



Care after Caring

Support for family carers facing and following bereavement

Summary report for carers' organisations

Each year in England, over 500,000 carers face the death of the person they were caring for. Preparing for the death of someone close and dealing with its aftermath is one of the most challenging experiences of life, but as with many challenges, it has the capacity to be profound, fulfilling and enriching. For those who were caring for the person, the 'legacies of caring' (Larkin and Milne 2017) bring extra dimensions to bereavement. Whether the carer felt prepared for the death or not, the physical, mental, financial and social strain of caring can have lasting impacts well beyond the death.

NHS England commissioned a project to scope models of bereavement support for former carers, as part of its Commitment to Carers programme. The report sets out what we know about carers facing and managing bereavement, and some of the recommendations that have been made to improve support. It summarises the policy context for supporting former carers as a framework. It draws on findings from consultations with former carers and those supporting them to lay out a series of aspirations for local areas and services. If these were in place, we would all be able to say '**we get the right support at the right time, before and after the person we are caring for dies**'. The report ends with 12 examples of local good practice in supporting carers facing and following bereavement.

What we know about carers and bereavement

Around 6.8 million people in the UK are carers, and this number is increasing (Buckner and Yeandle 2015). Many people who are caring do not recognise themselves as a carer: they are simply doing what they believe a husband, partner, daughter, father or neighbour should do, living out feelings of love, duty or reciprocity, or responding to what needs doing. Each year, around 2.1 million people's caring role comes to an end (Carers UK 2014, Hirst 2014). Around half a million carers will be involved in some type of end of life care provision each year (NCPC 2012, Payne and Morbey 2013) and this is likely to increase.

The majority of bereaved former carers will have been caring for someone known to be approaching the end of their life, because of a specific life-limiting illness or because of the complexities and frailties of old age. Other carers are bereaved through the death of a child: around 2,500 children and young people die each year in England and Wales as a result of a life-limiting condition (Sidebotham et al 2014).

Some carers have been caring for someone with a condition or in circumstances that increase their likelihood of a sudden death, such as mental illness or drug use. Around 6,000 people die by suicide each year and around one in 50 deaths are drug or alcohol related (Turnbull and Standing 2016), including both sudden deaths and those arising from long-term complications.

From caring into bereavement

Until recently, caring and bereavement received attention as discrete and independent stages of life, rather than as 'reciprocal experiences in which anticipation of loss hangs over caregiving activities, and the time spent providing care gives shape to mourning' (Masterson et al 2015, Li

2005). More and more people are likely to experience a caring/post-caring/caring cycle or simultaneous caring and post-caring as the need for informal care grows.

For most carers, the intense caring happens within a wider set of relationships and networks. While many carers of people at the end of life become very isolated, others experience a growth or strengthening of their networks and connections (Leonard et al 2015). The changes brought about by illness, caring and bereavement in one part of the family system or social network will have an impact on other parts of the system (Monroe and Oliviere 2009).

The legacies of caring

The 'legacies of caring' (Larkin and Milne 2017) is a helpful way of understanding the bereavement experiences that are particular to former carers and which are likely to impact on their bereavement (Holtlander et al 2017). Larkin and Milne (2017) identify some negative legacies on finances, social networks, physical health challenges and psychological health.

Most of the research about how carers experience bereavement has been carried out with those bereaved following terminal illness, particularly cancer and dementia, with much more attention paid to the experiences of those caring for adults than the lives of parent carers. Bereavement following a time of caring for someone with mental health problems or drug or alcohol misuse remains under-researched. The impact on individuals has been much more widely studied than the impact on families and social networks.

Different carers show different patterns in their bereavement (Aneshensel et al 2004) and the main theories have been described as (Schulz et al 2008; Boerner and Schulz 2009):

- **wear and tear**
- **stress reduction**
- **anticipatory grief**

One carer's bereavement might show elements of all three effects. For example, they might have worried about how they would cope following the death, and started to make plans (anticipatory grief). Following the death they might feel exhausted and isolated (wear and tear) but at the same time relieved that the strain and suffering is over (stress reduction). Yet as Skaff et al (1996) say, 'relief should not be confused with freedom from grief'.

