Care after Caring

Support for family carers facing and following bereavement

Summary report for GP practices and social prescribers

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 2.1million 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 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 (Holtslander 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 (Holtslander 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.

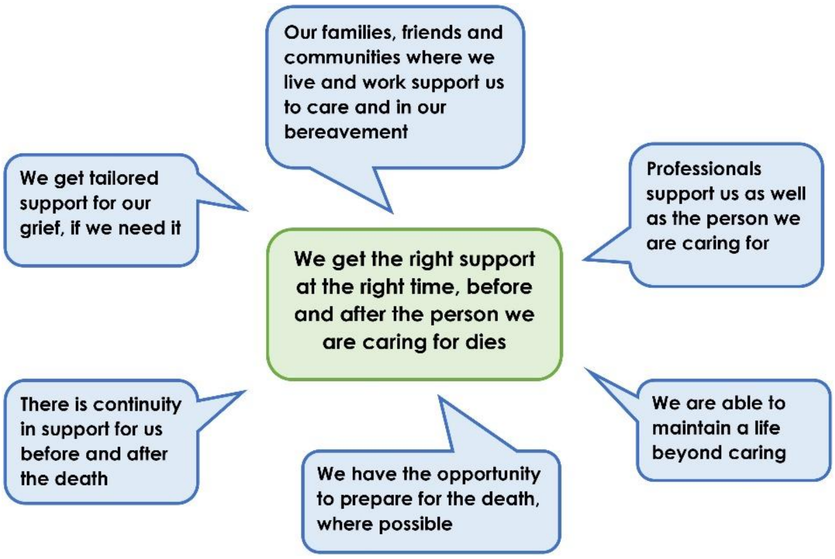

Figure 1: What needs to be in place for carers to get the right support before and after the person they are caring for dies

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

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: Giffard Drive Surgery, Hampshire

Giffard Drive Surgery calls itself ‘the caring practice’, and its support for carers is a key part of this approach. While the practice has a Carers’ Champion, responsibility for identifying and supporting carers is seen as everybody’s business. Appropriate, pragmatic sharing of information within the practice helps to identify carers’ needs and put support in place. A small practice list (9,100 patients) and low staff turnover make it easier for staff to be attuned to patients’ and carers’ social circumstances, but they have also been proactive in setting up systems which support holistic care.

The practice can support carers when either they or the person they care for is registered with them. The practice makes great efforts to identify as many carers as possible, through multiple routes such as at registration, through the local Patients’ Group, via a noticeboard in the practice, activities during Carers Week and through a monthly clinic with the Carers Coordinator. The practice also makes a habit of recording next of kin where possible, as well as informal carers such as neighbours and friends, where this permission has been given.

Once a carer has been identified, the Carers Champion who is a member of the reception team, contacts them. She sends them a Carer’s Pack which includes relevant phone numbers, details of how the surgery can support carers including her contact details and working hours, signposting to other useful organisations, and a leaflet on emergency planning. Carers are invited to register formally for the local carers’ organisation to be eligible for a Carers Assessment, and to register as a carer with the practice.

Support includes the monthly Carers Clinic, proactive contact with carers when someone is seriously ill or the carer thought to be in need of particular help, support from paramedics and the wider community health team, plus a locality-based Integrated Care Team, links with young carers’ groups and the local hospice, and a volunteer driver scheme.

When a carer is bereaved

The practice is usually informed about a patient’s death either by the family or by a fax from the hospice or hospital. Sometimes the information comes from the coroner. An alert is put on the patient’s record straight away and a message is sent around the practice with the name and date of birth of the patient who has died. Staff then look up the patient’s record and see who is in the household, if necessary, so that they are aware of the recent bereavement if a member of the family comes into the surgery. A condolence card is sent to the next of kin and/or registered carer, using the patient’s preferred name. If appropriate, a member of the practice staff attends the funeral, which is often welcomed by families as a recognition of the value of the patient’s life. Carers are also sent a bereavement pack (which is also available on the practice’s website) with information about what to do after a death, and links to useful organisations including the local Tell us Once service. It encourages them to make an appointment with one of the doctors if they would find this helpful. Several of the GPs have training in bereavement support. One is represented on the local End of Life Care committee, and takes a particular responsibility for supporting bereaved carers. Carers can also be referred on to other local services for further bereavement support.

Case Study: Rotherham Social Prescribing Service

The service was initiated by Rotherham CCG (previously Rotherham PCT) in 2011, when it invited Voluntary Action Rotherham and the wider voluntary and community sector to propose a service that could help reduce pressures on health services from patients with long term conditions. Social prescribing emerged as the favoured approach, working within a targeted case management scheme in primary care. The service offers GPs a worker to link patients with practical, social and therapeutic needs to support from local voluntary and community organisations.

GPs are funded to take time out of surgery sessions once a month to consider the needs of patients with long term conditions at integrated case management meetings. These involve health, social care and VCS practitioners. If it is felt that a patient or their carer could benefit from support from outside the health service, a referral is made (if they consent) to VAR's team of social prescribing advisors. An advisor then makes a home visit to assess the patient and carer's wider social needs. At this assessment, the adviser often becomes aware of difficulties such as bereavement, which might not be the reason for referral but are nonetheless a significant part of the challenges that the client is facing. The advisor and patient or carer develop an action plan together, and the advisor prescribes or refers on to suitable activities and services from the local voluntary sector. This includes arts and crafts groups, exercise classes, complementary therapy and counselling. Some clients only need information about VCS support, while others need enablers or befriending support to help build their confidence before accessing more specialist support and getting out and about. 4 to 6 months later, the advisor telephones to follow up with the client, and find out how they have been getting on with their prescribed activities.

The social prescribing service can only be a success if the activities and services that clients need are in place. This depends on a secure and vibrant voluntary and community sector. Right from the start of the project, the sector was supported through a grants funding programme managed and administered by Voluntary Action Rotherham.

Bereavement support

Although clients tend not to be referred for a social prescription due to bereavement, this often emerges as a challenge in their lives when they talk to advisers. To meet the needs of clients adjusting to life after bereavement, VAR referred a number of clients to Rotherham and Barnsley Mind for 1:1 counselling. Colleagues at Mind realised that a supportive group with other bereaved people might be more appropriate than individual counselling for some.

Mind was commissioned to run three eight-week bereavement workshops: structured, closed groups with around eight participants with a range of different types of bereavement. The emphasis is on normalising grief, understanding bereavement, and beginning to think about the future. Mind have noticed the particular challenges for former carers, whose loss of role is huge, and who are often facing significant changes to their life and finances as well as the emotional pain of the death. Many are still carers for another member of the family such as an elderly parent or a sibling with learning difficulties, and are having to manage their grief alongside their ongoing caring responsibilities.

Participants from the first workshop expressed a wish to continue meeting, and the possibility of a self-sustaining peer-led follow on group had always been part of Mind's vision for the service. A participant from the first workshop has begun volunteering and takes responsibility for organising the peer-led group, which continues to meet weekly for 1 ½ hours. There is no pressure to attend each week, and attendance is fluid. The peer-led group also now accepts referrals from IAPT and the Barnsley Bereavement Support Service. This includes those who are waiting for 1:1 support, those who have had 1:1 support and now want the experience of sharing in a group, and those whose preference is for peer support.

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