

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 a 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.