A significant aspect of bereavement, unique to that which follows a period of caring, is the withdrawal of professional support from health and social care services which had become an important part of the carer's social network (Holdsworth 2015, Harrop et al 2016). This secondary loss can leave carers feeling abandoned and invisible (Holtlander et al 2017, Watts and Cavaye 2018).

The bulk of research shows that while grief will often involve difficult adjustments and painful times, on the whole carers as a group do not show higher levels of distress after the death than before it, and many experience an improvement over time (Schulz et al 2008), unlike the increase in symptoms commonly associated with sudden bereavement (Schulz et al 2001).

However, carers' levels of distress are often already high before the person they care for dies, as a result of the strain of caring at the end of life; typically these levels are higher than among non-carers (Schulz et al 2008, Chentsova-Dutton et al 2002). So even if their distress reduces over time after the death, this does not necessarily mean a return to 'normal' (Breen 2012).

Also, despite the stability or improvement among the majority of carers, a minority of between 6-15% do continue to experience high levels of grief or symptoms of depression (Aneshensel et al 2004, Aoun et al 2015, Nielsen et al 2017). It is important to identify which carers might be at risk.

Risk and resilience

There are many interrelated risk and resilience factors that are associated with or affect people's outcomes in bereavement following caring, including their physical and psychological health and

their relationships (Stroebe et al 2006). The factors of most relevance to this report are those that are modifiable and can be influenced through support networks and organised services.

- **Care and support of the person who is dying.** There is growing evidence that, where possible, bringing about a 'good death' for the person who is dying also brings benefits for their carers.
- **Distress while caring.** Carers who show higher levels of depression, anxiety and pre-loss grief before the death are more likely to have difficulty adjusting to the death, and their symptoms may get worse after the death. These findings challenge the concept of 'anticipatory grief' as a protective factor.
- **Strain and exhaustion.** Some carers with a heavier burden do experience relief after the death, but other studies have found that those who are more overloaded and unsupported are more likely to experience difficulties in bereavement.
- **Family dynamics.** Supportiveness, conflict resolution, communication and congruent grieving patterns in the family seem to be protective factors for bereaved carers.
- **Social support.** Carers who have good social support while they are caring are more likely to do better when they are bereaved.
- **Benefit from caregiving.** Those reporting more benefits from caring for adults seem to be at greater risk of poor outcomes after the death, possibly because it deprives them of an important part of their identity.
- **Preparedness.** A sizeable minority of carers report they were unprepared for the death, and this is associated with more difficulties in bereavement including lasting feelings of grief and regret.
- **Household finances and work.** Lower income, economic hardship and stopping work before or after bereavement is associated with worse bereavement outcomes.

What does this mean for how support should be provided?

There is a lack of evidence for preventative interventions in supporting carers facing bereavement, especially in the real world and beyond specialist palliative care settings. Despite these challenges, some clear principles emerge from the literature to guide support for carers that will improve their experiences of bereavement. Whether provided by family, friends, employers, community groups or formal organised services, support should aim to

- ensure that the death is **as a good as possible**, which will also benefit the carers
- **reduce the burden of care**
- support carers to maintain a **life outside caring** and to think ahead to a **life after caring**
- support carers to **prepare for the death and for their own life afterwards** emotionally as well as cognitively and practically
- **provide welfare advice and financial assistance**

Formal organised carers' support services, end of life care and other health and social care organisations should also develop pathways of support that aim to

- **identify carers facing bereavement as early as possible**
- **look beyond 'next of kin'** to consider the assets and needs of wider friends and family and the social network supporting the primary carers, and how these can be enhanced
- support **communication** within the family and social network and with the healthcare team
- **explore carers' individual and family needs for practical and emotional support** before and after the death and **identify how these might best be met**

- **collaborate with other community and professional organisations** to improve signposting, share skills and knowledge
- provide **emotional support at appropriate levels** to help carers develop coping strategies to deal with their pre-loss grief and mental health difficulties
- promote **continuity of care** where possible before and after the death so that carers do not feel abandoned
- **build on the experiences of bereaved carers** in developing resources
- be **accessible** and **respectful** to carers with varying levels of (health) literacy, facing different levels of stigma and constrained from accessing support in different ways by their caring role.

Our aspirations

Our report sets out a series of aspirations as a series of 'we' statements (see figure 1) which would ensure that all carers get the support they need before and after the death.

