Issues Paper:
Stakeholder views and evidence relating to bereavement support for carers

December 2017
Acknowledgements:
The authors acknowledge the six stakeholders who offered their time and expertise during the interviews. Their contribution has been critical to the project’s outcomes. We would also like to thank key staff from the funding body, the Australian Government Department of Health Palliative Care Section, Primary Care, Dental and Palliative Care Branch for their assistance. In particular, the ongoing support from Zoë Clews and Cora Shiroyama throughout the project is gratefully acknowledged. Information contained in this publication does not necessarily reflect the views of the Australian Government Department of Health.

Suggestion citation:
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<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Advance Care Planning</td>
</tr>
<tr>
<td>ACSQHC</td>
<td>Australian Commission on Safety and Quality in Health Care</td>
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<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<tr>
<td>DPM</td>
<td>Dual Process Model</td>
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<tr>
<td>LGBTI</td>
<td>Lesbian, Gay, Bisexual, Trans and Intersex</td>
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Executive summary

This issues paper is the result of a program of research into services and needs for people experiencing prolonged grief. It is the major deliverable from one of three sub-projects which comprised Phase 2 of this research and arose from a recommendation of the Phase 1 report (Thompson et al. 2017a):

Recommendation 13: Support research and evaluation about the impact of interventions designed to enhance end-of-life care and prepare and support carers for bereavement (e.g. advance care planning, family meetings etc.).

In order to address this recommendation, the issues paper focused on three research questions:

1. What do peak carer organisations perceive as service gaps and needs in bereavement support for carers and/or former carers?
2. What does the literature identify as the most effective ways to prepare carers for bereavement?
3. What does the literature identify as the most effective ways to support carers post bereavement?

The Centre for Health Service Development, a multidisciplinary research centre based within the Australian Health Services Research Institute at the University of Wollongong, has undertaken this research on behalf of the Palliative Care Section, Primary Care, Dental and Palliative Care Branch of the Australian Government Department of Health.

Section 1 of the issues paper provides some brief background information on the needs of carers in relation to bereavement, identification of risk and protective factors, and theoretical models which have been developed to explain and predict outcomes for bereaved people in general, and carers in particular. This information is available to assist the reader in interpreting and understanding the findings from the interviews and literature review, and to provide a framework for discussing those findings later in the paper.

The methodology of the project is described in Section 2. Semi-structured interviews with six representatives of peak carer organisations were conducted to collect information on current bereavement pathways and services for carers and identify unmet needs and service gaps. Effective ways to support carers prior to and after bereavement were investigated by carrying out a targeted review of the intervention literature. The final list of 46 original studies included in the review comprised 30 articles describing 22 pre-bereavement interventions, and 16 articles describing 13 post-bereavement interventions.

In Section 3, findings are presented from the interviews with representatives of six peak organisations that serve, or have regular contact with, carers of people with life-limiting illness. It begins by describing respondents’ views on the unique bereavement needs of carers, both before and after the death of the care recipient, and their opinions on the best ways to meet
those needs. The nature and effectiveness of current pathways into bereavement support are then explored, and gaps and unmet needs identified.

Section 4 presents the findings from the literature review. Interventions delivered during active caring could be grouped into two broad categories: those focused on the patient-carer dyad, aiming to improve family relationships and/or end-of-life care; and those focused mainly or exclusively on the carer, aiming to increase knowledge, enhance coping and/or provide practical and emotional support. Interventions delivered after the patient’s death included extensions of palliative care service provision, brief interventions targeting specific, grief-related issues for carers, and group-based support services.

Results in relation to each of the three research questions are summarised in Section 5. This section also includes discussion of the findings around the issues highlighted in the introduction to this issues paper. Finally, Section 6 presents conclusions and recommendations.

No one, standard pathway into support services could be identified for bereaved carers. Interviewees described the service system as fragmented, with a need for greater coordination at state and national levels. Certain populations of carers were particularly under-served: those in rural and remote areas, those from culturally and linguistically diverse groups, and those identifying as part of the LGBTI community. Suggestions for improvements included establishing a national telephone bereavement counselling service, with links to or information about local service providers. A bereavement-specific website may also be useful; however the current generic online portal for carers was not seen as providing sufficient specific information to be of much use to bereaved carers.

Although bereavement support was considered an essential element of palliative care, other pathways into support are also required. Not all carers are in contact with palliative care, and some who are may not want to return to those services for bereavement support. Carers may self-refer into bereavement support or they may receive a referral via primary care. Respondents made a strong case for the need to strengthen these alternative pathways. This would require additional education, training and support for primary care practitioners and for employees at all levels in residential aged care facilities.

The public health approach to bereavement support was regarded as a promising model for service design, as it promoted the concept of service provision based on identified need. For those on the lowest tier of the three-tier model, with the lowest level of need, service improvement efforts might focus on building community capacity in recognising and responding to grief-related distress. For those on the second tier, with some indicated need, the use of validated screening tools and non-specialist interventions may help prevent escalation of problems. Finally, those with symptoms of complex or prolonged grief would require help and encouragement to seek specialist treatments.

Currently, the strongest evidence of benefits for bereaved carers comes from evaluations of programs to improve assessment of, and response to, carer needs in palliative care; multi-component interventions for dementia carers; and group-based post-bereavement programs. Findings from the interviews and the literature review suggest that bereaved carers may benefit from programs to address ‘restoration-oriented’ coping, such as access to training,
further education and employment services and financial counselling. Although there are some high-quality studies that show positive impacts on relevant outcomes, there is a need for further research to establish the most effective ways to prepare and support carers, both during active caring and after bereavement.

It is recommended that the Department of Health:

1. Consider adopting a public health approach to bereavement support, both for carers and for the wider community.

2. Promote improved access to standardised assessment and referral (including self-referral) to specialised bereavement interventions based on need.

3. Facilitate better education of palliative care professionals to enable improved communication with patients and carers around end-of-life issues, including discussing prognosis, addressing spiritual concerns, explaining interventions and processes, and providing psychoeducation around grief and loss.

4. Continue to promote comprehensive approaches to carer support in palliative care including standardised, systematic assessment of, and response to, carers’ psychosocial and spiritual needs.

5. Continue to promote the use of Advance Care Planning where appropriate as an important way of improving preparedness among terminally ill people and their carers.

6. Review current funding models for palliative care services to identify options to extend funded service delivery to bereaved persons of both palliative and non-palliative patients.

7. Promote continuity of palliative care beyond bereavement, including opportunities for carers to reconnect with services to the extent that they wish to do so (e.g. for memorial services, to bring relationships with staff members to a satisfying conclusion, or to seek answers to questions about end-of-life care issues that may be concerning them).

8. Support appropriate training about the needs of carers in relation to grief and bereavement for primary care practitioners and staff at all levels in residential aged care facilities, so they are better able to recognise and respond to those needs.

9. Promote improved links between residential aged care facilities and palliative care services so that residents, carers and staff may be better supported during end-of-life care.

10. Assess the need for a central, national portal – telephone, online or both – for the provision of bereavement counselling and/or referral to local services, as a first port of call for bereaved carers and others in the community.
11. Promote community capacity building around discussing, recognising and responding to loss, grief and bereavement through Primary Health Networks, community health services and other appropriate means.

12. Support research to develop and evaluate promising interventions to support carers before and after bereavement, particularly those based on a sound theoretical framework.

13. Encourage the development of innovative, evidence-based approaches to addressing the needs of under-served groups of carers including Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse groups, members of the LGBTI community, and people living in rural and remote parts of Australia.
1 Introduction

This issues paper presents stakeholders’ views on the needs of carers in relation to bereavement and evidence on interventions to address those needs. It is designed to address one of the short-term recommendations arising from Phase 1 of the project Research into services and needs of people experiencing complicated grief (Thompson et al. 2017a), namely:

Recommendation 13: Support research and evaluation about the impact of interventions designed to enhance end-of-life care and prepare and support carers for bereavement (e.g. advance care planning, family meetings etc.).

In order to address this recommendation, the issues paper focuses on three research questions:

1. What do peak carer organisations perceive as service gaps and needs in bereavement support for carers and/or former carers?
2. What does the literature identify as the most effective ways to prepare carers for bereavement?
3. What does the literature identify as the most effective ways to support carers post bereavement?

The Centre for Health Service Development, a multidisciplinary research centre based within the Australian Health Services Research Institute at the University of Wollongong, has undertaken this research on behalf of the Palliative Care Section, Primary Care, Dental and Palliative Care Branch of the Australian Government Department of Health.

1.1 Phase 1 and Phase 2 projects

The Phase 1 project was carried out between June 2016 and March 2017 and aimed to provide policy advice on issues relating to complicated grief in accordance with the policy framework provided through the National Palliative Care Strategy 2010 – Supporting Australians to Live Well at End of Life. A mixed methods approach was taken, using multiple qualitative and quantitative data sources, followed by a facilitated workshop to review the findings and identify steps to progress the proposed recommendations.

One recommendation was that the term ‘prolonged grief’ should be preferred over alternatives (e.g. ‘complicated grief’); consequently this is the term used throughout this report.

The Phase 2 project was commissioned in May 2017 to continue this program of research. It incorporated three sub-projects, one of which (Sub-project 3) resulted in the current issues paper. This sub-project was designed to identify effective bereavement support strategies for carers engaged with palliative care services.

The other two sub-projects addressed recommendations 11 and 12 of the Phase 1 report, respectively:

Recommendation 11: Facilitate knowledge transition by disseminating the findings of this research into prolonged grief to stakeholders, particularly in the primary care, aged care and palliative care sectors (e.g. through an issues paper).
Phase 2 Sub-project 1 involved a number of activities to disseminate findings from the Phase 1 project to various audiences including primary care and residential aged care. Sub-project 2 focused on documenting pathways into bereavement support and supporting better access through the primary care and palliative care sectors. Findings from these sub-projects are reported elsewhere (Morris et al. 2017; Thompson et al. 2017b).

1.2 Background

There is a large literature around the unique needs of carers and the impacts of caring on various aspects of carers’ lives. Less information is available about carers’ adaptation following the death of the care recipient; however, some studies have identified risk and protective factors that may affect bereavement outcomes. These have been incorporated into a range of theories that seek to explain and predict individual differences in bereavement outcomes and ultimately to influence those outcomes through targeted interventions.

A comprehensive review of the literature on carers’ needs, the impacts of caring, and risk and protective factors for bereavement outcomes is beyond the scope of this project. Instead, the sections below provide some background information to aid in understanding and interpreting the interview data and the intervention literature presented in this report.

1.2.1 Needs of bereaved carers

The health and social care system relies on the generosity of informal carers to provide much of the care required at end-of-life, especially for those who wish to die at home (Currow 2015). It therefore has a vested interest in supporting carers during this time. Caring for someone with a life-limiting illness presents considerable technical, psychological and physical demands, for which many carers are largely unprepared. They are expected to take on the role, regardless of their own personal resources or skills (Williams and McCorkle 2011).

Providing informal care for a person with a life-limiting illness can be seen as a ‘health hazard’ due to its profound impacts on carers (Currow 2015). Adverse effects of caring may include anxiety, depression, stress and fatigue (Grande et al. 2009b). These are compounded by the adverse effects of bereavement itself, which may include physical health problems, increased risk of mortality from many causes, a wide range of psychological symptoms including guilt, anger, loneliness, sleep disturbances, and psychiatric diagnoses such as depression and post-traumatic stress disorder (Stroebe et al. 2006). For example, family carers for terminal cancer patients have increased risk for physical and mental morbidity; their psychological burden may exceed that of the patient (Williams and McCorkle 2011).

Information on carers’ needs is available from recent Australian surveys. The Carers NSW 2016 Carer Survey was completed by 1,958 participants including 123 former carers (Carers NSW, 2016). Carers reported lower levels of well-being compared with the Australian population, especially among people from culturally and linguistically diverse (CALD) groups, Aboriginal and Torres Strait Islander people, those living outside metropolitan Sydney, and those with less
financial resources. Almost three-quarters of carers were reliant on some form of government assistance and a third had a disability or long-term illness in the past 12 months. Psychological distress was more common among younger carers and those spending more hours per week in caring duties. Interestingly, former carers reported better health and well-being than current carers, with these levels improving consistently over time since the end of their caring role (Carers NSW 2016).

Carers may ignore their own needs in order to concentrate on providing the best possible care for the care recipient. When providing end-of-life care, carers require psychological support, information, practical help with patient care and domestic matters, and access to financial help, respite and out-of-hours support (Grande et al. 2009b). However, service providers face challenges in meeting these needs due to tensions between the carers’ role as provider and as care recipient in their own right (Grande et al. 2009b). In fact, carers may have not just two but three roles, also being considered co-workers with palliative care professionals (Currow 2015; Ussher et al. 2009). Role conflict may inhibit carers from seeking help to meet their own needs (Grande et al. 2009b).

People are influenced by societal norms and expectations that they will look after their own partners or parents with disability or life-limiting illness, and therefore may not identify themselves as carers (Currow 2015; Grande et al. 2009b; Ussher et al. 2009). Other barriers to help seeking may be a wish to preserve a sense of normality or gain a sense of mastery, or to use caregiving as an expression of love for the care recipient (Grande et al. 2009b). They may underestimate the impact of caring on themselves, or the severity of their own distress (Ussher et al. 2009). It is crucial, therefore, to assess carers’ needs along with those of the terminally ill patient (Currow 2015; Grande et al. 2009b).

The risks of failing to meet carers’ needs during palliative and end-of-life care are summed up by Waldrop (2008), who explains that a lack of psychosocial care can leave family caregivers with guilt, unanswered questions and a feeling of responsibility for unmanaged symptoms. Carers may even be surprised by the death when it occurs. This may have adverse impacts on the bereavement experience.

‘Family caregivers may miss opportunities for meaningful final communication, live with unanswered questions about the dying process, and they may ultimately attempt to adapt to a major loss while dealing with unresolved issues and unsettled memories of the death experience.’ (Waldrop 2008 p. 275)

Insight into the needs of carers following bereavement is available from a qualitative exploration of life after caring (Cronin et al. 2015). Forty bereaved carers took part in either semi-structured interviews or a focus group to understand their post-caring experiences (Cronin et al. 2015). Three themes emerged from their responses: the loss of the caring world, which left a ‘post-caring void’; the idea of ‘living in loss’ with a host of complex emotions as well as practical matters to deal with; and ‘moving on’ to care for self and others.

Loss of the caring world was accompanied by a loss of identity, role and purpose, as well as potentially the abrupt withdrawal of government benefits and regular contacts with health services which had previously provided structure and routine. Emotional reactions included
relief, guilt and anger. Bereaved carers spoke of feeling abandoned and de-valued by society. Some carers felt they were still ‘on duty’ and struggled to re-establish healthy self-care habits (such as exercise or normal sleeping patterns) after the disruption of intensive caring. However, carers also talked about the tasks of ‘moving on’, getting out of the house, getting involved in social activities or paid work, and possibly taking new caring roles out of choice or necessity (Cronin et al. 2015). The findings of this study were broadly consistent with a model of post-caring trajectories developed by Larkin (2009), described below.

