, Ms Geri Malone, National Professional Officer

Health Care Consumers Association ACT

SNELL, Ms Kerry, Consumer Representative Program Coordinator

STEVENS, Dr Adele, President

McMASTER, Dr Yvonne Helen, Private capacity

PASCHUK-JOHNSON, Mrs Oxana, Private capacity

Monday, 2 July 2012

Waratah Room, NSW Parliament House, Sydney

Witnesses**Royal Australasian College of Physicians**

BOLITHO, Dr Leslie AM, President

Medical Oncology Group of Australia

BOYLE, Associate Professor Frances AM, Former Executive

FRANCIS, Ms Kay, Executive Officer

Catholic Health Australia

CLARK, Professor Katherine Jane

LAVERTY, Mr Martin, Chief Executive Officer

PHILIP, Associate Professor Jennifer

Palliative Care New South Wales

CLEASBY, Mr Peter, President

HANSEN, Ms Linda, Chief Executive Officer

HammondCare

COLE, Associate Professor Andrew Malcolm Dermot, Chief Medical Officer
 MACLEOD, Professor Roderick, Senior Staff Specialist in Palliative Care
 MCVEY, Dr Peta, Clinical Nurse Consultant, Palliative Care
 RAGUZ, Ms Angela, General Manager, Residential Care

Flinders University

CURROW, Professor David, Professor of Palliative and Supportive Services

Palliative Care Queensland

ENGWIRDA, Mrs Fiona Ann, State Council Member, Consumer Representative
 KRISTENSEN, Mr John-Paul, Chief Executive Officer
 VORA, Associate Professor Rohan, President

Blue Care

PARKER, Associate Professor Deborah, Director, University of Queensland/Blue
 Care Research and Practice Development Centre
 ROBINSON, Mrs Marie, Community Care Adviser

University of Notre Dame and St Vincents Sacred Heart

PHILLIPS, Professor Jane, Professor of Palliative Nursing

Australasian Chapter of Palliative Medicine

VORA, Associate Professor Rohan, President-Elect

Wednesday, 4 July 2012

Committee Room G6, Parliament of Victoria, Melbourne

Witnesses**St Vincent's Hospital**

BOFFA, Ms Rebekah, Acting Co-Convenor, Special Interest Group, Tertiary
 Palliative Care, Caritas Christi Hospice

Centre for Palliative Care

BOUGHEY, Associate Professor Mark, Co-Deputy Director
 PHILIP, Associate Professor Jennifer, Co-Deputy Director

Peter MacCallum Cancer Centre

BOURKE, Ms Jenni, Senior Clinician, Occupational Therapy Department
 DOIDGE, Ms Olivia, Occupational Therapist

Peninsula Home Hospice

BOVENIZER, Ms Rachel, Chief Executive Officer

BURNET, Mr Richard, Private Capacity**Southern Metropolitan Region Palliative Care Consortium**

BOVENIZER, Ms Rachel, Chair, Southern Metropolitan Region Palliative Care Consortium

Victorian Healthcare Association

CARR, Mr Trevor, Chief Executive

COLEMAN, Mr Gary, Private Capacity**Palliative Care Victoria**

BOVENIZER, Ms Rachel, Board Member, Palliative Care Victoria

DREDGE, Ms Lesley, Policy and Projects Manager

WAANDERS, Mrs Odette, Chief Executive Officer

Victorian Healthcare Association

EVANGELISTA, Ms Eloisa, Research and Policy Officer

Eastern Palliative Care Association Inc.

