

# 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.<sup>1</sup> The Senate subsequently extended the time for reporting to 19 September 2012 and then again to 10 October 2012.<sup>2</sup>

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

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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.<sup>3</sup>

### **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;

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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.<sup>4</sup>

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.<sup>5</sup>

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.<sup>6</sup> 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

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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.'<sup>7</sup>

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.'<sup>8</sup>

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.<sup>9</sup>

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.<sup>10</sup>

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].<sup>11</sup>

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.<sup>12</sup>

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

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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.<sup>13</sup>

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.<sup>14</sup>

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.<sup>15</sup>

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.'<sup>16</sup>

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...

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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.<sup>17</sup>

### **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).<sup>18</sup> 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.<sup>19</sup>

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.<sup>20</sup>

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.

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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.