Bereaved family members were contacted through funeral directors in Victoria and Western Australia and asked about their adaptation to their loss and their use of formal and informal supports (Aoun et al. 2015). Risk of poor bereavement outcomes was assessed using a screening tool to detect symptoms of prolonged grief. Three distinct groups were identified: high risk, meeting all five criteria for prolonged grief (6.4%); moderate risk, experiencing separation distress and some other symptoms for at least six months (35.2%); and low risk, with no cognitive or behavioural symptoms of prolonged grief (58.4%). All groups relied mainly on family and friends, and the moderate risk group also accessed bereavement support through palliative care follow-up programs or general practitioners. Those in the high risk group felt their mental and physical health had become much worse since their bereavement. Although they were utilising similar informal and community supports as the other groups, these were not sufficient to meet their needs. Consequently, they were more likely to use formal supports such as counsellors, psychologists, psychiatrists and social workers.

The findings of this study provide support for a public health model of bereavement support advocated by Australian researchers (Aoun et al. 2012). This approach acknowledges that most bereaved people will not require formal supports but will manage their grief with the help of family and friends. The three-tiered model proposes that bereavement support and services should be provided on the basis of identified need. Most people (at the base or ‘universal’ level) will not need formal supports but should have access to information. At the second, ‘selective’ or ‘targeted’ level, bereaved people would receive additional support and assessment as required, to prevent escalation of their problems. At the top tier or ‘indicated’ level, those at highest risk would require specialist treatment (Figure 1).
Aoun and colleagues (2015) found in their survey that the proportions of respondents in the high, moderate and low-risk groups were remarkably similar to those suggested by the public health model. They concluded that:

‘Rather than a ‘one-size-fits-all’ approach to bereavement care, there is merit in providing flexible and targeted bereavement services, many of them informal and within local communities as well as formal offerings of health services.’ (Aoun et al. 2015, p.11/14)

Providing services on the basis of need would require a systematic way to identify and assess need for bereavement support, but this is often not done, or done poorly with non-standardised tools (Breen et al. 2014). There is a lack of valid, reliably predictive screening tools with a solid theoretical foundation (Breen et al. 2014). The effectiveness of the public health approach will also depend on building community capacity to understand and respond to grief. In particular, education and involvement of primary care providers is critical (Breen et al. 2014).

1.2.2 Risk and protective factors

Knowledge of risk and protective factors may assist in accurate identification of carers who are more likely to suffer adverse bereavement outcomes and thus promote better targeting of interventions (Schut and Stroebe 2010). Factors that may be associated with carer outcomes in bereavement include intrapersonal characteristics such as gender, age and education level, and interpersonal characteristics such as the relationship with the deceased (Williams and McCorkle 2011). However, evidence on the impacts of these factors on outcomes such as psychological distress, quality of life, depression and anxiety is mixed.
According to one review, most studies have demonstrated no difference between male and female carers, or between carers of different ages, on psychosocial outcomes during the end-of-life or bereavement phases (Williams and McCorkle 2011). One of the studies reviewed reported worse outcomes for older carers in bereavement (Williams and McCorkle 2011). These reviewers also found no difference in bereavement outcomes for spouses versus other carers. However, in another review, spouse carers were identified as having greater risk for poor bereavement adjustment compared with adult children (Gauthier and Gagliese 2012).

One reason why findings vary between studies is that researchers may or may not control for confounding variables (e.g. employment status) that also influence bereavement outcomes (Williams and McCorkle 2011). Another explanation may be that intrapersonal and interpersonal factors interact to predict the risk of poor bereavement outcomes (Schut and Stroebe 2010). For example, research has demonstrated that husbands react more strongly than wives to the death of a spouse, and mothers react more strongly than fathers to the death of a child (Schut and Stroebe 2010). There is also evidence – albeit limited – that certain types of interventions may be more suited to males and others more suited to females. Because of these inter-relationships, more attention is needed to moderating and mediating relationships among risk and protective factors in bereavement (Schut and Stroebe 2010).

While intrapersonal and interpersonal risk factors may help draw attention to carers at risk of poor outcomes, situational risk factors are arguably more amenable to preventive intervention. Such factors include the quality of end-of-life care, the place of death and the preparedness of carers for bereavement. A process that might promote preparedness is Advance Care Planning (ACP), which involves eliciting and documenting the patient’s goals of care and preferences for end-of-life care in a systematic way (CareSearch 2017). Several studies have shed light on the influence of these factors on bereavement outcomes.

A prospective study investigated whether carers’ grieving and mental health were related to satisfaction with end-of-life care and whether the care recipient died in their preferred place (Grande et al. 2009a). In a post-bereavement postal survey, former carers were asked whether they felt the place of death had felt ‘right’. They were also asked about unmet support needs and symptom severity during the care recipient’s last month of life. Although only 62.5% of the home hospice patients died at home, 84.2% of carers said the place of death felt ‘right’. However, place of death was only marginally and non-significantly related to post-bereavement physical and mental health function and grief. Instead, support with pre-bereavement psychological distress, practical help with patient management and good symptom control appeared to be protective factors. Multivariate analyses controlling for demographic variables demonstrated that carers whose needs for psychological support and information were not met during end-of-life care reported significantly worse grief and mental health in bereavement (Grande et al. 2009a).

Bereavement services did not have a significant relationship with outcomes in this study (Grande et al. 2009a). In contrast, a nationwide survey of former carers in South Korea found positive consequences of access to bereavement services (Kang et al. 2013). A total of 501 family members who had provided care for terminal cancer patients completed measures of positive and negative consequences of caring as well as a measure of depression. Multivariate
analyses were performed to predict positive consequences of caring, controlling for patient and carer characteristics. Carers who had received bereavement support from palliative care professionals were significantly more likely to report an increased sense of personal mastery, enhanced appreciation for others, greater meaning and reassessment of priorities in life following bereavement (Kang et al. 2013).

The role of preparedness for death was investigated in a prospective, longitudinal study of carers whose family member had recently been placed in a nursing home (Schulz et al. 2015). Participants were 217 carers enrolled in a randomised controlled trial of a carer support intervention, of whom 89 experienced the death of their care recipient during the course of the study. Preparedness was measured using a single item, ‘If your loved one were to die soon, how prepared would you be for his/her death?’ Carers were also asked six questions about engagement in ACP, and were screened for symptoms of complicated grief. ACP was strongly associated with preparedness for the death. In multivariate analyses, greater preparedness was associated with less risk of complicated grief (Schulz et al. 2015). This relationship held even after controlling for engagement in ACP, suggesting that mental and emotional preparation has a protective role, over and above the practical and legal aspects of preparation that are promoted by an Advance Care Directive.

1.2.3 Theoretical models to guide intervention

Established theoretical models and standards provide a firm foundation for the development and testing of bereavement interventions for carers. The importance of a theoretical basis for interventions has been emphasised by previous reviews (Gauthier and Gagliese 2012; Ussher et al. 2009). This section presents a brief overview of the most influential theory of bereavement coping, the Dual Process Model (DPM; Stroebe and Schut 1999). Three models specific to carers’ responses to bereavement are also described (Hebert et al. 2006; Larkin 2009; Masterton et al. 2015). Pre- and post-bereavement grief in dementia caregiving is addressed by a staged model (Meuser and Marwit 2001).

The DPM was developed in response to criticisms of earlier theories of grieving, notably the concept of ‘grief work’ which originated with Freud, was developed by Lindeman and was later incorporated into the attachment theory of Bowlby (1917, 1944 and 1980 respectively, cited in Stroebe and Schut 1999). Grief work was defined as a:

‘...cognitive process of confronting a loss, of going over the events before and at the time of death, of focusing on memories and working toward detachment from the deceased. It requires an active, ongoing, effortful attempt to come to terms with loss.’ (Stroebe 1992, cited in Stroebe and Schut 1999)

Although intuitively appealing, the concept had a number of shortcomings, including lack of relevance across cultures and between genders, and inconsistency in operational definitions (Stroebe and Schut 2010). Drawing on a more generic psychological theory of stress coping, Stroebe and Schut (1999) hypothesised that bereavement was associated with two distinct types of stressors - loss-oriented and restoration-oriented - each requiring specific types of coping. Loss-orientation referred to behaviours focused on the deceased person including rumination about the death, memories of life as it was, yearning for the deceased, and mourning. Restoration-orientation referred to processes of adjustment to life without the
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While loss-oriented stressors were largely captured by the earlier theory of ‘grief work’, restoration-oriented stressors had been neglected. According to the DPM, however, each of these stressors was associated with a set of vital tasks.

An important aspect of the DPM is analysis of cognitive processes that regulate attention to these tasks. These processes are characterised as ‘oscillation’ between loss- and restoration-orientated coping, that is, between confrontation and avoidance of the two sources of stress (Stroebe and Schut 1999). Oscillation is seen as ‘necessary for optimal adjustment over time’ (Stroebe and Schut 1999 p. 216). Therefore one implication of this model is that bereavement support should promote flexibility and attention to both types of tasks. A later modification emphasised the importance of both negative and positive appraisals of these tasks (Stroebe and Schut 2010). Focusing on positive memories (loss-orientation) or optimistic thoughts (restoration-orientation) can sustain coping, but negative states such as loneliness (loss-orientation) and discomfort with the changed environment (restoration-orientation) must also be confronted in order to move through the processes of grieving.

The DPM has inspired considerable research, becoming a dominant model of bereavement coping (Stroebe and Schut 2010). Although the DPM was originally applied to bereaved spouses, it is now seen as having a wider application. It provides a framework for understanding problematic grieving, including prolonged grief, and has influenced the development of numerous interventions, several of which are reviewed below.

In order to understand the bereavement experiences of former carers, Larkin (2009) conducted semi-structured interviews and used a grounded theory approach to develop a model of the post-caring trajectory. Three phases emerged, the first of which was the ‘post-caring void’ described by the majority of participants. This feeling of emptiness or vacuum was only partly attributable to the death of the care recipient; importantly, it was also linked to the loss of the caring role itself and thus can be seen as an element in bereavement that is exclusive to carers (Larkin 2009). For example, health and welfare professionals who had regularly visited carers’ homes suddenly disappeared from their lives once the care recipient died. For carers, these visitors had represented an important social network and now they were ‘on their own’.

The second phase, ‘closing down the caring time’, involved changes in routine and adjustment to life beyond the caring role. This took time and effort; for example, remembering not to buy particular items that the care recipient had needed, or not to park in a disabled parking space, or not to make meals for the care recipient (Larkin 2009). Former carers also had to deal with practical, legal and financial tasks and catch up with domestic and social activities that had been neglected.

The final phase, ‘constructing life post-caring’, often involved increased contact with family members. Former carers reported that family relationships had changed (mostly for the better) and this was related to the end of the caring role as they had more time and energy available. They also reported increased time spent on interests such as sport, adult education, travel or community work; regular attendance at various activities helped rebuild a sense of routine in daily life. Three-quarters of those interviewed said these activities had been restricted during caring and this was a major motivating factor in pursuing such interests following the death of the care recipient. Respondents’ histories of caring also influenced the types of activities they
undertook, with many volunteering for carer support groups or taking up new caring roles (Larkin 2009). This study and the resulting model highlighted aspects of adjustment to bereavement that may be unique to the post-caring experience.

The idea that psychological preparedness for a death is an important factor in bereavement dates back at least to the work of Lindeman in 1944 (cited in Hebert et al. 2006) and has been supported by recent research (e.g. Schulz et al. 2015, described above). Hebert and colleagues (2006) built on this previous theorising and evidence to develop a theoretical framework around preparing carers for the death of a terminally ill person. They proposed that preparedness does not depend on duration or intensity of care, but is a multi-dimensional construct that incorporates carers’ perceptions of medical, psychosocial, spiritual and practical issues. For example, factors that might affect preparedness include uncertainty about the course of the illness, carers’ pre-existing mental health status, existential concerns, and available financial resources (Hebert et al. 2006). Good management of the patient’s pain and other symptoms, and good communication between carers and health care providers, appear to support preparedness.

‘A frequent source of frustration for families is that health care providers never discussed the fact that their loved one was dying. Common complaints are that conversations do not occur or are couched with ambiguous language (e.g. “the patient may not get better”).’ (Hebert et al. 2006, p. 1168)

Hebert and colleagues (2006) hypothesised that better end-of-life conversations would provide a crucial foundation for preparedness for death. Preparedness, in turn, would protect against adverse bereavement outcomes. While end-of-life conversations could have a direct impact on preparedness, they may also have indirect effects via other factors such as ACP, dealing with conflict, addressing cultural or spiritual concerns and psychoeducation around grief and loss. The authors highlighted the need for empirical guidance on how best to improve communication skills and practices among clinicians who provide end-of-life care (Hebert et al. 2006). This model has important implications for interventions to support carers and ameliorate or prevent problematic grief.

If carers’ needs can be identified during palliative care, there are opportunities to provide continuity of care through the end-of-life phase and beyond. Schut and Stroebe (2010, p. 96) highlighted the potential benefits of early risk assessment and ‘naturally occurring possibilities for follow-up assessment’. Consistent with this idea, Masterton and colleagues (2015) argued that caring and bereavement should be seen as part of a continuum, rather than as separate entities, and service delivery responses to bereaved carers should be shaped around continuous care. Bereavement care was seen as more effective when it began with attention to the carers’ needs before the death. These researchers developed a model of the lived experience of caring for a spouse or partner with terminal cancer. For each of the four phases of the model, they nominated specific challenges, therapeutic targets and goals of intervention (Table 1).
Table 1  A model of continuous care to improve bereavement support for carers (adapted from Masterton et al. 2015)

<table>
<thead>
<tr>
<th>Illness phase</th>
<th>Challenge</th>
<th>Therapeutic targets</th>
<th>Intervention goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease progression</td>
<td>Reducing burden (e.g. poor health, financial consequences, social isolation due to caring – these can exacerbate distress)</td>
<td>Negative cognitive appraisals (e.g. feelings of being overwhelmed by the caring role)</td>
<td>Positive reframing (identifying positive aspects of the caring role; using coping strategies; seeking support)</td>
</tr>
<tr>
<td>End of life</td>
<td>Anticipatory grief (which may be compounded by past losses and changes in the patient)</td>
<td>Strain (e.g. anxious uncertainty, feelings of being stuck or over-stretched); helplessness (e.g. inability to help the loved one, loss of control over own life)</td>
<td>Combat intrusive grief; improve communication with health care providers</td>
</tr>
<tr>
<td>Death of the care recipient</td>
<td>Loneliness and isolation (feelings of emptiness)</td>
<td>Lack of social support (may involve role reversal as carer now accepts care); regret (especially toxic if it increases over time)</td>
<td>Re-engagement with social activities; clarify and address ‘unanswered questions’ to resolve guilt and regret (especially for substitute decision-makers)</td>
</tr>
<tr>
<td>Living on after loss</td>
<td>Adaptation</td>
<td>Low self-efficacy (which hinders ability to adopt new and adaptive actions)</td>
<td>Build self-efficacy and social support (e.g. highlight learning and transformation of attitudes to life through caring)</td>
</tr>
</tbody>
</table>

In the case of dementia, the ‘work’ of grieving begins before the patient’s death, as spouses and adult children grieve multiple losses: loss of the relationship, changing communication, loss of freedom and valued social and recreational activities, a sense that they have lost control over their own lives, as well as grieving for what the patient has lost (Meuser and Marwit 2001). Known as ‘anticipatory grief’, this type of grieving begins with diagnosis and intensifies over time with the patient’s decline in function. Although there may be initial relief when the patient dies, this is short-lived; that is, anticipatory grief does not replace or completely alleviate post-death grieving (Meuser and Marwit, 2001). This can be problematic for carers because their families and friends may view the death as a relief, both for the patient and for the carer who no longer faces heavy responsibilities (Holland et al. 2009). Thus, carers who experience intense grieving after bereavement from dementia may feel that others discount or minimise their loss, leading to a form of grieving known as ‘disenfranchised grief’ (Holland et al. 2009).