There is a significant gap for many carers between these aspirations and the reality of the support they get, despite a wide-ranging policy context including overarching strategies, policies supporting carers, policies around end of life and bereavement care.

We get the right support at the right time, before and after the person we are caring for dies

Responsibility for supporting carers before and after a death is shared between families, friends, communities and services (National Palliative and End of Life Care Partnership, 2015). Much of the research, literature and thinking about how best to support bereaved carers has emerged from studies of those who have accessed specialist services. Less is known about the everyday experiences of the majority of bereaved people (Rumbold and Aoun 2014). Yet not everyone needs this level of support, and it is generally accepted that people do not need routine referral for bereavement counselling simply because they have been bereaved (Stroebe et al, 2017). The role of informal networks and communities in supporting dying people and those caring for them - and ways these can be enhanced - has been set out helpfully in public health approaches to palliative care but generally these approaches are much less developed in relation to supporting bereaved people. An assets-based approach to bereavement support prioritises building community capacity 'before (or at least alongside) mobilizing a professional response' (Rumbold and Aoun 2015).

This approach looks first to carers' own resources and networks to meet the challenges of caring and bereavement. These can be supplemented by community supports and professional help if the social networks are not supportive or if the carer does not want to place additional burden on them (Rumbold and Aoun 2015) or if the carer is experiencing an otherwise complex response to bereavement.

A model of support

A three-component model of bereavement support was first set out in the NICE guidance on Supportive and Palliative Care for Adults with Cancer (2004) and has subsequently been informed by the public health model of bereavement (Aoun et al 2014) and expanded by the National

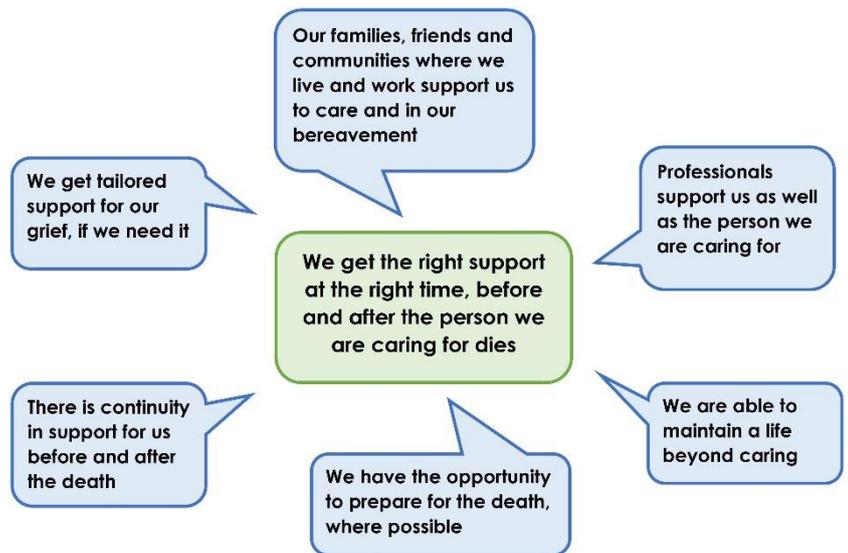


Figure 1: What needs to be in place for carers to get the right support before and after the person they are caring for dies

Bereavement Alliance (2016). This provides a framework for supporting carers facing and following a death. The components are

- Universal: for all bereaved people. Community capacity building, provision of information about bereavement and sources of support
- Selective or targeted for bereaved people seeking support or those at risk of developing complex needs. Non-specialist support including social support/self-help groups; trained bereavement support workers
- Indicated for a minority of bereaved people with complex needs and/or prolonged/complicated grief. Specialist interventions provided by specialist bereavement counsellors/practitioners or specialist mental health/psychological support for those with mental health problems that pre-date or are triggered by their bereavement.

Case study: Carers Leeds

Carers Leeds has always had a vision for supporting bereaved carers. Support for carers at this point began with an informal 'moving on group' run by carers support workers, which introduced bereaved carers to one another, and provided some emotional support. The focus was very much on re-introducing carers into society, so the activities involved group trips and outings.