HOGAN, Ms Louise, Manager Human Resources and Public Relations

MOODY, Ms Jeanette, Chief Executive Officer

PEDLEY, Ms Christine, Manager, Allied Health

Australia and New Zealand Paediatric Palliative Care Reference Group

HYNISON, Dr Jenny

McCARTNEY, Ms Kim, Private Capacity**Peninsula Health**

MORGAN, Ms Deidre, Senior Occupational Therapist, Palliative Care

Very Special Kids

MURPHY, Ms Andrea, Executive Manager, Family Services

Leukaemia Foundation

SMITH, Mr Andrew, Registered Occupational Therapist

Victorian Aboriginal Community Controlled Health Organisation

WRIGHT, Ms Cherie, Victorian Aboriginal Care Project Coordinator

Thursday, 5 July 2012

Balcony Room, South Australian Parliament, Adelaide

Witnesses

Silver Chain Group

CARMODY, Mr Stephen, Chief Operating Officer

University of Tasmania

CHEEK, Mrs Colleen, Rural Clinical School

Silver Chain Western Australia

COCKAYNE, Mr Mark, General Manager, Health; and Director, Hospice Care Service

Resthaven Inc.

JENKIN, Mr Peter, Nurse Practitioner Candidate

McKECHNIE, Ms Susan, Executive Manager, Community Services

Cancer Voices South Australia Inc.

MARKER, Ms Julie, Deputy Chair

YIALLOURIS, Mr Chris, Executive

Tasmanian Health Organisation—North West

ROUSE, Dr Allan

SA Health

SWETENHAM, Ms Kate

Tuesday, 10 July 2012

Parliament House, Canberra

Witnesses

Department of Health and Ageing

BALMANNO, Ms Rachel, Acting First Assistant Secretary, Ageing and Aged Care Division

BUTT, Mr David, Deputy Secretary

CREELMAN, Ms Alice, Assistant Secretary, Cancer and Palliative Care Branch

McCARTER, Ms Sharon, Assistant Secretary, eHealth Division

SMITH, Ms Ann, Assistant Secretary, Acute Care Branch

SMYTH, Mr Nathan, First Assistant Secretary, Population Health Division
TRACEY-PATTE, Mr Keith, Assistant Secretary, Ageing and Aged Care Division

Palliative Care Australia

BLACKWELL, Dr Scott, President
LUXFORD, Dr Yvonne, Chief Executive Officer
WHITE, Dr Ian, National Policy and Communications Manager
YATES, Professor Patsy, President Elect

Pharmacy Guild of Australia

CUTHILL, Mr Harvey, National Councillor
LEAHY, Mr Denis, Committee Member, New South Wales Branch

Aged and Community Services Australia

MERSIADES, Mr Nicolas, Senior Aged Care Adviser
PORTER, Ms Wendy, Residential Care Manager, Western Australia

COTA Australia

ROOT, Ms Jo, National Policy Manager
YATES, Mr Ian, AM, Chief Executive

Amaranth Foundation

SANTAMARIA, Mr Gregory John, Director
WHYTE, Mrs Julianne Mary, Chief Executive Officer

Wednesday, 25 July 2012

Gumtree Room, Chifley Resort, Alice Springs

Witnesses**Central Australian Aboriginal Congress**

AH CHEE, Ms Donna, Acting Chief Executive Officer
BOFFA, Dr John, Public Health Medical Officer

Purple House

BROWN, Ms Sarah, Chief Executive Officer, Western Desert Aboriginal Corporation and Manager

Northern Territory Department of Health

MIEGEL, Mr Fred, Clinical Nurse Manager, Territory Palliative Care, Central Australia

Monday, 13 August 2012

Parliament House, Canberra

Witnesses

Austin Health

SILVESTER, Associate Professor William, Director, Respecting Patient Choices

WILKINSON, Associate Professor Dominic, Private Capacity

APPENDIX 3

The 13 standards for providing quality palliative care for all Australians

Source: Palliative Care Australia, Standards for Providing Quality Palliative Care for all Australians, May 2005, pp. 6–7

<http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf>

(accessed 9 October 2012).

Standard 1

Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver's and family's needs and wishes are acknowledged and guide decision-making and care planning.

Standard 2

The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.

Standard 3

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

Standard 4

Care is coordinated to minimise the burden on patient, their caregiver/s and family.

Standard 5

The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

Standard 6

The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.

Standard 7

The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

Standard 8

Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.

Standard 9

Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.

Standard 10

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Standard 11

The service is committed to quality improvement and research in clinical and management practices.

Standard 12

Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 13

Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.