In a series of focus groups with dementia carers, Meuser and Marwit (2001) documented the contrasting grief narratives of spousal and adult-child carers. There were significant levels of pre-bereavement or anticipatory grief at each of four stages of dementia progression: mild, moderate, severe, and bereaved. Overall levels of grief declined over time. For former carers, anticipatory grief appeared to reduce the impact of post-death grief, at least initially; both spousal and adult-child carers reported feeling relief at first, but high levels of grief over time (Meuser and Marwit 2001). This study resulted in the development of the Dementia Caregiver Grief Model and related interventions (Meuser et al. 2004, cited by Ott et al. 2010).
2 Methods

2.1 Interviews

Semi-structured interviews with peak carer organisations were conducted to collect information on current bereavement pathways and services for carers and identify unmet needs and service gaps.

Email invitations were sent to representatives of nine peak organisations that represent, or have regular involvement with, carers who may experience bereavement in the course of their caring roles. Where necessary, the initial email was followed up with another email or telephone call.

Six individuals agreed to be interviewed. Interviews took place between 12 and 25 October 2017. They were all conducted by telephone with one interviewer (KW) and took an average of 40 minutes each (range 31-51 minutes). The discussions were loosely guided by an interview schedule (Appendix 1) but tended to range freely over several relevant topics depending on the particular interest of the person being interviewed.

Detailed notes and records were made of each interview. These were written up into more complete notes and analysed using a framework approach based on the research question and interview schedule.

2.2 Literature review

A number of search strategies were trialled using different terms and modifiers and the results examined in order to create the optimal set of terms to maximise relevant material and minimise irrelevant material. The final search used the following terms:


This was run in Scopus, Web of Science, Medline with Full Text, MEDLINE, PsycINFO and CINAHL Plus with Full Text, resulting in 497 citations imported into EndNote. After removing duplicates, 304 citations remained.

These were subjected to two levels of screening. For the first screen, the reference list was divided alphabetically among three researchers (DM, CT and KW) who read the titles and abstracts and sorted the references into four groups:

1. Include (n=87): intervention studies and reviews of interventions
2. Include – context (n=83): background studies (e.g. discussing risk and protective factors)
3. Questionable (n=25): unclear whether the participant group was in scope
4. Exclude (n=107): participant group out of scope; not relevant to carers or bereavement

Participant groups initially excluded (out of scope) were:

- Bereaved children and adolescents
- Parents experiencing perinatal loss
- Adults with physical or intellectual disability
- People bereaved by suicide or other traumatic or sudden death
- Studies specific to a particular condition (e.g. HIV, lung cancer)

For the first four groups it is doubtful whether these people could be described (or would self-identify) as carers. The fifth group of studies was thought to be too narrow in focus to have application to carers in general. However, after discussion, the scope was broadened to include specific conditions (e.g. motor neurone disease, kidney disease, and dementia). In addition, interventions aimed at a family unit (e.g. bereaved spouse and their children/adolescents) were included if results were reported for adult participants.

The folder of ‘questionable’ references was reviewed by one team member (CT). The broader scope allowed the inclusion of three references from the ‘questionable’ folder. The fourth reference to be included from this folder was a review that provided contextual information. The remaining 20 references were excluded for the following reasons:
- No intervention evaluated (n=11)
- No bereavement outcomes reported (n=5)
- Out of scope - adults with disability, bereavement by suicide (n=5)

The second screen was conducted by one researcher (KW) based on a reading of abstracts and, where necessary, the downloaded papers. First, the ‘include’ folder was examined for any references that did not describe either (1) evaluation of an intervention for carers, or (2) a review of interventions for carers. References that did not fit either category were transferred to the ‘include – context’ folder (n=24), leaving 63 references for full text review. Then, the ‘include-context’ folder was examined for relevance to carers and bereavement, resulting in 15 further exclusions.

During the full text review process, eight additional articles were identified through reference lists and database searching. Reasons for exclusion at the final step were as follows:
- Review article (n=11)
- No bereavement outcomes reported (n=6)
- No outcomes reported for carers (n=3)
- Language other than English (n=3)
- Focus on neonatal or infant death (n=2)
- Not peer reviewed (n=1)
- Describes a study reported elsewhere, with no new information (n=1)

Interventions that included any component of care delivered before the patient’s death were classified as ‘pre-bereavement’. For example, the usual care provided by palliative care services
may include limited follow-up after bereavement. However, if palliative care services provided additional follow-up (over and above the usual care) after the patient’s death, this was classified as ‘post-bereavement’.

Six reviews that included at least one new study (not already in our list) that reported post-bereavement outcomes for carers were described in the ‘reviews’ sections below.

The final list of 46 original studies included in the review comprised 30 articles describing 22 pre-bereavement interventions, and 16 articles describing 13 post-bereavement interventions. Figure 2 is a flow chart of the review process.

**Figure 2** PRISMA diagram of literature review process
3 Views of stakeholders on carers’ bereavement needs and services

This section presents the findings from the interviews with representatives of six peak organisations that serve, or have regular contact with, carers of people with life-limiting illness. It begins by describing respondents’ views on the unique bereavement needs of carers, both before and after the death of the care recipient, and their opinions on the best ways to meet those needs. The nature and effectiveness of current pathways into bereavement support are then explored, and gaps and unmet needs identified.

3.1 Bereavement needs of carers

3.1.1 Prior to bereavement

For carers, bereavement is an extended process that begins before the death of the patient. It is not just about dying, but involves many additional losses: loss of the relationship with the patient, which may be irrevocably changed through illness; loss of the hopes, dreams and plans of a couple or a parent for their child; loss of a social life as friendships fall away. Some diagnoses, especially dementia, have a stigma attached which can make it more difficult for patients and their carers to continue interacting with their usual social networks. They may feel alienated from friends and family. This can lead to social isolation for the patient-carer dyad.

Perhaps most importantly in the context of bereavement, there is a loss of identity for the carer, who may relinquish a career, hobbies, travel and other valued activities in order to spend their time providing care. The caring role can become almost all-absorbing.

‘Carers tend to lose their former identity, especially if they stop working. They become socially isolated. A lot of times when you become a carer your old friendship group doesn’t work for you anymore because you don’t have common interests with those people any more, and they don’t quite know how to deal with you.’ (P5)

‘With dementia, you also grieve for the loss of the relationship you once had with the person. It’s a slow process and the person themselves is changed by the condition.’ (P6)

Some respondents conceptualised the caring role as a journey involving various stages, beginning with diagnosis. The diagnosis may ‘come out of a crisis’ (P6), which may be a step change following a period of slow decline for the patient during which time the carer has been searching for information and answers. The process of diagnosis itself may place considerable strain on the carer and be associated with a grief reaction.

In the case of a disability or chronic illness, the stages of the ‘caring journey’ may progress slowly, with important milestones such as transition to residential care or palliative care accompanied by increases in the intensity of grief. Awareness that the person is dying may dawn slowly, or it may come as a shock, even though health professionals regard it as an expected death.

‘Even in the case of expected death, carers are still overwhelmed by it. It’s the ultimate thing, really, isn’t it?’ (P2)
However, in the case of injury or sudden-onset illness such as stroke or diagnosis of advanced cancer, there is likely to be considerable shock and disorientation at the rapid transition to the caring role. These carers have no opportunity to prepare themselves.

‘Then you have carers who have to grapple with the fact that this event has happened, they are being asked to make decisions and absorb information in the context of a condition they know very little about, and things happen really fast …’ (P4)

3.1.2 After bereavement

Respondents pointed to different post-bereavement issues for carers depending on whether the death occurred as a result of a short or a long illness; however, they agreed that both groups of carers had increased vulnerability to poor outcomes as a result of their role. These problems stemmed directly from the fact that active caring can dominate a person’s life to the exclusion of many, if not all, other pursuits.

A bereaved carer, like any other bereaved person, may experience a huge range of emotions including anger, resentment, disbelief and numbness. Guilt can be particularly problematic, as carers are prone to wondering whether they did enough or could have done more to help.

‘We all go through a sense of complete guilt … we should all remember that we did the best we could at the time.’ (P1)

‘Unanswered questions’ and dissatisfaction with end-of-life care for the patient can also complicate bereavement for carers. The idea that the patient did not receive best possible care can become a distressing preoccupation. Respondents saw it as important to provide opportunities for carers to air their questions and get answers from an authoritative source, hopefully to put their minds at rest.

Another source of vulnerability for carers can be a sense of abandonment by a system that is set up to care for the patient, and ceases support once that person has died. Respondents were concerned about carers who were reluctant to approach the treating team or palliative care team after the death, or even to mention their situation to their GP.

‘I think that for bereaved carers there is a sense that when the treatment for the person who has passed away is finished, that there’s little support really available for them within that system.’ (P4)

Long-term carers are also vulnerable to financial insecurity following bereavement. Many are reliant on government payments and allowances which are withdrawn when their caring role ends. For example, a couple under 65 years of age may be receiving both a disability pension and a carer payment with various supplements. Once the person with the disability dies, the carer is transferred onto the Newstart Allowance which is a considerable drop in income. Carers in paid employment earn less on average than non-carers due to the demands of the caring role. If they had been living in public housing, their eligibility may change when the person with the disability goes into residential care or dies, forcing them to find alternative accommodation.
‘So financial considerations will weigh really heavily on them. It’s not just the grief of loss, it’s also I won’t have any money, I’ve been caring for this period of time, I don’t think I’ve got any chance of getting a job.’ (P5)

As well as providing material support, work is a source of purpose and identity and regular social contact that may not be available to full-time carers. Following bereavement, such carers are vulnerable to social isolation and loss of identity. The cumulative effect of other stressors, combined with a lack of social support and material resources, can become overwhelming for carers.

‘Transitioning out of the caring role is itself a struggle. If you’ve become a full-time carer, say you were an accountant before, but you’ve spent the last 10 years in a caring role, there’s that loss of identity. When that person passes away you are there, “What’s me? What is my role in life now?” So that is a massive issue for carers, and it’s getting them through that process, not just a bereavement process for the loved one but it’s what happens next, what do I do next, what happens to my life?’ (P2)

‘There can be a bit of lack of purpose in life, because the caring role is so immersive and all absorbing, once that person passes away there can be a bit of a vacuum.’ (P6)

‘When you’ve been a carer, you’ve been a 24/7 carer, you’re not just a family member, that’s your whole job, your identity, that’s your role in life. So for carers that bereavement is not just the loss of the person they cared for, but it’s the loss of their role, their identity. It’s like being sacked ... it’s like being made redundant.’ (P1)

‘They’ve lost any other identity, they’re socially isolated, a lot of them, they may be facing a dire financial future and then there’s all the normal stuff [because] the person they love is dying.’ (P5)

Several groups of carers with special needs were mentioned by respondents. These included people from culturally and linguistically diverse groups, people living in rural and remote areas, and people in the LGBTI community. It should be noted that the needs for these groups are different, ranging from issues around availability of palliative care services in their local area, to provision of culturally appropriate and inclusive end-of-life care that acknowledges the role and needs of the carer.

3.2 Effective ways to prepare carers for bereavement

3.2.1 Pre-bereavement support

Respondents nominated a number of strategies to support people who are providing care for someone with a life-limiting illness. These included strategies focused on the carers themselves, to ensure they feel confident and supported in their caring role. High quality palliative care was also seen as having benefits for carers during the patient’s end-of-life phase and beyond.

Peak bodies offer various support groups for carers, at which they can connect with others in a similar situation. Respondents believe carers derive comfort and practical assistance from these
meetings, which generally have a group facilitator. They provide opportunities to make friends and ease the social isolation often associated with the caring role. Early engagement with peak bodies also means carers have access to information about the stages of, and transitions in, the ‘caring journey’ to prepare them mentally for what lies ahead.

‘And certainly the last of those stages is when the person you are caring for is dying and after they’ve died, and possibly too when they go into a hospice. So they get information on what to expect, what their likely problems are going to be, and where they can go to for support. And they get that early on if they engage with services early on.’ (P5)

There are also several national telephone numbers which carers can contact, depending on the patient’s diagnosis. For example, the dementia helpline is available to those caring for dementia patients, and where necessary carers who contact this line are put in touch with services that can provide practical help, such as regional carer resource centres. The Carer Gateway website (www.carergateway.gov.au) was also mentioned by respondents, but was seen as too generic to be of much assistance to carers with specific questions or needs in relation to bereavement.

Counselling was seen as having a role in preparing a carer emotionally for the death, although ‘you can never be totally prepared’ (P2). One respondent suggested extending the focus of counselling to consider issues around life after caring:

‘A bit like Advance Care Planning for carers ... who are going to find themselves with a potential big hole in their lives ... So I think planning for life after this would be quite a useful and sensible thing.’ (P2)

Up until this point, and even during the end-of-life phase, carers may be reluctant to think or talk about themselves or what happens afterwards. They may try to avoid the issue, preferring to concentrate on the patient’s needs. However, several respondents emphasised the value of having honest and open conversations about the prognosis, the patient’s wishes and the carer’s needs. They felt that health care providers should be honest with the patient, friends and family; honesty was seen as respectful. Denying death also denied people the opportunity to have those important conversations.

‘We have a volunteer here whose husband died recently, he had been in hospital 11 months, and to everybody else it was obvious that he was dying, except nobody at the hospital said he was dying. So when he passed away it was possibly a bigger shock that it should have been, and I think that’s the issue ...’ (P1)

ACP was mentioned as one important way to encourage and facilitate conversations around death and dying, and resolve questions about the patient’s wishes for end-of-life care. Having an Advance Care Directive in place can avoid family conflicts, particularly when some family members have different values to others, or to those of the patient.

‘Often the family that wasn’t there throughout your caring journey turns up when the person you are caring for is dying and have all sorts of new and forceful opinions on what needs to happen next and that can actually cause quite a lot of family...’
Other important elements were good communication with the treating team, and information about the end-of-life interventions, what to expect and how to respond. This information should preferably be in writing rather than delivered verbally.

‘You need to make sure that communication between the treating team and the family is really good, and where you see that done well, that’s a gateway that allows people to resolve those questions and move on.’ (P4)

Several respondents asserted that high quality palliative care could have a protective effect on carers, as long as carers’ needs were considered along with those of the patient. This was not limited to specialist palliative care, but also recognised the role of community care services and residential aged care facilities in providing the palliative approach to people outside of the hospital system. The psychosocial and spiritual components were particularly important in enabling patients and carers to engage with ‘grief, loss, meaning, purpose’:

‘We would argue that we have the greatest impact on bereavement in the pre-death phase.’ (P3)

‘A good experience of receiving help, holistic help, will embolden them to seek help again in the future, you can’t really overestimate the [importance of the] quality of the relationships.’ (P4)

One respondent emphasised the need to consider the carer as part of the palliative care team. Because that person has been providing constant care for some time, they are likely to know the patient’s wants and needs. They may recognise medical symptoms quickly, because they know the patient better than anyone else.

‘What isn’t good is if they’ve been doing all that stuff and then the palliative care team comes in and says, don’t worry, sit back, the professionals are here to take over, you’ve done good but we’ll take over from you at this point. Their caring role needs to be respected, they need to have the information everybody else has got in that team, including the health information, and they need to be treated as an integral part of the team providing palliative care.’ (P5)

### 3.2.2 Post-bereavement support

Carers’ post-bereavement needs for support will vary. Some people who have been carers for a long time may need to be retrained for employment, re-connected socially, and may benefit from programs to build confidence. Alternatively, a carer may be financially secure and highly driven professionally, with other aspects of their life in order. Respondents also pointed out that the bereavement needs of people who have not been in contact with palliative care should also be addressed: ‘unexpected death is completely different’ (P1).