People were initially invited to join the group for one year, but group facilitators realised that many people needed longer, and some needed more intense support. The organisation decided it needed to extend its offer to bereaved carers, and a proposal was made to the CCG in 2014 for a two-year pilot to provide specific bereavement support. The CCG funded the pilot and extended funding for a further year. The service is now supported through core funding for Carers Leeds from Leeds City Council: staff have counselling skills to provide tailored 1:1 support to bereaved carers.

Getting support – referral in to the service

Most carers using the service have had some knowledge of Carers Leeds before the death, and may have had a Carers Support Worker for a time. This might have been long term support, for example for those caring for someone with dementia, or it may have been through a short but intense period when the person in hospital. Sue's introduction to carers is much easier because people generally have good experiences of support from their Carers Support Worker. Carers Leeds is trusted, and by extension so is she.

Reception and phone staff at Carers Leeds are primed so that when someone rings up to cancel their membership or newsletter, they are given the offer of bereavement support.

Some referrals do come from outside the organisation, from GPs, Community Matrons, Connect4Health, and social workers. As long as they had a caring role before the death, they can benefit from the project. Sometimes, former carers who didn't know about Carers Leeds before the death have some regrets when they find out about the support they could have accessed.

In the early days, Sue worked with some carers before the death on specific pre-bereavement or end of life issues, for example helping a wife talk through the practicalities of the paperwork and preparation that would be good to put in place, and talking about anticipatory grief. Now, she tends to give information and advice to the Carers Support Worker already working with the carer, rather than them having to get used to someone else.

The support offer is of up to **6 weekly or fortnightly sessions** which can be extended to 12 and can continue in exceptional circumstances (eg if the bereaved carer also has other continuing caring responsibilities). This tailored support includes support with the emotional aspects of loss, including feelings that are confusing, painful or less possible to share. It also includes practical and social support such as helping people find groups to join and accompanying them for the first couple of times.

The **monthly support group** has continued, but is now more flexible and people can continue coming for as long as they want.

The work is evaluated using Core-10 in the first sessions and then again at the end of a piece of work, as well as through gathering feedback. :

Talking. Off-loading problems. Important to have the right person to talk to.

Being able to talk about the circumstances of XXX's death and to weep about it.

Also helps me to be able to start and to carve a life for me after XXX's death without the feeling of guilt.

Case study: St Nicholas Hospice

St Nicholas Hospice is seeking to build a compassionate community to help everyone manage loss, change, death and bereavement. This public health approach has led to changes in the way the hospice offers support for patients and their families and carers, which continues into bereavement. Through this approach, the hospice hopes to raise awareness and information as well as mutual support.

A service that epitomises St Nicholas' ethos of humanity, compassion and community empowerment is its flagship volunteering scheme: Hospice Neighbours. Local volunteers are trained and supported to help patients, families and carers in their own homes by taking away life's unnecessary stresses. This might include tasks such as collecting a prescription, going to the post office, or sitting and having a chat over a cup of tea.

Carers are welcome to attend a range of group support, often alongside patients. Open groups include Breathing Space, a monthly group for those living with breathlessness, a weekly Creative Writing group, weekly Mindful Movement group and fortnightly Women's group. Carers are also welcome at Positive Living Groups which run over four weeks, and include specific group for those living with dementia.

The bereavement service also contributes to the development of compassionate communities. The service routinely evaluates and consults with its Service User advisory group, and looks to recent research and thinking on public health models of bereavement.

Over the years, this has resulted in significant changes to the way the service is structured. For example, the group identified a need for greater diversity in methods, and so the 'traditional' bereavement groups have been supplemented by cookery, home maintenance classes, walking and creative activity, as well as with drop-in facilities.

The service also recognises that most bereaved people will cope with their own resources and opportunities to meet others, while 10-20% will need therapeutic support, and are probably less likely to experience change via peer support in the first instance. For this reason, the hospice offers bereavement support across the three components outlined in the NICE guidance and in the public health model.

The offer includes the structured, closed Bereavement Support Group which meets twice a year for six weeks. Nicky's Way is a six week programme for bereaved children and young people. Open groups include a walking group, activity groups and café-style groups run by trained volunteers with professional staff on hand to help maintain the safe space. 1:1 support is also available to any bereaved adult or child in the area, not just focussed exclusively on the hospice population. Support is based on need, and may vary from a telephone call or a chat over a cup of tea to ongoing bereavement counselling where issues can be worked at in depth.

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