

Chapter 5

Carers

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

The valuable role of carers

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

5.3 Palliative Care Australia noted that:

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

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

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

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

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

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

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

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

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

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

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

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

The challenges faced by carers

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Senator BOYCE: Bed pans.

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

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

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

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

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

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

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

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

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

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

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

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

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

National Carer Strategy and other government support for carers

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Other support services for carers

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

Respite services for carers

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Respite for parents

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

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

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

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

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

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

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

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

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

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

Other support services for carers

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

LifeCircle

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Amaranth Foundation

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

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

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

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

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

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

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

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

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

Information for carers

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

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

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

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

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

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

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

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

5.48 The PCOC's submission described CareSearch as:

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

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

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

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

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

Bereavement services

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

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

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

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

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

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

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

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

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

Committee view

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

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

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

Recommendation 5

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

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

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

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

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

Recommendation 6

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

Other issues for carers

Carer Allowance

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

CHAIR: Exactly.

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

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

Carer payment

5.65 Although the committee did not receive evidence concerning the adequacy of the Carer Payment, it acknowledges that monetary support is provided by the federal government to carers who are unable to work as a result of taking on that role. Such support is provided through the Carer Payment. The Carer Payment:

provides financial support if you are unable to work in substantial paid employment because you are providing full-time daily care to someone with a severe disability or medical condition, or to someone who is frail aged.⁶⁵

5.66 The Department of Human Services identifies the eligibility requirements:

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

64 Mr Richard Burnet, Senator Rachel Siewert and Senator Sue Boyce, *Committee Hansard*, 4 July 2012, p. 39.

65 Department of Human Services, *Carer Payment* <http://www.humanservices.gov.au/customer/services/centrelink/carers-payment> (accessed 3 October 2012).

You may be eligible for Carer Payment (caring for a person 16 years or over) if you provide constant daily care in the home of the person you care for and he or she:

- is aged 16 or more with a severe disability or medical condition or is frail aged, or
- is aged 16 or more with moderate care needs and has a dependent child who either is under six or is aged 6–16 and eligible for Carer Allowance.

The person you care for must also either:

- receive an income-support payment from us or from the Department of Veterans' Affairs,
- be unable to receive an income-support payment from us or the Department of Veterans' Affairs because they have not lived in Australia long enough to be eligible, or
- meet the care-receiver income and assets tests.⁶⁶

Committee view

5.67 The committee has concerns about how families in circumstances such as those of Burnet family with terminally ill children may become vulnerable if changes to eligibility are made to Commonwealth family and carer payments in the future. The committee emphasises the need for any changes to Carer Allowance and/or the Child Care Rebate⁶⁷ to account for the special circumstances of families in these extremely difficult situations. In particular, the committee notes that any move to abolish or means-test the Child Care Rebate may have significant financial impacts on families such as the Burnets who care for terminally ill children.

Recommendation 7

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

Recognising carers in funding models

5.69 The committee heard that the activity-based funding (ABF) model for sub-acute care (coming into effect on 1 July 2013, as described in chapter seven) does not accurately reflect the nature of palliative care, nor place enough value on the role of carers. Dr Yvonne Luxford, Chief Executive Officer of Palliative Care Australia

66 Department of Human Services, *Carer Payment* <http://www.humanservices.gov.au/customer/services/centrelink/carers-payment> (accessed 3 October 2012).

67 The Child Care Rebate is not income-tested and it pays up to 50 per cent of out-of-pocket expenses for child care up to an annual cap. For the 2012-13 income year, the Child Care Rebate annual cap is \$7,500 per child per year. See Child Care Rebate <http://www.mychild.gov.au/childcarerebate/default.aspx> (accessed 20 September 2012).

(PCA), noted that an activity-based health funding model assumes that 'a service event is one patient with one clinician'.⁶⁸ The submission from PCA argued that the pricing model for activity-based funding should include an expanded notion of the 'patient' to include family and carers.⁶⁹ It explained:

The concept of the patient in palliative care is unique within the health system. In addition to the person with a terminal illness, palliative care treats and supports the family, carers, loved ones, and others. This care delivery to all related individuals, and inherent expansion of meaning of the concept of the term patient is integral to the philosophy of palliative care. It is essential that this expanded notion of a patient is recognised within the funding models.

Given that the plans for ABF indicate a service event is between one patient and one health professional, it is essential that an expanded concept of patient be applied to palliative care. PCA understands that it is already the intention of the Independent Hospital Pricing Authority (IHPA) to treat bereavement services delivered to the carer/s and loved one/s of a deceased patient as a service event, this conceptual expansion may offer a mechanism to expand the overall concept of patient in palliative care delivery.⁷⁰

5.70 PCA argued that non-clinicians such as a care worker assisting with showering or a volunteer carer who needs funding for training needs should be properly recognised within the costing model.⁷¹

5.71 Similarly, the submission from the Eastern Palliative Care Association drew attention to the problems with activity-based funding in being unable to recognise the complex contributions of carers:

Activity Based Funding in sub-acute care as proposed pays no attention to the needs of carers. As stated previously, the needs of carers are critical to allowing the clients to die in their place of choice. To only count face to face treatment with the client does not acknowledge the support needed for the carer. Work with the carer needs to be recognised and funded accordingly in the new funding system.⁷²

5.72 Associate Professor Rohan Vora, President of Palliative Care Queensland, illustrated to the committee the estimated costs of institutional care, compared to the costs of home-based care:

Prof. Vora: ...If you are talking about an acute bed in a hospital it is probably around \$1,000 to \$1,300 a day for an acute bed. We know that a

68 Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 25.

69 Palliative Care Australia, *Submission 98*, p. 17.

70 Palliative Care Australia, *Submission 98*, p. 82.

71 Palliative Care Australia, *Submission 98*, p. 82.

72 Eastern Palliative Care Association, *Submission 42*, p. 4. See also Ms Jeanette Moody, *Committee Hansard*, 4 July 2012, p. 8.

palliative care bed in Queensland is costed at about \$950 a day. We know that if you go down to a step-down facility where maybe you do not have as much need for acute intervention, pain management and a whole lot of ancillary services, it is probably around \$600 or \$700 a day. And in a nursing home, as we heard before, maybe it is \$150 to \$200 a day above what is already subsidised to put in the extra care. So it all depends on where the person is.

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

Senator BOYCE: For them.

Prof. Vora: That is right—and then the carer gets stressed, depressed and all the issues that go around that, so how do we pull those costs in? You might do that and exploit all the carers. They get burnt out.⁷³

Committee view

5.73 The committee commends the work of unpaid carers around Australia who put tremendous effort and energy into caring and serving those receiving palliative care. These carers are often the very close family members and loved ones of the patients. The strain experienced by carers often goes unnoticed and the committee heard that the experience of caring is often an escalating, stressful burden which does not end when the patient dies, but continues during the time of grief and bereavement. The committee especially thanks the carers who took the time to share their experiences during this inquiry.

5.74 The committee agrees that the new activity-based funding model for healthcare should take into account the complexity of palliative care provision (that is, not just one patient and one clinician) and recognise the crucial role played by carers in relieving additional healthcare cost burdens on governments and society. Carers volunteer countless hours in the service of patients and loved ones with terminal illnesses and this contribution should be reflected in the design of appropriate funding models.

Recommendation 8

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

73 Associate Professor Rohan Vora, Palliative Care Queensland and Senator Sue Boyce, *Committee Hansard*, 2 July 2012, p. 29.