‘I think identifying those people who are more vulnerable, who haven’t got a definite pathway in the next stage of their life, is quite important. It’s important to identify those carers and assist them in developing that plan for the next phase of life.’ (P2)
Most carers will need a little time to adjust to their changed situation. Some respondents were concerned about a proposal to reduce the length of time that carer payments are available following bereavement. Currently, carers have 12 weeks until Centrelink withdraws certain benefits, and it is during this time that the carer can start to adjust and build a new identity, as well as attending to the funeral and other practical tasks. Some carers may avail themselves of counselling during this time to help start creating a new identity, setting goals and so on. Forcing carers immediately into job seeking was seen as counterproductive by some respondents.

‘You are busy with all those tangible and legal things and while you’re busy, you’re okay, and the moment you stop being busy is when you struggle …’ (P1)

However, because Centrelink is in contact with many carers soon after bereavement, this can also be an opportunity to disseminate information about bereavement support. One respondent suggested that Centrelink could include a brochure with its letters to ensure carers are aware of local services.

Peer support is offered by some peaks via regular, facilitated group meetings. The principle behind this type of support is that carers are looking to have their experiences reflected back to them. Talking to others in the same situation can be effective and also gives carers an opportunity to make new connections. Nevertheless, respondents pointed out that it can be ‘a struggle’ to get people to attend groups. A better alternative might be videos or podcasts featuring carers, which may be both less threatening and more accessible (via the internet) at any time.

Written information can also help – for example, a help sheet or bereavement guide, containing reassurance that it’s okay to feel sad, advice on turning anniversaries into something more positive, and encouragement to see a doctor if depressed or experiencing symptoms of prolonged grief. These documents may include other suggestions such as writing thoughts and feelings in a journal, or sharing experiences with family and friends.

‘Isolation becomes a huge part of the carer’s life as social networks break down, so maybe trying to re-establish those networks, see old friends again, make new friends. We just encourage them to keep trying. After you’ve had a full-time caring role, you may not feel confident at first, you may not be used to making decisions about even ordinary things or coping in social gatherings any more, but we encourage people to just continue and over time they do get comfortable with that again.’ (P6)

If a carer has symptoms of prolonged or difficult grief, they need to be helped to seek individual support from a health professional. It may take time to persuade them as often people try to avoid this step: ‘No-one really likes going to counselling!’ (P4)

3.3    Role of peak bodies in bereavement support

Some of the peak bodies consulted in this research focused exclusively on carers’ needs, whereas others served patients with particular diagnoses and also provided support to their carers. Most offered some kind of telephone advisory service for carers, providing a point of
contact where they could obtain information, discuss current issues, and if necessary be referred, either within the organisation or to an external provider, for further assistance.

‘... when they reach a situation where their caring has changed or the way they feel about their caring has changed and they want some help, then they go through to an advisory line, and usually when they ring in they’ll talk for a very long time. Some will be on the phone for 45 minutes. They’ve come in with a simple enquiry and then they want to tell their story, sometimes over and over again. In this case they’ll be coming in and saying, I’m in a mess, I don’t know what to do, can you help me, I’ve just found out my husband’s dying, I can’t think clearly, I’m falling apart ...’ (P5)

Carer support was also provided in the form of booklets or leaflets on a range of topics, and some organisational websites had dedicated pages for carers. Several of the organisations operated face-to-face counselling services for carers to support them during active caring, and there was some capacity – albeit limited – to continue this counselling after the patient had died. Respondents spoke about other peak bodies that also provided counselling to carers either directly or via brokerage arrangements. There was a perception that such services had become more restricted in recent times due to budget constraints.

If carers wish to access bereavement counselling via a peak body, it appears to be an advantage to be ‘on the books’ of that organisation before the patient’s death. For example, one respondent said the standard counselling service would cease at the death of the patient but could be continued on application, which may or may not be approved, ‘because it’s not about supporting the caring relationship’. Although bereavement was recognised as an important issue for carers at the local level, there was no dedicated focus on bereavement at the organisation level and specific bereavement counselling was not available. In contrast, another respondent said their organisation had counsellors who specialised in bereavement-related issues. The availability of bereavement services through peak bodies appears to vary depending on which state or territory the carer lives in, and the diagnosis of the patient.

3.4 Pathways into bereavement support from health and aged care

Earlier Australian research identified three pathways into bereavement support: palliative care, primary care and self-referral to bereavement counselling (Thompson et al. 2017a). Each of these pathways were mentioned by respondents in the current study and are discussed in more detail below. The current study also explored the role of residential aged care as a pathway into bereavement support for carers.

3.4.1 Palliative care

Palliative care was seen as the main route into bereavement support, at least for those who had been in contact with a palliative care team prior to the death. All respondents felt that palliative care had a major role to play in helping to prepare the family and ensuring they are supported. Community-based palliative care services in particular were nominated as a good source of information because of their regular contact with carers in the patients’ homes.

‘I do believe that palliative care is a pivotal place for bereavement care to be offered and signposted, particularly if they are coming into the home and regularly seeing the circumstances.’ (P1)
‘Bereavement care should be an unquestioned part of the continuum of care in palliative care.’ (P4)

However, one respondent warned against seeing bereavement as the ‘sole preserve’ of palliative care as these services had limited capacity to provide follow-up services to carers – this was only possible until around three months after the death. Another pointed out that specialist palliative care was not equally available to all. For example, those who die in aged care settings may receive the palliative approach, but there is likely to be less ‘institutional support’ for carers as part of this service delivery model, compared with specialist palliative care.

‘And this is why bereavement really needs to be looked at independently of palliative care ... Many people won’t actually experience significant grief reactions until quite a bit down the track, which would be two, three years on, and that’s way beyond the time that palliative care services would be involved.’ (P3)

‘Of course palliative care is a huge part, but it depends on where the person is located at the time. Many move into aged care, because their needs escalate to the point where it’s difficult to look after them in the community, so a lot of times the person is not living with the carer when they pass away …’ (P6)

One respondent mentioned the work of Palliative Care Australia in running workshops for palliative care providers around the needs of carers. Another emphasised the importance of considering the impacts on family of the end-of-life phase, and taking steps to reduce those impacts. This might include taking care with the language used – for example, the phrase ‘actively dying’ may not mean much to carers. If they are providing end-of-life care at home, carers need to know in concrete terms what this is and how long it might last, as well as how to respond.

The best model would be a good relationship with the palliative care team that continues for a period of time following the death, but this might not be feasible or suitable for everyone. At the least, palliative care providers can be talking to carers before the death, planting the seed of an idea about the availability of bereavement support, and giving information about where to go for help.

‘It’s a tricky thing to do, but I think there are definitely some benefits for people for provision [of information] where it may be that you don’t need that information right now, and you may not absorb terribly much of it, but you at least have a sense that someone has spoken to you about it ... a professional relationship that’s been cultivated, so that you know where to go when you think, actually, things aren’t right and I need some help.’ (P4)

‘They don’t need to give a lot of time, they can find the right moment in time, the right member of the family, to have that conversation.’ (P2)

3.4.2 Primary care and self-referral

For many carers, the pathway into services relied on general practitioners to identify and respond to grief-related issues with appropriate referrals. Most respondents felt that primary
care could or should be a vital pathway to bereavement care. The effectiveness of primary care depended, however, on carers having a good relationship with their GP, and on the GP being alert to the potential for bereavement-related problems and proactive in following up with the carer.

‘We encourage GPs, as far as we can, to find out if somebody has a carer, especially since carers often come with the patient to appointments, but not just to leave them sitting in the waiting room ... And that way they come to know of the caring situation. Because the carer will develop health conditions through the bereavement period and leading up to the death.’ (P5)

‘Most people go to their GP first for any issues, so that would ideally be the best place to look for carer support.’ (P6)

‘A good GP will have a supportive relationship with that person and know the person well. Even where the relationship is new, being able to know when things aren’t right and being confident to broach that subject and what the referral pathways are, I think that makes an enormous difference.’ (P4)

One respondent pointed out that supporting carers was a ‘clinical imperative’; there is evidence that good supports at home will make the patient’s clinical care more effective. Following the death, the GP’s role may be to talk carers through what support is available and reassure them that support is effective, ‘because really difficult grief comes with a lot of hopelessness’ (P4). A carer may not believe there is anything that can be done to help them through prolonged grief whereas the GP can provide education around the value of seeking individualised, specialist counselling.

Apart from the role of primary care, access to post-bereavement support was also largely dependent on carers’ ability to identify and use their local services, depending on their needs. This was regarded as not necessarily a bad thing, because of the evidence supporting self-referral to bereavement services based on identified need.

‘So it really depends on the individual’s mind set, what their other family supports are, what their economic situation is, and what their health and mental health needs are. So it’s a really hard question to answer because it could be anything.’ (P2)

‘There would have been a time quite some years ago when the belief was, everybody needs bereavement counselling. In fact, that’s actually not the case at all and if it’s not appropriately targeted you can actually end up doing more harm than good.’ (P3)

3.4.3 Residential aged care

Provision of bereavement support in residential aged care facilities was seen by respondents as ‘hit and miss’, with no consistent approach across the sector. They acknowledged that some facilities do this very well, providing personal and compassionate care for the family as well as the client. However, the carer’s relationship with residential care can be fraught. Carers often have complicated feelings about these institutions, especially at the point of the transition which can be a source of grief and guilt.
‘When we talk to carers in that situation, the focus of the conversation is around their adjustment ... how they are making that adjustment from having that person at home to having them in a residential care facility. And a lot of time, those are quite long conversations, because you don’t get the sense that there’s a lot of support available for that person in making the transition.’ (P4)

‘A lot of carers feel guilty about sending someone into residential aged care, because they see that the quality of care for the person has gone down, their condition seems to be deteriorating. But they’re at a point where it would be unsuitable to take care of them in the community, so they can’t even take them out. So it’s a whole disempowering cycle.’ (P6)

Several respondents expressed concerns about the quality of care in general, and the capacity of residential aged care to provide any additional services:

‘I think a number would not [provide bereavement care], because they seem to be struggling to provide adequate care for the people in the residential aged care facility, let alone to anyone else.’ (P5)

According to respondents, one barrier to the expansion of bereavement support in residential aged care may be funding constraints and/or the business models of providers, who would need or want to ‘attach a cost’ to that role. There were also questions about who, within the facility, would be qualified to provide such care. With relatively few registered nurses on the staff, most day-to-day care was provided by people with ‘minimal’ training which was not likely to include dealing with family bereavement. Facilities may have a relationship with local churches, who could assist with pastoral care. There were, however, questions around whether such care would be suitable for people who do not have a religion or faith.

One respondent expressed concern that residential aged care facilities run by faith-based organisations may not recognise same-sex partners, involve them in decision making or offer bereavement support. This respondent pointed to research on the treatment of the LGBTI community in aged care, but also acknowledged that some provider organisations had set up systems to ensure quality care for people in this community.

In general, respondents believed that it was more difficult to recognise the role of the carer in a residential aged care environment. They saw a need for formal mechanisms to allow carers to be involved in the day-to-day care as much as they wished, and also to incorporate patients’ and carers’ views in quality assurance processes. One of the peak organisations had developed and implemented a good practice model for residential aged care incorporating policy and education around the importance of carers. This organisation provided training within facilities on how to ensure carers are kept informed and involved in service provision. This respondent saw scope to include bereavement support within this model of care in the future.

Most respondents said it was extremely important for residential aged care facilities to engage with issues around bereavement support for carers. They saw this as ‘best practice’ in residential care. Both patients and carers required access to psychosocial and spiritual support. Such access could be improved and promoted by ensuring these components of care are
included in any funding models and mechanisms, so that facilities are enabled – and obliged – to offer a broad range of services including bereavement support.

‘If you could get nursing homes equipped and resourced to do this work, I think they’re really well placed to do it, because they kind of become part of your family throughout that experience, because they are providing that daily and intimate care for your loved one.’ (P4)

3.4.4 Other pathways

Milestones provide an opportunity for services to get back in touch with carers to see how they are faring after the patient’s death. For example, cancer services may send a card at the anniversary of the death. Providers outside the health system can also play a similar role. One respondent mentioned a memorial service run annually at Christmas by a local funeral director. This was open only to former clients but was very well attended and ‘worked magnificently well’ to bring former carers together for mutual support and remind them about the availability of bereavement support services, should they be required.

3.5 Service gaps and unmet needs

Several respondents commented on the lack of a ‘standard pathway’ for carers into bereavement support. Services were seen as ‘ad hoc’ and ‘fragmented’ with no timely, coordinated, state-based responses to carers and their bereavement needs. The only exception nominated by respondents was Victoria, where there is access to the Australian Centre for Grief and Bereavement.

‘Generally we have a very poorly developed system nationally when it comes to bereavement support.’ (P3)

‘There is no clearly defined pathway that we can say to a carer when they come in and say, the person I cared for has passed away, or that living bereavement, you know, when they’ve gone into a nursing home or just been diagnosed with end-stage dementia or whatever … We work between 8.30 and 5, and bereavement doesn’t happen neatly between 8.30 and 5.’ (P1)

One respondent suggested setting up a national telephone hotline for bereavement support, so that the number could be given to carers either during palliative care or via other avenues such as primary care. Another wondered how many people called the Australian Centre for Grief and Bereavement from interstate after finding them online.1 A telephone service could provide counselling to callers and also refer to local service providers. To be effective, such a service would need an extensive and up-to-date directory of local providers, which would be expensive to establish and maintain. However, it could ensure some consistency across the country and improve access for all bereaved people, including those not in contact with palliative care services.

1 A national telephone bereavement support service already exists but does not appear to be well known. It was not mentioned by any of the interview respondents. Griefline was established by a Victorian hospice but is now run as an independent, not-for-profit organisation (http://griefline.org.au/, accessed 12 December 2017).
Difficulties in accessing pathways to bereavement support are compounded in rural and remote areas. Carers who are trying to provide end-of-life care at home face serious barriers, including limited community care and medical support. There may be no local palliative care beds to which a person can be transferred in a timely way if urgent assistance is needed with symptom management or respite for the carer.

‘A lot of the people who are giving their view, saying I’d rather die at home, haven’t experienced what that might mean, and neither have their families. Also, in metropolitan areas, you can get a lot of home care support, you can get medical support, but if you’re in a regional or remote area and especially if you live out of town, dying at home is a whole different thing.’ (P5)

Following the death, the challenges for carers in rural and remote locations may continue due to a lack of access to bereavement support or an unwillingness to engage with the services that are available. There may be community perceptions that this is something a person should deal with by themselves, or concerns about privacy and confidentiality in small communities where everyone knows each other.

‘There is certainly a different mentality of people in the country, people try and be more self-sufficient. There is a different mindset, and services generally in health, mental health, disability and so on are harder to access.’ (P2)

‘People have overheard health service providers discussing their case in the next aisle in Coles and Woollies … that’s a reality in small towns.’ (P1)

Although online services may be seen as a potential solution to access issues, respondents were critical of this approach. One obvious problem with online portals is that not everyone has internet access or thinks to use this channel of communication. Another is that people may not self-identify as carers. Further, generic portals such as the Carer Gateway are not designed to provide information on specific diagnoses or caring situations, but serve all carers across the domains of disability, mental health and aged care. Although they have a search function for local services, they may not provide sufficient information about access pathways to answer carers’ questions. For example, a check of the Carer Gateway search function (www.carergateway.gov.au/find-a-service/service, accessed on 5 December 2017) found no listing of bereavement counselling services under the ‘counselling’ option.

