

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.

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.