‘It’s not good policy, people don’t go online looking for this sort of thing, because most of the time the carer doesn’t even know they can get support … a lot of the time it’s seen as, it’s just what you do. You’re a family, and it’s just what you do to support that person.’ (P6)

Respondents would like to see wider availability of appropriate psychosocial and spiritual support services, which ideally should be community based and linked with primary care. However, they expressed mixed feelings about the capacity of GPs to serve as a key gateway into bereavement support. Carers may have medical needs in addition to their psychosocial needs, making the GP an essential contact. Nevertheless, respondents reported that carers’ experiences of dealing with GPs were not always positive.
‘GPs work on a business transaction model, you’re allocated your 15 minutes or your 30 ... they are not good for referring to our sorts of organisations for support, and not good at referring onwards, no ...’ (P1)

‘There could be a massive role, but you’re in there for 10 minutes and you get churned around. With time and space, GPs could provide that support but people in the medical world, the clinical world, have this focus on the client, not on family members around that person, they’ll see the person who is ill for 10 minutes but the rest of the time it’s up to the carers.’ (P2)

There were also contrasting views on the value of consumer directed care and whether this could lead to an increase in the availability of psychosocial and spiritual support, including bereavement support, for carers. To maximise the value, carers need to know what services are available, and may also need help with decision making.

‘We hope now that with home care packages and community care moving towards consumer directed care, we hope that would mean that more providers will get on board and accessibility will improve.’ (P6)

‘It’s like saying to people, you need a service, go buy it from your local provider, whoever that might be, whether it be your local church, your best friend down the road, your local pub, Lifeline or whatever. That’s devolving the whole service delivery down to a transaction, in my opinion, and I don’t think that carers, and having been through that, you are in no state to make those rational decisions.’ (P1)

Bereavement support should be offered in a way that reflects ‘contemporary best practice’ (P3). The public health approach to bereavement support (e.g. Aoun et al. 2012) was seen as a useful model for service design. This is a tiered approach in which services are targeted according to need. At the top tier of the model, a small proportion of bereaved people require specialist interventions for complex problems such as prolonged grief. A somewhat larger proportion may benefit from non-specialist support provided by peer groups, volunteers or community groups. At this intermediate level, screening may be beneficial to assess their risk of future complications so that timely referral for more specialised help can be made if necessary. The majority of bereaved people have a low level of need and fit the profile of the lowest tier of the public health model.

‘What we don’t want to do is to pathologise death and dying and consequently bereavement, but recognise that there are people who are going to need some very in-depth and specialist support and that really ties in to availability of appropriate mental health services.’ (P3)

Poor bereavement outcomes can be associated with people ‘putting on a brave face’ (P4) or not trusting that the people around them will want to listen and be supportive. Building community capacity to detect and respond to grief-related distress is consistent with a public health approach. Capacity building could begin early with developing resilience among young people. It could also include an element of public education around bereavement and knowing what supports are available and why it might be a good idea to access them.
'I don’t think we place enough emphasis on skilling people to make the most of informal support that’s around them through family and friends, and also skilling family and friends up to be helpful.’ (P4)

Another service gap identified by respondents relates to the financial challenges faced by full-time carers in their adjustment to life after caring. Although some small programs are available via peak bodies to help carers return to employment following bereavement, a more systematic approach may be warranted. Services or programs could be developed to assist carers with training or preparing for entry to further education, job seeking and future life planning. For carers who are below retirement age, finding employment may be an important step towards both financial security and building self-esteem, confidence and a new sense of purpose.
4 Evidence on interventions for bereaved carers

This section presents the findings of the literature review. Interventions delivered during active caring could be grouped into two broad categories: those focused on the patient-carer dyad, aiming to improve family relationships and/or end-of-life care; and those focused mainly or exclusively on the carer, aiming to increase knowledge, enhance coping and/or provide practical and emotional support. Interventions delivered after the patient’s death included extensions of palliative care service provision, brief interventions targeting specific, grief-related issues for carers, and group-based support services.

4.1 Interventions to prepare carers for bereavement

Studies of risk and protective factors for prolonged grief among carers have demonstrated the importance of the period leading up to bereavement (Schut and Stroebe 2010). In the case of expected deaths from cancer or other chronic illness, there may be opportunities to reduce carer stress and increase coping skills and knowledge before the patient’s death, potentially leading to better outcomes in bereavement.

Most of the pre-bereavement interventions for carers identified by this review were provided in the context of palliative care. This is consistent with a focus in palliative care on meeting the needs not only of the patient but also their family and other significant people in their lives. The National Consensus Statement: essential elements for safe and high-quality end-of-life care (Australian Commission on Safety and Quality in Health Care (ACSQHC) 2015) sets out a set of guiding principles for delivery of palliative care, which includes the following:

Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs. (ACSQHC, 2015, p. 4).

The Consensus Statement identifies patient-centred care as an essential element of end-of-life care processes. Processes of patient-centred care that are particularly relevant for carers may include conversations around the patient’s wishes, values and goals to guide end-of-life care planning, communication between the family and the multi-disciplinary care team, and substitute decision making. Interventions can be implemented during the end-of-life phase to improve these processes and thus enhance carers’ coping and resilience, preparing them for bereavement.

Pre-bereavement interventions may also be provided for carers well ahead of the end-of-life phase, depending on the nature of the patient’s terminal illness. This is particularly the case in dementia care, where the carer may be faced with the loss of a relationship, future plans and hopes, some years before the patient’s death (Ott et al. 2010). Interventions designed to address this anticipatory or disenfranchised grief have also been included in this review and are described below.

4.1.1 Reviews

We identified five reviews of interventions that reported post-bereavement impacts for carers. Of the three articles that described the evidence for interventions at end-of-life, one focused on end-of-life care pathways (Chan et al. 2016), another focused on music therapy (Bradt and
Dileo 2010) and the other had a broad focus, encompassing brief, group-based psychotherapies, relaxation training and community-based support groups as well as specialised end-of-life care (Gauthier and Gagliese 2012). One article reviewed psycho-social interventions for carers of cancer patients (Ussher et al. 2009). The remaining article was a narrative review on the effectiveness of supportive counselling and therapy provided either before or after bereavement (Schut and Stroebe 2010).

Music therapy may involve a wide variety of activities, ranging from listening (e.g. song choice, lyric analysis, using music to facilitate reminiscence or relaxation) to music-making (e.g. singing, playing instruments, song-writing and improvisation; Bradt and Dileo 2010). A systematic review of music therapy in end-of-life care included five studies that met quality criteria; however these mostly reported outcomes only for patients. Only one study reported carer outcomes. Patients who took part in music therapy reported high levels of satisfaction on items measuring perceived benefits for their ‘loved one’ (Wlodarczyk 2007, cited by Bradt and Dileo 2010).

Only one study met inclusion criteria for a review of the impact of end-of-life care pathways on outcomes for patients and carers (Chan et al. 2016). This was a cluster randomised controlled trial conducted in Italy and involving 232 patients, of whom 34% were cared for in accordance with the Liverpool Care Pathway (Costantini et al. 2014, cited by Chan et al. 2016). Outcomes were measured by interviews with family members at two- to four-months after the patient’s death. Use of the pathway was associated with better control of breathlessness. However, no carer outcomes were assessed in this study.

Gauthier and Gagliese (2012) considered a range of carer outcomes, including adjustment to bereavement, in their review of specialist end-of-life care for cancer patients. Eight interventions, described in 10 studies, were included in the review. The authors concluded that end-of-life care may have favourable impacts on bereavement outcomes for carers, but there was insufficient evidence to draw conclusions about the impacts of bereavement support groups or relaxation training (Gauthier and Gagliese 2012).

Psycho-social interventions for carers of cancer patients were reviewed by Ussher and colleagues (2009). They identified four studies, of which two were randomised controlled trials (Kissane et al. 2006; Walsh et al. 2007) which were already included in our review. The other two studies (Hudson et al. 2005; McCorkle et al. 1998) were subsequently obtained and are reviewed below. Overall, the reviewers concluded that there was little high-quality evidence to guide practice for interventions to reduce carers’ pre-bereavement distress and improve coping with the caring role. However, some interventions had demonstrated positive impacts on other outcomes including distress following bereavement (Ussher et al. 2009).

In their narrative review, Schut and Stroebe (2010, p. 96) explored the idea that pre-loss interventions for carers could provide valuable opportunities for early risk assessment and ‘naturally occurring possibilities for follow-up assessment’. Such interventions would imply a beneficial level of continuity of care from the palliative and end-of-life phases to bereavement. However, in accordance with two previous reviews of end-of-life care, they found no evidence of effects on post-loss bereavement. In their conclusions, these reviewers recommended that
future efforts should focus on groups most at risk of poor bereavement outcomes, as well as examining potential moderators and mediators of treatment effects (Schut and Stroebe 2010).

There is a large literature focusing on interventions to support carers of patients receiving various types of specialist care. For example, numerous reviews have recently been published examining ways to support carers of cancer patients (Ferrell and Wittenberg 2017; Fu et al. 2017; Sutanto et al. 2017). However, these studies do not generally report post-bereavement outcomes for carers, putting them outside the scope of the current review.

4.1.2 Intervention studies

We identified 22 interventions for carers in the pre-bereavement period, described and/or evaluated in 30 articles. Most were delivered via palliative care or cancer services with a smaller number delivered to carers of patients with other types of terminal illness (dementia, n=5; motor neurone disease, n=1; renal failure, n=1). A wide variety of post-bereavement outcomes were reported, including: psychological distress; quality of life; social support; coping and resilience; and grief. A few studies reported measures of positive adaptation to caring, such as preparedness, competence and rewards of caregiving. Studies were included if they reported any relevant post-bereavement outcomes or specific, grief-related pre-bereavement outcomes such as anticipatory grief.

Thirteen interventions were evaluated with a randomised controlled trial, four with single group pre- and post-test designs, and the remainder with single group post-test or qualitative methods. Nine of the 13 highest quality (i.e. RCT) studies reported significant impacts on carers, indicating that there is a range of effective interventions available for the pre-bereavement period.

4.1.2.1 Interventions for the patient-carer dyad in palliative care

ACP allows the care team and family members to understand the patient’s wishes when they can no longer communicate, making decision-making easier and preventing unnecessary and potentially distressing treatments. Some researchers have suggested that this in turn may benefit carers in bereavement; however, there is as yet little evidence of benefits beyond the patient’s death (Thompson et al. 2017a).

Song and colleagues (2015, 2016, and 2017) conducted a randomised controlled trial of an ACP intervention for patients with renal failure. Sharing Patients’ Illness Representations to Increase Trust (SPIRIT) was delivered by nurses over two sessions and involved assessment, tailored information, development of a document detailing the patient’s wishes, and preparation of the carer for end-of-life decision making and the associated emotional burden. The control group received usual dialysis care. Carers who were bereaved during the trial reported less anxiety, depression and post-traumatic stress if they had received SPIRIT, compared with controls (Song et al. 2015). There were also improvements in dyad congruence (that is, whether patient and carer agree on the goals of care) and the carers’ confidence in their ability to make appropriate decisions on the patient’s behalf, for African-American (but not white) participants who received SPIRIT (Song et al. 2016). In a qualitative study, bereaved carers reported that they had been comfortable with the discussions and felt they were a good opportunity to talk about difficult issues. The SPIRIT process had clarified the patient’s wishes and improved their
relationship. Carers felt the discussions had made end-of-life decision making easier and consequently they felt more peaceful during bereavement (Song et al. 2017).

Two studies described the impacts of interventions delivered in community-based palliative care settings. A randomised controlled trial compared usual care with an intervention providing a standardised needs assessment of the patient and carer with data presented to the interdisciplinary palliative care team meetings (McMillan et al. 2011). The needs assessment covered the dyads’ physical, spiritual and psychosocial needs, based on a theoretical model for peaceful death (Emanuel and Emanuel 1998, cited in McMillan et al. 2011). The short, structured presentations were delivered verbally and in writing but not accompanied by suggestions for changes to care plans. Quality of life improved for patients and carers in the intervention group but there were no other reported improvements in carer outcomes. The study also measured bereavement outcomes which were to be reported elsewhere; however a database and internet search (including contacting the first author) was unable to locate this information.

Community-based palliative care was extended to allow for follow-up visits to carers at two and six weeks following the patient’s death (Redshaw et al. 2013). In qualitative interviews, the nurses who delivered this care said they considered bereavement support a vital part of their service. The visits gave carers an opportunity to talk about the patient’s death, the funeral and the grief they and other family members were experiencing. By enabling the carer to be the focus of attention, the visits provided an outlet after the patient’s death, and also allowed the nurses to bring the relationship with the carer to a satisfactory conclusion (Redshaw et al. 2013).

Specialised oncology home nursing services were provided to terminally ill patients and their carers by graduates of an advanced nursing program in cancer symptom management (McCorkle et al. 1998). The nurse served as a central care coordinator and the model of care featured 24-hour access to nursing personnel. Content of the program included systematic assessment, symptom management, coordination of community and health care resources, and facilitating communication about the dying process within the family. There were two control groups: one received standard home care and the other received office care only. The intervention group reported significantly less psychological distress than the office care group, with treatment effects enduring for up to 13 months after the patient’s death (McCorkle et al. 1998).

Lack of family cohesion and problematic relationships are risk factors for complicated grief (Burke and Niemeyer 2012). Family Focused Grief Therapy is designed to address this risk by identifying dysfunctional families and providing additional support during palliative care (Kissane et al. 2006; Masterton et al. 2013). A randomised controlled trial demonstrated that the intervention was effective in reducing psychological distress and depression among family members six and 13 months after the patient’s death, but only in the 10% of families that were most distressed, depressed and poorly adjusted at baseline (Kissane et al. 2006). There were no intervention effects on grief, social adjustment or family functioning. In a second randomised controlled trial, 57 families received up to six sessions of Family Focused Grief Therapy, while 55 families received usual care (Masterton et al. 2013). All had been assessed as ‘at risk’ according to their scores on the Family Relationships Index. Interim findings indicated that the
intervention improved communication within the families (Masterton et al. 2013). At six months following bereavement, rates of complicated grief were lower among intervention participants (17%) than controls (25%) although it was not stated whether this difference was statistically significant.

Two studies evaluated Dignity Therapy, a brief psychotherapy designed to provide hope and a sense of meaning to people with a terminal illness (Bentley et al. 2014; McClement et al. 2007). In an interview with the therapist, the patient recounts memorable or meaningful aspects of his or her life. The therapist records and transcribes the interview and edits the document, which is then discussed and further refined with the patient. Family members may take part in the therapy and are generally the recipients of the resulting document. Eighteen family carers of adults with motor neurone disease completed measures of carer burden, depression, anxiety and hopefulness before and after Dignity Therapy (Bentley et al. 2014). There were no self-reported changes, after statistically controlling for the patient’s change in health status. Carers reported mixed feelings about the process, but half believed the document would be an ongoing source of comfort in their bereavement (Bentley et al. 2014). An earlier study of 60 bereaved carers provides some support for this assertion. Carers were surveyed nine to 12 months after the patient’s death, and 76% of participants reported that the Dignity Therapy document had continued to be a source of comfort, while 78% said it had helped them during their grief (McClement et al. 2007). The document was often kept in a ‘safe’ place with other important family items and memorabilia, shared with other family members, and used as the basis for a eulogy or obituary.

4.1.2.2 Interventions for the carer in palliative care

The intervention studies in this group were carried out in palliative care settings and focused on efforts to enhance usual care for spouses and other family members. The types of interventions included telephone and online support, assessment and care planning, therapy and resources. Six of the 10 interventions were evaluated via randomised controlled trials.

The Educate, Nurture, Advise, Before Life Ends (ENABLE) program provided support for palliative care carers via three, weekly telephone calls, with a follow-up call one month after the intervention, and a second follow-up after the patient’s death (Dionne-Odom et al. 2015, 2016). Nineteen of the 44 participants were randomised to receive the calls at the time of enrolment into the program, which was immediately after a new diagnosis, recurrence or progression of the patient’s advanced stage cancer (‘early’ group); the remainder had the intervention ‘delayed’ by 12 weeks. Analyses that looked backwards from the time of the patient’s death found that carers in the ‘early’ group had significantly less stress and depression in the final weeks than the ‘delayed’ group, but no differences in quality of life (Dionne-Odom et al. 2015). However, at 8-12 weeks following bereavement there were no differences between the groups in depression or complicated grief (Dionne-Odom et al. 2016).

Two ‘carer advisors’ with backgrounds in social work and nursing provided advice and support on patient care, carers’ physical health needs, respite, future planning, psychological health, relationships and social networks, and finances (Walsh et al. 2007). This intervention was designed to supplement usual care across seven specialist palliative care teams. A total of 137 carers were randomised to receive the intervention, which consisted of up to six visits or telephone calls over a six-week period. If the patient died, the intervention was discontinued.
and the carer was followed up four months later. There were no significant differences between the intervention and control groups on scores for psychological distress, carer strain, quality of life, satisfaction with care, or grief (Walsh et al. 2007).

Promising preliminary results were found from a small-scale evaluation of stress management counselling delivered by telephone to 19 carers of people receiving hospice care (Kilbourn et al. 2011). The Caregiver Life Line (CaLL) intervention involved 10 to 12 weekly phone calls during the weeks leading up to, and in some cases beyond, the patient’s death. The study’s design precluded a rigorous assessment of the benefits of the intervention but demonstrated feasibility and acceptability. Participants reported reduced stress and depression and increased social support and quality of life following the intervention. They were also better able to find benefit in their caring experiences (Kilbourn et al. 2011).

Best practice standards for bereavement care recommend early screening and assessment of the carers’ needs, structured information and support at various points in the grief trajectory, and access and referral to individualised support services as required (Hall et al. 2012). These elements were incorporated into two interventions that provided a comprehensive approach to carer support in palliative care settings.

The Victorian Bereavement Support Standards for Specialist Palliative Care Services (Hall et al. 2012) were recently used as the basis for an intervention in palliative care services in Denmark (Toft Thomsen et al. 2017). The intervention had four components: risk and needs assessment at care entry; an inter-disciplinary conference to prepare a care plan; targeted support as needed; and establishment of an electronic medical record for the carer. The intervention reached 76 carers (46%) of 164 patients recently admitted to home hospice care. Of these, 57 (75%) had a care plan prepared at an inter-disciplinary case conference following the initial assessment of risks and needs. Thirteen received targeted support, and of these eight had an electronic medical record established. Staff believed they used more time and resources during the end-of-life phase as a result of the intervention but then less during the bereavement phase. They perceived that the intervention provided more ‘cohesive and preventive support’ during caregiving compared with the usual more ‘sporadic’ contact after bereavement (Toft Thomsen et al. 2017, p. 5).

One of the co-authors of the Standards was involved in the randomised controlled trial of a comprehensive intervention delivered to 150 carers of people receiving palliative care for advanced cancer (Hudson et al. 2013). Delivered by a Family Caregiver Support Nurse, the psycho-educational program was based on the transactional model of stress and coping. Components included a carer guide book, assessment of carer needs, establishing a care plan and delivery of tailored support via home visits and telephone calls. One week after the intervention ended, participants reported greater competence and preparedness than those in the control group, but no difference in psychological distress (Hudson et al. 2013). Eight weeks after the patient’s death, psychological distress had increased more for control group members than for intervention participants, with small to medium effect sizes (Hudson et al. 2015).

An earlier trial of a similar psycho-educational program found limited treatment effects (Hudson et al. 2005). The program was delivered to 54 carers in addition to standard home-based palliative care services, with a control group of 52 carers. The intervention aimed to
prepare carers by providing information and opportunities to develop skills and knowledge of relevant issues, focusing on carers’ needs, helping them make meaning from their situation, promoting self-care, and advising them on care planning, goal setting and their own rights. Perceived rewards of caregiving at five weeks after baseline were stable for the intervention group and declined for controls. At eight weeks after the patient’s death, those in the intervention group perceived greater rewards of caregiving than controls. No other treatment effects were found. The authors noted that there were no negative sequelae of the intervention despite potentially distressing content (Hudson et al. 2005).

The internet was used as a platform for a third comprehensive intervention to support carers of patients with advanced lung cancer (DuBenske et al. 2014). The Comprehensive Health Enhancement Support System (CHESS) featured online discussion groups, one-on-one support, coping techniques, decision aids, action planning tools, and a clinician report in which the carer entered patient data to send to a clinician, with alerts when symptoms exceeded threshold values. Participants (including the control group, who received a list of potentially useful websites) were given a laptop and access to the internet if needed. Multivariate analyses controlling for initial carer scores and patient distress found that carers in the CHESS group had significantly lower burden and less negative mood than those in the control group. Post-bereavement outcomes were not reported in this published study, but a 2013 news release indicated that impacts of CHESS had been measured at three and five months after the patient’s death. At these follow-up measures, intervention group participants had lower levels of depression and anger than control group participants, regardless of their pre-bereavement levels. These findings were presented at a conference (Society of Behavioral Medicine, 22 March 2013) but do not appear to have been published in a peer-reviewed journal.

A DVD resource designed for carers of people in palliative care was produced in collaboration with a carer steering committee and evaluated with 15 current carers and 15 carers who had been bereaved for at least six months (Thomas and Moore 2015). The content of the DVD covered the following themes: the caring role; self-care; family and social support; the palliative care team; practical issues; end-of-life discussions and care; and bereavement. The vast majority (93%) of the carers who reviewed the DVD said they were satisfied or very satisfied with it, and 97% said it was quite or very realistic. Qualitative data indicated the resource was acceptable to carers and health professionals (Thomas and Moore 2015).

Two group-based interventions which aimed to improve carers’ physical and mental health during active caring and bereavement were also identified by the review.

Existential Behavioral Therapy is a manualised group treatment based on ‘third wave’ cognitive behavioural therapy (CBT) and existential psychology, designed to support carers through caring and grieving (Fegg et al. 2013). The intervention consisted of six sessions (22 hours) covering the following content: mindfulness, death, bereavement, self-care, finding meaning, activating resources, personal values for reorientation, goodbye to the group, and next steps. The control group in this randomised controlled trial received access to usual care. Of the 133 carers who completed the study, 59 were bereaved before the intervention began, and a further 44 were bereaved shortly before or during the intervention. Multivariate analyses controlling for pre-treatment differences and other factors found significant post-treatment differences between intervention and control on anxiety and quality of life, with medium to
large effect sizes. At 12 months there was a significant effect of the intervention on depression and quality of life and negative affect was lower in the intervention group than the control group (Fegg et al. 2013).

Qualitative interviews with carers who received Existential Behavioral Therapy identified two key elements of the intervention: social support and self-regulation strategies (Kögler et al. 2013). The group provided opportunities for self-disclosure and understanding the experiences of others, and also helped participants to develop useful strategies around mindfulness and acceptance, a focus on the positive, and orientation to new goals (Kögler et al. 2013). A third study demonstrated the importance of the mindfulness component of the therapy: mindfulness mediated the impacts of the intervention on all outcome variables except meaning in life (Kögler et al. 2015). At the 12-month follow-up point, people who had completed baseline measures but declined the intervention had stronger reductions in anxiety than either intervention or control participants, although the intervention group had the most improvement in quality of life (Thurn et al. 2015). This follow-up study highlighted the importance of initial screening and targeting of the intervention to those who need it most.

Singing in a group has the potential to support immune system function for cancer patients and their carers via three key components: emotional expression, meaningful activity and social support (Fancourt et al. 2016). Mood questionnaires were completed and salivary cortisol and cytokine levels (indicators of stress and immune system responsiveness) were measured before and after cancer patients, current and bereaved carers took part in practice sessions with five choirs associated with a cancer care centre in Wales. Singing was associated with improved mood, reduced cortisol and increased cytokine activity for all three groups of participants. Bereaved carers had a stronger immune system response compared with current carers and patients, despite similar baseline psychological scores and similar baseline and change in mood scores (Fancourt et al. 2016).

### 4.1.2.3 Interventions for dementia carers

The current review identified a number of interventions designed to address anticipatory and/or disenfranchised grief among dementia carers. Although some do not report post-bereavement outcomes, they are included here because of their focus on grief as an outcome of treatment. Most of the studies in this group evaluated multi-component interventions, with some components targeting both patient and carer, and others targeting just the carer.

Three randomised controlled trials evaluating multi-component interventions for family carers in dementia have reported positive impacts on outcomes such as resilience, coping and grief (Haley et al. 2008; Holland et al. 2009; MacCourt et al. 2017). Six sessions of coaching, plus two follow-up sessions, were offered to 123 carers who could choose to receive the intervention in one of five ways: individually (face-to-face or by telephone) or as part of a group (face-to-face, telephone or online; MacCourt et al. 2017). The intervention led to significant improvements in grief, coping, empowerment and resilience from baseline to completion, and those in the intervention group scored better on all four measures at completion compared with the control group. This study did not report post-bereavement outcomes.

The Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project provided a range of interventions based on the principles of CBT to carers during their active caring phase (Holland...
et al. 2009). A sample of 224 bereaved carers who had been involved with REACH at the time of the patient’s death were followed up to examine post-bereavement outcomes. The intervention was associated with significant improvements in ‘normal’ grief symptoms and a marginal reduction in the risk of complicated grief, with no impacts on depression. The researchers noted differential effects of the REACH strategies, with those addressing cognition and behaviour having the most impact on complicated grief, whereas provision of information and emotional support was most effective for normal grief symptoms (Holland et al. 2009).

Post-bereavement impacts were also observed in a follow-up to the New York University Caregiver Intervention project (Haley et al. 2008). This intervention comprised three components: individual and family counselling sessions; a weekly support group; and ‘ad hoc’ counselling provided face-to-face or by telephone. Researchers followed up 254 carers (including 122 intervention group participants) for up to two years following the patient’s death. Compared with the control group, intervention group participants were more likely to have low levels of depressive symptoms both during active caring and following bereavement (Haley et al. 2008).

All three of the multi-component interventions reviewed above included an element of tailoring to the carers’ assessed needs. Similarly, Ott and colleagues (2010) reported positive impacts from a tailored program with five components based on the Dementia Caregiver Grief Model (Meuser et al. 2004, cited by Ott et al. 2010). In a small-scale, pre- and post-test study, spouse carers of people with dementia experienced significant reductions in grief, depression and anxiety and increases in positive mood states and self-efficacy after receiving the intervention over a five-month period. However, these gains were not sustained at the eight-month follow-up measure if the patient had died or gone into a nursing home (Ott et al. 2010).

Paun and colleagues (2015) used a quasi-experimental, pre- and post-test study design to evaluate chronic grief management for dementia carers. This manualised treatment was delivered in a group setting over a 12-week period, employing guided discussion to deliver information and teach skills in communication, conflict resolution and chronic grief management. The comparison group received two telephone calls. At the end of the intervention, participants reported significant improvements on the ‘heartfelt sadness and longing’ subscale of the chronic, anticipatory grief measure, and at the six-month follow-up they reported less guilt than at baseline. The authors also reported ‘promising’ differences between the intervention and comparison groups at the end of the intervention and at follow-up on measures of chronic, anticipatory grief and guilt (Paun et al. 2015).

4.2 Interventions for carers following bereavement

As for the pre-bereavement interventions, most of the post-bereavement interventions for carers identified by this review were based in palliative care settings. Bereavement care is an integral part of the suite of end-of-life interventions in palliative care. One of the guiding principles of the National Consensus Statement: essential elements for safe and high-quality end-of-life care states that “care for families and carers extends to the period after the patient has died” (ACSQHC 2015 p.5). The Victorian Bereavement Support Standards for Specialist Palliative Care Services (Hall et al. 2012) provide guidance on how this might be achieved in practice.
For example, the Standard relating to screening and assessment sets out a recommended timeframe which includes trauma assessment as soon as practicable after the patient’s death, a phone call at 12 weeks post-bereavement, and the offer of comprehensive bereavement assessment at six months if there are indications of increased risk for prolonged grief (Hall et al. 2012). The Standard relating to bereavement support strategies recommends that specialist services are targeted to those with elevated risk or current psychosocial and/or spiritual distress. Referral may be made for an evidence-informed therapy, bereavement support groups or online services (Hall et al. 2012).

Although palliative care is an important pathway into bereavement support, a recent Australian study identified two other major pathways: primary care and self-referral to bereavement counselling (Thompson et al. 2017a). These are especially important for many people who have not had previous contact with palliative care, or who have lost contact with palliative care services in the months following bereavement.

4.2.1 Reviews

There is a large literature on the efficacy of specialist bereavement interventions in general including several recent literature reviews. For example, a review of the evidence for grief counselling identified 45 intervention studies that met criteria for inclusion (Waller et al. 2016). Wilson and colleagues (2016) identified 38 evaluations of bereavement services, which could be categorised as either crisis intervention (providing immediate help to people in acute grief), services provided later in the grieving process to enhance recovery, or specialist treatments for complicated or prolonged grief. Other recent reviews that focused on clinical management of complicated or prolonged grief (Simon et al. 2013; Wittouck et al. 2011) did not restrict their scope to carers. High-quality evaluations of specialist bereavement treatments continue to emerge in this rapidly developing field (e.g. Bryant et al. 2014; Shear et al. 2016).

In contrast, there is a relative lack of reviews focusing on post-bereavement support pertinent to the carer experience. Because of its focus on carers, the current review necessarily excludes much of the general bereavement literature. Further, because of the risk factors for prolonged grief, evaluations of specialist treatments tend to have a broader focus beyond carers to all bereaved people, including those who have lost someone to an unexpected, perhaps violent or traumatic death, which is out of scope for the current review. The broader literature on bereavement support in general, and on prolonged grief treatments in particular, has been reviewed elsewhere (Thompson et al. 2017a).

One review (Waldrop 2008) included seven studies on bereavement care for older people whose spouses had received end-of-life care. Six of these interventions were group based, and one was delivered to individuals. Most had limited or no treatment effects. The one exception (Caserta et al. 2004, cited in Waldrop 2008) has been included below.

4.2.2 Interventions for former carers

Post-bereavement interventions were included in this review if:

1. participants had been carers of someone with a life-limiting illness (e.g. follow-up care provided by palliative care or cancer services); or
2. the context indicated that a large proportion of those in the sample were probably carers (e.g. interventions targeting bereaved spouses).

We identified 13 interventions for carers in the post-bereavement period, reported in 16 articles. The vast majority were delivered via palliative care or cancer services; one provided support following all deaths in a particular hospital; and in two studies the setting was unclear. Outcomes included psychological distress, spirituality, daily functioning, sleep quality and various measures of grief intensity and grief coping. Seven studies incorporated qualitative techniques either as the main data collection method or to complement the use of surveys and standardised measures. Three interventions were evaluated with a randomised controlled trial.

Family members who see their loved one’s end-of-life care as less than optimal may experience more difficulties in bereavement, and are also more likely to make formal complaints to health services (Ford et al. 2013). To address these issues, and bridge the gap between the brief advice given immediately after the death and referral (or self-referral) to bereavement counselling, some hospitals and health services have trialled follow-up programs for bereaved family members in the days and weeks immediately after the patient’s death. These generally involved contact (e.g. a phone call, letter or condolence card) at specific times following bereavement, with the offer of more support as required. Three quality improvement interventions of this type were identified by the current review.

All relatives of patients who died within one large hospital in the UK were sent a condolence card immediately following the death, followed by a letter approximately a month later offering a meeting with a clinician involved in the patient’s care (Ford et al. 2013). If the carer accepted the offer, their questions were sent to the clinician and a meeting took place, facilitated by the leader of the bereavement follow-up program. Administrative data collected by the program indicated that seven to ten percent of those who received the card indicated that they had questions about the end-of-life care their relative received. Some of these were able to be resolved by a phone call with the bereavement team. Cards were sent to 1,390 people in 2010 and 1,240 in 2011, with 93 and 77 meetings respectively organised by the bereavement follow-up service (Ford et al. 2013). Qualitative feedback indicated that carers felt the program gave them an opportunity to reflect, validate feelings, build a sense of meaning and gather information to ‘lay to rest’ any doubts or concerns.

Another hospital-based follow-up service was provided to bereaved parents of paediatric cancer patients (Berrett-Abebe et al. 2017). This was more elaborate, consisting of multiple phone calls, letters, information sheets, cards and notes from the oncology clinic over a period of two years. The program was coordinated by a social worker and delivered by the clinicians who had provided the patient’s care. A focus group with eight parents who had completed at least 12 months of the intervention found it was positively evaluated. They appreciated the communications and took comfort from the fact that their children had not been forgotten. There was a desire for extended contact with the service as well as peer support gatherings (Berrett-Abebe et al. 2017).

One hundred and forty bereaved family carers (81% spouses) of cancer patients completed a survey four to eight months after the patient’s death to evaluate an institutional bereavement program (Morris and Block 2015). The program had five components: acknowledging the death
(e.g. through letters, cards and memorial events), information and education about grief (e.g. through a booklet, website, and seminars), formal support services (group sessions and individual therapy), staff support and education, and program evaluation and research. Carers valued the letter of condolence and bereavement guide booklet, with 69% and 72% respectively reporting that these interventions had a positive or somewhat positive impact on their grieving (Morris and Block 2015). Contact with the patient’s nurse and oncologist was also seen as helpful in the grieving process by 93% and 90% of respondents respectively.

A further four studies described formal evaluations of brief therapies targeted to individuals who had lost family members to cancer or another life-limiting illness.

Bereavement Life Review was completed by 20 bereaved carers, who completed measures of depression and spirituality before and after the intervention (Ando et al. 2015). The therapy involved two sessions, two weeks apart. During the first session, the therapist interviewed the carer about their memories of the deceased. The narrative was transcribed into a book and then discussed with the carer at the second session. Participants reported significant increases in spirituality and decreased depression after Bereavement Life Review (Ando et al. 2015).

The demands of the caring role can interfere with healthy sleep patterns, leading to longer term problems in bereavement (Carter et al. 2009). Eleven bereaved carers of cancer patients each received two, two-hour sessions of CBT specifically targeting insomnia and sleep-related issues. Participants reported that they were able to change their sleep-wake behaviours as a result of the therapy, often resulting in improved sleep quality (Carter et al. 2009). Depression scores improved consistently from baseline to the follow-up measures at three and five weeks, although no statistical tests were reported, possibly due to the small sample size.

Weekly sessions of soft tissue massage were provided to 18 bereaved family carers of patients who died in palliative care (Cronfalk et al. 2010). The sessions were provided over an eight-week period, mainly in the carers’ own homes, but in some cases carers returned to the hospital for the therapy. The evaluation consisted of interviews with the carers after the intervention concluded, and a follow-up phone call at six to eight months afterwards. Thematic analysis highlighted the benefits of the massage therapy. Participants appreciated the timely help, liked having a regular appointment to look forward to, and found the therapy restful and renewing. They saw it as providing consolation and helping them to restructure daily life. At six months, all but one had ‘moved on’ with their lives, indicated by their return to work, social lives and travel (Cronfalk et al. 2010).

In a small-scale randomised controlled trial, Holtslander and colleagues (2016) evaluated the Finding Balance intervention, a set of guided, self-administered writing exercises for bereaved spouses of cancer patients. The exercises were designed around the Dual-Process Model (DPM) of coping with bereavement (Stroebe and Schut 1999) and outcome measures included an index of restoration-oriented and loss-oriented grief coping. A nurse facilitator delivered the intervention over two sessions in participants’ homes. There was a small, significant increase in restoration-oriented grief coping and small changes in loss-oriented grief coping in the intervention group. The balance between these two types of grief coping suggested that the intervention group was paying greater attention to the grieving process itself. Qualitative data indicated that participants were satisfied with the intervention, felt it validated their emotions
and helped them to move forward, and gave them new ideas for finding balance in the grieving process (Holtslander et al. 2016).

Two studies reported on group interventions for carers who had been bereaved by the death of a family member in a palliative care setting (Näppä et al. 2016; Wittenberg-Lyles et al. 2015). Ten bereavement groups, each with between three and eleven participants, were run over a two-year period by a palliative care nurse, social worker and member of the clergy (Näppä et al. 2016). The groups had weekly, two-hour meetings for five weeks. In a quasi-experimental evaluation design, the 38 participants were compared with 25 carers who were unable to take part and 61 who did not want to take part (i.e. declined the initial invitation). There were no differences in grief between participants and non-participants at five weeks after the intervention. At the one-year follow-up, those who declined the intervention had lower levels of grief than participants and those unable to take part. There were no differences in depression symptoms among the three groups at either time point, and no change in anxiety over time for any of the groups (Näppä et al. 2016).

An online support group was created using Facebook, with group membership restricted to 16 bereaved carers (Wittenberg-Lyles et al. 2015). The group was facilitated by a researcher and participants were given guidelines, information and questions to prompt discussion. These materials were based on the DPM (Stroebe and Schut 1999). Participants completed surveys when they joined the group and when it ended, nine months later, and the content of their posts was analysed qualitatively. Depression scores were mild on average at baseline, decreasing to minimal at the end of the intervention, and there were low levels of self-reported anxiety at both time points. In total, participants made 71 posts and 268 comments, and most talk was restoration-oriented, with carers sharing strategies and giving and seeking advice, or loss-oriented, with carers discussing triggers for grief and coping strategies (Wittenberg-Lyles et al. 2015).

Three group-based interventions for bereaved spouses (and, in one case, their children) were evaluated, one as a demonstration project (Caserta et al. 2004) and the other two with randomised controlled trials (Lund et al. 2010; Ayers et al. 2013).

The Pathfinders demonstration project involved 84 widows and widowers over the age of 50 in an 11-week program to develop self-care skills and facilitate social support and personal growth (Caserta et al. 2004). The approach and content of the weekly, two-hour classes were informed by the DPM and aimed to promote restoration-oriented coping. The following self-care topics were covered: taking charge of one’s health, stress management, managing finances, understanding grief, medication management, exercise and physical activity, accessing community services, healthy nutrition, maintaining a clean and safe home, social functioning and personal growth. On average, participants reported statistically significant improvements over time in each of the self-care areas. Almost all (97%) reported that they had applied at least some of the content from the classes in their daily lives (Caserta et al. 2004).

A series of studies reported on the Living After Loss group intervention (Lund et al. 2010; Utz et al. 2013a, 2013b) which was developed by the same team of researchers, and was also based on the DPM (Stroebe and Schut 1999). The 170 bereaved spouses randomly assigned to the intervention group attended weekly, 90-minute sessions for up to 14 weeks with educational
content focusing on either restoration-oriented or loss-oriented grief coping strategies (in alternate weeks). Sessions run for the control group focused only on loss-oriented strategies.

On average, all participants declined in loss-orientation and increased in restoration-orientation over time, with no differences between the groups on grief coping (Lund et al. 2013). Change in depression, loneliness and personal growth was also similar between the groups (Utz et al. 2013a). Group dynamics – that is, factors such as the extent to which participants helped each other and felt supported – had a greater impact on outcomes over time than group allocation (Utz et al. 2013b). The authors concluded that a group setting may not be suitable for addressing restoration-oriented grief coping strategies as needs differ among individuals (Lund et al. 2010).

In response to this series of findings, the same research team developed a new intervention, Partners in Hospice, aimed at family carers of cancer patients who died in palliative care settings (Caserta et al. 2016). This tailored intervention is delivered individually, following an initial needs assessment, via weekly home visits or phone calls over a 14-week period (plus a ‘booster’ around the anniversary of the patient’s death). Like Living After Loss, this new intervention is based on the DPM and includes components on restoration-oriented grief coping. A randomised controlled trial is under way but no outcomes have been reported yet (Caserta et al. 2016).

Bereaved spouses and their children took part in a Family Bereavement Program which aimed to build positive parenting techniques and address parents’ and children’s grief and demoralisation (Ayers et al. 2013, Sandler et al. 2010). The adult component involved 12, two-hour group sessions plus two individual therapy sessions to tailor the intervention to the family’s needs. The control group received self-help books. Families were followed for up to six years after bereavement. At the six-year follow-up, adults in the intervention group had significantly less psychological distress and depression than those in the control group (Sandler et al. 2010). They were also less likely to be above the threshold for moderate to severe depression.
5 Summary and discussion

This section summarises the findings for each of the three research questions. The first was addressed by the interviews; the second and third by the literature review. It is followed by a discussion of the findings around the issues highlighted in the introduction to this issues paper, namely the needs of carers; risk and protective factors for carers in relation to bereavement; and relevant theoretical models which might guide the development and evaluation of interventions.

5.1 Research question 1

What do peak carer organisations perceive as service gaps and needs in bereavement support for carers and/or former carers?

The caring role can be conceptualised as a journey involving several stages, which may begin abruptly with an injury or sudden-onset illness, or gradually with a slow decline in the function of the person being cared for. Each transition in the caring ‘journey’ may be accompanied by a sense of loss and grief, from the initial diagnosis, through each step change in function or treatment approach, to entry into palliative care or residential aged care. Thus, carers are likely to need bereavement support long before the death of the person being cared for.

For carers, grief after bereavement can be complicated by factors relating to the end-of-life care. Carers may become pre-occupied with questions around the treatment provided, or feel guilty that they did not do more. These issues can also be problematic for other bereaved people who are not primary carers. However, there are some distinctive features of bereaved carers that require particular attention in designing and providing services for this group.

Long-term carers have several sources of vulnerability in grieving that stem from the fact that they have suspended or relinquished other roles in order to spend their time providing care. A bereaved carer is faced not only with the loss of a loved one, but also loss of identity and purpose in life. Several respondents likened this to the impact of losing a job, being ‘made redundant’. Financial considerations may also weigh heavily on full-time carers who face losing government allowances and are then expected to enter the job market soon after the person’s death, possibly with diminished chances of success due to a long absence from employment. The difficulties of bereaved carers are compounded by social isolation, as old friendships and valued social activities have fallen away during the caring journey.

Peak bodies that have regular contact with carers provide a range of support services, including facilitated meetings at which carers can share their thoughts, feelings and experiences with others in a similar situation. There are national telephone advisory lines for various diagnosis groups, and an online portal, the Carer Gateway, that carers can search for information about local services (although not bereavement counselling). There is also a national grief telephone service, Griefline (http://griefline.org.au/), although this does not appear to be widely known and was not mentioned by any of the respondents in this study.

Respondents felt that Advance Care Directives could have a positive, protective impact on carers in the patient’s end-of-life phase and during bereavement. ACP provided a chance to have important conversations about death and dying, the patient’s wishes and the carer’s
needs. Documenting the patient’s wishes may help prevent family conflict and decision-making stress, which could make early bereavement a little easier for the primary carer.

Palliative care may also have a protective effect as long as carers’ needs are considered along with those of the patient. Respondents emphasised the importance of treating carers with respect. This might include excellent communication with the treating team, being honest about the patient’s prognosis, keeping the carer informed, and ensuring the carer is comfortable and confident with any tasks or interventions they need to perform for the patient. Carers who have a positive experience of receiving high-quality, holistic care during this time may be more likely to seek out help later if they experience complex or prolonged grief-related distress.

Primary care practitioners will be the first point of contact for many bereaved carers who find they are experiencing problematic somatic symptoms or psychological distress following the death of the person they cared for. This makes primary care a vital part of the pathway into bereavement support. However, the effectiveness of this pathway will depend on GPs being aware of the possibility that the former carer’s problems are grief-related, and having access to information about the appropriate responses in terms of assessment, psycho-education and referral to specialist interventions if indicated.

The concept of self-referral to bereavement counselling was also supported by respondents, who highlighted the evidence that such counselling is most effective when delivered according to identified need. Service providers – including those outside the health system, such as funeral directors – could play an important role in prompting self-referral by contacting carers at certain milestones following the bereavement, for example, to attend memorial services. These brief contacts were also an opportunity to provide information or reminders about the formal and informal supports available to bereaved carers.

Respondents had mixed views on the potential for residential aged care facilities to serve as another pathway into bereavement support for carers. Although most felt it was an important service that facilities should provide to carers, they expressed doubts about the capacity of the sector to identify and respond to carers’ bereavement needs.

5.2 Research question 2
What does the literature identify as the most effective ways to prepare carers for bereavement?

Pre-bereavement interventions for the patient-carer dyad have been designed to facilitate better end-of-life planning and care and/or to strengthen family relationships. For example, ACP was associated with reduced carer depression in bereavement (Song et al. 2016) possibly because it made end-of-life decision-making easier (Song et al. 2017). The most rigorous of these studies (Masterton et al. 2013; Song et al. 2015, 2016, and 2017) suggest potential benefits of structured assessment processes and tailored support for carers in palliative care settings.

Scheduled weekly phone calls or home visits with carers during their active caring phase do not appear to have longer term impacts in the post-bereavement period (Dionne-Odom et al. 2016; Walsh et al. 2007). However, interventions that provided a comprehensive approach including...
needs assessment, care planning and tailored support have had significant positive impacts on post-bereavement psychological distress (Hudson et al. 2015).

Some innovative methods for supporting carers in the pre-bereavement period were identified, including an internet-based system with a comprehensive set of resources (DuBenske et al. 2014), a DVD produced with extensive input from a committee of carers (Thomas and Moore 2015) and singing groups for cancer patients, family carers and bereaved carers (Fancourt et al. 2016); however, post-bereavement benefits have not yet been convincingly demonstrated.

In dementia care, there is some evidence that multi-component interventions tailored to carers’ needs can improve well-being and grief coping both during active caring and following the patient’s death (Holland et al. 2009; Haley et al. 2008).

5.3 Research question 3

*What does the literature identify as the most effective ways to support carers post bereavement?*

Several articles described programs which extended palliative care services to include more structured bereavement care (Berrett-Abebe et al. 2017; Ford et al. 2013; Morris and Block 2015). However, these efforts were focused on quality improvement rather than research, and the resulting studies do not provide high quality evidence of effectiveness.

There are promising findings from brief, individual post-bereavement interventions targeting particular issues that may affect carers, such as insomnia, loneliness and meaning in life. More rigorous evaluation is required before these interventions can be considered evidence-based. For example, a guided writing exercise appeared to encourage and facilitate oscillation between loss-oriented and restoration-oriented grief coping. Balancing these two types of grief coping is seen as promoting healing (Stroebe and Schut 1999). Although this study used a randomised, controlled design, it had only 19 participants, of whom only nine received the intervention (Holtslander et al. 2016). It remains to be seen whether these positive results from this very recent study can be replicated with a larger sample.

Two studies demonstrated benefits of group-based interventions for carers. One of these was delivered during active caring (Existential Behavioral Therapy; Fegg et al. 2013) and one after the patient’s death (Family Bereavement Program; Sandler et al. 2010). Both interventions had significant, long-term impacts on depression. Compared with those in control groups, carers who completed these interventions also had less negative mood and improved quality of life (Fegg et al. 2013) and reduced psychological distress (Sandler et al. 2010). Qualitative data collected from participants in Existential Behavioral Therapy indicated that carer groups can offer both social support and opportunities to learn and develop self-regulation strategies (Kogler et al. 2013). Several other group support programs were also evaluated but were not found to be effective, or the study designs precluded conclusions about effectiveness.

5.4 Are there unique issues for carers in bereavement?

Representatives of peak organisations interviewed for this project highlighted a range of issues in bereavement that may be specific to carers. Their comments are consistent with findings
from descriptive and qualitative studies of carers and theoretical perspectives on the caring trajectory (Cronin et al. 2015; Larkin 2009; Williams and McCorkle 2011).

The death of the care recipient is one of many losses faced by carers over the course of their ‘caring journey’. This journey may begin abruptly through a diagnosis of advanced cancer or health crisis such as a stroke, with carers completely unprepared for their new role. Alternatively, caring responsibilities may accumulate gradually due to the slow decline of an aging parent or partner with organ failure or dementia. Over time, caring can become all-absorbing, dominating the person’s life to the exclusion of many other pursuits.

The caring journey is accompanied by grieving for multiple losses. These include changed relationships with the care recipient, family and friends, the need for carers often to relinquish social lives, interests and activities (often including employment) to provide time and energy for caring, and the loss of future plans and hopes. Transitions in the journey – such as moving into palliative care or residential aged care – may exacerbate this grief. The finality of death itself can be shocking and overwhelming, even if expected.

After the death, carers must deal with multiple issues in addition to the loss of a loved person. Distressing emotions such as guilt and uncertainty about end-of-life care can complicate grief, as can family conflict over surrogate decision making. Loss of the caring identity and the routines associated with regular medical appointments can leave carers feeling aimless and abandoned. There may be worries about future employment, financial security and accommodation. Overall, these cumulative losses make carers vulnerable to poor outcomes in bereavement.

Research into the post-caring experience confirms respondents’ views of caring as a continuum of losses which creates unique issues for bereaved carers (Cronin et al. 2015). Immediately after the death of the care recipient, carers tend to report a feeling of emptiness or ‘post-caring void’, which gives way to concerns about dealing with the practical and legal tasks as well as the powerful emotions that arise. Ultimately, most carers are able to re-establish a life beyond caring, although many return to caring roles through volunteering because of the skills they have developed and the meaning this role provides (Larkin 2009). The identification of distinct phases of caring may assist in targeting and designing post-bereavement interventions. There are some interesting parallels between Larkin’s (2009) description of the post-caring experience and the DPM (Stroebe and Schut 1999, 2010), indicating that former carers are engaged in both loss-oriented and restoration-oriented coping.

Carers’ responses to bereavement will depend, in part, on their pre-bereavement resources such as mental health, self-efficacy, social support, education levels and income (Cronin et al. 2015). However, pre-bereavement stressors can also play a role, particularly pre-existing psychological distress and role overload. Profound feelings of loss may persist for several years after the care recipient’s death (Cronin et al. 2015).

Research into risk and protective factors for bereavement outcomes has identified several potential targets for intervention. Recent studies suggest that carers may benefit from greater efforts to prepare them for the death of the care recipient, and from high-quality end-of-life care that addresses carers’ psychosocial needs (Grande et al. 2009a; Schulz et al. 2015).
However, identifying carers who are most at risk of poor bereavement outcomes remains a challenge due to a lack of valid and reliable screening tools (Breen et al. 2014). Relationships between demographic variables and risk of complex or prolonged grief are complex. There is a need for further investigation of the ways in which intrapersonal and interpersonal factors interact to increase risk or to protect carers in relation to bereavement outcomes (Schut and Stroebe 2010).

A major complicating factor in designing interventions for bereaved carers is that not all of them identify as carers, and they may not want or need help. Simply offering a service to the next-of-kin may not be sufficient (Ussher et al. 2009). Specific issues for certain groups of carers were highlighted by respondents and are mentioned in some studies. Such groups include people living in rural and remote areas, members of the LGBTI community, and cultural groups including Aboriginal and Torres Strait Islander people. There appears to be a lack of evidence on how to engage these groups in palliative care and/or bereavement care and how to address their particular needs through targeted interventions.

Australian researchers have advocated a public health model of bereavement support based on need (Aoun et al. 2012) which has some empirical support (e.g. Aoun et al. 2015). The importance of targeting interventions to those who need them the most has been highlighted by previous reviewers (Schut and Stroebe 2010). This recommendation is supported by two studies which followed up carers who declined to take part in support groups (Näppä et al. 2016, Thurn et al. 2015). People who refused the offer of Existential Behavioral Therapy were less distressed at baseline than participants and reported larger decreases in anxiety over time than participants or controls (Thurn et al. 2015). Similarly, those who declined a post-bereavement support group had lower anxiety at baseline and less grief one year later than either the intervention or comparison group participants (Näppä et al. 2016). An earlier study found significant reductions in distress following a pre-bereavement intervention for ‘at risk’ families, but only for those carers who were most distressed at baseline (Kissane et al. 2006).

These findings clearly indicate that not everyone has the potential to benefit from bereavement interventions, probably because they have low levels of pre-existing distress and more personal resources to deal with their grief. Not only is there a risk of harm from inappropriate interventions, universal inclusion of bereaved individuals in evaluation studies is likely to diminish the power to detect an intervention effect.

5.5 Support for theoretical models of caring and bereavement

The DPM (Stroebe and Schut 1999) is an important theory which has guided the development of several post-bereavement interventions reviewed above, including materials for an online support group (Wittenberg-Lyles et al. 2015) and guided writing exercises (Holtslander et al. 2016), the group-based Living After Loss program (Lund et al. 2010) and the subsequent, individually focused Partners in Hospice Care (Caserta et al. 2016). Researchers have concluded that the group setting may not be suitable for restoration-oriented tasks (Lund et al. 2010) and results are not yet available for an individual therapy designed to encourage a balance between restoration-oriented and loss-oriented coping (Caserta et al. 2016). To date, although this is a dominant theory in the field of bereavement, there is relatively little evidence that it provides a basis for efficacious treatments for carers. Other reviewers have suggested that the DPM could
be refined and made more relevant to carers by incorporating pre-bereavement factors relating to providing care for a person with a life-limiting illness (Gauthier and Gagliese 2012).

The concept of carer preparedness for the patient’s death includes, but is not limited to, ACP (Hebert et al. 2006). Some support for preparedness as a protective factor for carers was provided by three studies of the SPIRIT ACP intervention for renal dialysis patients and their carers (Song et al. 2015, 2016, 2017). A randomised controlled trial demonstrated that the intervention reduced carers’ distress during end-of-life care (Song et al. 2015) and improved their confidence in making important decisions on the patient’s behalf (Song et al. 2016) although it is unclear why significant findings were limited to African American participants. A qualitative study which followed up with bereaved carers found that discussion around ACP had helped them in various ways, including making end-of-life decision making easier. As a result, former carers reported feeling less distressed in bereavement (Song et al. 2017). These studies measured just one aspect of preparedness.

Further support for this concept comes from a randomised trial of a specialised oncology nursing intervention (McCorkle et al. 1998). One aspect of the intervention involved facilitating communication about the dying process. Intervention participants reported less psychological distress during end-of-life care and up to 13 months after the care recipient’s death. This finding suggests that improved communication may have a protective effect, but requires replication. Although promising, the concept of carer preparedness requires further research, with clearer operational definition and measurement. The model proposed by Hebert and colleagues (2006) implies that interventions to educate clinicians how to have better conversations around death and dying may be beneficial for patients and their carers.

Several interventions were designed to enhance continuity of care from the end-of-life phase to bereavement, but the research designs preclude any conclusions about impacts. For example, extending a palliative care service to include several follow-up visits to former carers was viewed positively by the nurses who delivered the service (Redshaw et al. 2013). Masterton and colleagues (2015) have proposed a structured framework around continuity of care for bereaved carers, with suggested therapeutic targets and intervention goals at each of four illness phases. However, it appears this model is yet to be systematically tested through the design and evaluation of interventions.

The principles of CBT were incorporated into the REACH program for dementia carers (Holland et al. 2009). Interestingly, the cognitive and behavioural aspects appeared to protect against prolonged grief, whereas information and emotional support helped with ‘normal’ grief symptoms. Elements of CBT were also included in a phone support program (Kilbourn et al. 2011) and a treatment for sleep problems (Carter et al. 2009). Mindfulness, which is a recent ‘third-wave’ addition to CBT, was a key active ingredient in Existential Behavioral Therapy (Kögler et al. 2015).

A variety of other theoretical models have inspired both pre- and post-bereavement interventions for carers. These include the transactional model of stress and coping, which was the basis for a comprehensive psycho-educational program (Hudson et al. 2013, 2015); the Model for a Peaceful Death (Emanuel & Emanuel 1998, cited in McMillan et al. 2011) which provided a protocol for standardised assessment and reporting of carers’ needs in palliative
care; and the Dementia Caregiver Grief Model (Meuser et al. 2004, cited in Ott et al. 2010) which describes factors associated with anticipatory and disenfranchised grief. A multi-component program based on this model had positive impacts on dementia carers’ well-being and lessened their pre-death grief (Ott et al. 2010).

One recently published study (Toft Thomsen et al. 2017) described a pre-bereavement intervention explicitly designed to meet the Victorian *Bereavement Support Standards for Specialist Palliative Care Services* (Hall et al. 2012). The intervention incorporated elements of the Standards such as systematic assessment of carer needs, care planning and tailored support. Administrative and qualitative data were used to demonstrate its feasibility and acceptability to palliative care staff, but impacts on post-bereavement outcomes for carers have yet to be demonstrated.
6 Conclusions and recommendations

No one, standard pathway into support services could be identified for bereaved carers. Interviewees described the service system as fragmented, with a need for greater coordination at state and national levels. Certain populations of carers were particularly under-served: those in rural and remote areas, those from culturally and linguistically diverse groups, and those identifying as part of the LGBTI community. Suggestions for improvements included establishing a national telephone bereavement counselling service, with links to or information about local service providers. A bereavement-specific website may also be useful; however the current generic online portal for carers was not seen as providing sufficient specific information to be of much use to bereaved carers.

Although bereavement support was considered an essential element of palliative care, other pathways into support are also required. Not all carers are in contact with palliative care, and some who are may not want to return to those services for bereavement support. Carers may self-refer into bereavement support or they may receive a referral via primary care. Respondents made a strong case for the need to strengthen these alternative pathways. This would require additional education, training and support for primary care practitioners and for employees at all levels in residential aged care facilities.

The public health approach to bereavement support was regarded as a promising model for service design, as it promoted the concept of service provision based on identified need. For those on the lowest tier of the three-tier model, with the lowest level of need, service improvement efforts might focus on building community capacity in recognising and responding to grief-related distress. For those on the second tier, with some indicated need, the use of validated screening tools and non-specialist interventions may help prevent escalation of problems. Finally, those with symptoms of complex or prolonged grief would require help and encouragement to seek specialist treatments.

Currently, the strongest evidence of benefits for bereaved carers comes from evaluations of programs to improve assessment of, and response to, carer needs in palliative care; multi-component interventions for dementia carers; and group-based post-bereavement programs. Findings from the interviews and the literature review suggest that bereaved carers may benefit from programs to address ‘restoration-oriented’ coping, such as access to training, further education and employment services and financial counselling. Although there are some high-quality studies that show positive impacts on relevant outcomes, there is a need for further research to establish the most effective ways to prepare and support carers, both during active caring and after bereavement.

6.1 Recommendations

It is recommended that the Department of Health:

1. Consider adopting a public health approach to bereavement support, both for carers and for the wider community.

2. Promote improved access to standardised assessment and referral (including self-referral) to specialised bereavement interventions based on need.
3. Facilitate better education of palliative care professionals to enable improved communication with patients and carers around end-of-life issues, including discussing prognosis, addressing spiritual concerns, explaining interventions and processes, and providing psychoeducation around grief and loss.

4. Continue to promote comprehensive approaches to carer support in palliative care including standardised, systematic assessment of, and response to, carers’ psychosocial and spiritual needs.

5. Continue to promote the use of Advance Care Planning where appropriate as an important way of improving preparedness among terminally ill people and their carers.

6. Review current funding models for palliative care services to identify options to extend funded service delivery to bereaved persons of both palliative and non-palliative patients.

7. Promote continuity of palliative care beyond bereavement, including opportunities for carers to reconnect with services to the extent that they wish to do so (e.g. for memorial services, to bring relationships with staff members to a satisfying conclusion, or to seek answers to questions about end-of-life care issues that may be concerning them).

8. Support appropriate training about the needs of carers in relation to grief and bereavement for primary care practitioners and staff at all levels in residential aged care facilities, so they are better able to recognise and respond to those needs.

9. Promote improved links between residential aged care facilities and palliative care services so that residents, carers and staff may be better supported during end-of-life care.

10. Assess the need for a central, national portal – telephone, online or both – for the provision of bereavement counselling and/or referral to local services, as a first port of call for bereaved carers and others in the community.

11. Promote community capacity building around discussing, recognising and responding to loss, grief and bereavement through Primary Health Networks, community health services and other appropriate means.

12. Support research to develop and evaluate promising interventions to support carers before and after bereavement, particularly those based on a sound theoretical framework.

13. Encourage the development of innovative, evidence-based approaches to addressing the needs of under-served groups of carers including Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse groups, members of the LGBTI community, and people living in rural and remote parts of Australia.
References


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Appendix 1 Interview schedule for carer peak organisations

1. What is your role at your organisation?

2. Please provide a brief description of your organisation and its focus.

3. What are your general observations about the needs of bereaved carers?

4. In your experience, how do carers commonly access bereavement support?

5. In your experience, do carers have specific bereavement support needs during engagement with palliative care services?

6. What do you think are the most effective ways to prepare carers for bereavement?

7. What do you think are the most effective ways to support carers post bereavement?

8. What service gaps and/or unmet needs (if any) are there for carers and former carers in terms of bereavement / prolonged grief support?

9. What role is there for primary care in providing bereavement support to carers?

10. What role is there for residential aged care services in providing bereavement support for family members/carers?

11. Please discuss any other issues pertinent to carers accessing bereavement support through primary care and palliative care.

12. If a briefing paper is produced on issues for carers relating to bereavement support and prolonged grief, is there specific information you would like to see included, and are there specific ways you would like it disseminated?