Care after caring

Supporting family carers facing and following bereavement

Alison Penny **June 2019**

hospice UK

National Bereavement Alliance

The National Bereavement Alliance

The National Bereavement Alliance is a group of more than 50 national, regional and local organisations that support bereaved people and those caring for them.

We share a vision that all people should have awareness of, and access to, support and services throughout their bereavement experience. All members of the Alliance contribute to this vision through their own aims and objectives, in various ways and at various times.

While we are highly diverse in the primary focus of our work, we share a common interest in support for bereaved people. We collaborate strategically to provide a collective voice representing the needs of bereaved people and those supporting them.

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Hospice UK

Hospice UK is the national charity for hospice and palliative care. We work to ensure all adults and children living with a terminal or life-shortening illness receive the care and support they need, when they need it.

We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life. No one should die in avoidable pain or suffering.

Our mission is to transform the way society cares for the dying and those around them. To empower individuals, communities and populations to embrace the ethos of hospice care and extend its breadth and reach to improve everyone's experience of death, dying and bereavement.

In our five year strategy (2017-2022), we have committed to working with communities to build capacity and resilience to care for those at the end of life.

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About this report

This is the report of a project to scope models of bereavement support for former carers, commissioned by NHS England in support of its Commitment to Carers programme.

Acknowledgements

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Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide.

Ambitions for Palliative & End of Life Care (2015)

The caring role is such a big part of the bereavement…the before is as much part of the bereavement as the actual death itself.

Bereavement support worker

I didn't know what to expect. I thought 'I've been a sportsman all my life, I'm tough, I'm going to be alright'.

Bereaved former carer

Introduction

Carers are people who provide unpaid care to an ill, disabled or older family member or friend. Looking after someone close is part of what it means to live in relationship with others. Caring can bring a sense of fulfilment, growth, meaning and pride. But it can also come at significant personal cost, with carers facing health, social and financial difficulties. Despite policy initiatives intended to ease the strain, many carers have needs that go unmet, and struggle to carry on (Carers UK 2018).

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.

About this report

This report aims to share good practice and ideas to improve outcomes for bereaved carers. Some of these are things that can be put in place before the death, to improve outcomes in bereavement. Others are ways of improving support after the death to make it more sensitive to the 'legacies of caring' (Larkin and Milne 2017).

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**

An individual 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 other 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

This 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).

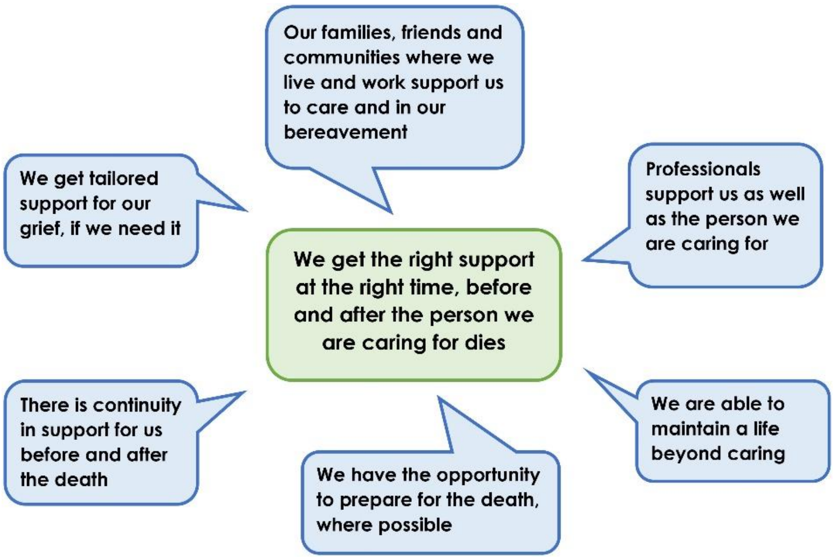


Figure 1: What needs to be in place for carers to get the right support before and after the person they are caring for dies

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

1. Universal: for all bereaved people. Community capacity building, provision of information about bereavement and sources of support
2. 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
3. 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 studies

The report ends with a series of case studies which illustrate good practice in relation to the aspirations set out above. These are

- Cruse Bereavement Care and the ExtraCare Charitable Trust Bereavement Supporter Project
- Leeds Bereavement Forum
- Rainbow Trust Children's Charity Parent Voices Count group
- Giffard Drive Surgery support for carers at the end of life
- University Hospitals Birmingham NHS Foundation Trust Bereavement Care and Pathway
- St Giles Hospice Bereavement Help Points
- Carers Network end of life carers project
- Cambridgeshire and Peterborough CCG End of Life Care data sharing and dashboard
- Carers Leeds support for bereaved carers
- St Nicholas Hospice building a compassionate community: hospice neighbours, carers and bereavement services
- Voluntary Action Rotherham and Mind Rotherham and Barnsley
- London Borough of Waltham Forest Social Prescribing Service.

Introduction

> Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide.
>
> Ambitions for Palliative and End of Life Care (2015)

> If you don't know you're caring, you don't know how much energy or how much of your life is being taken from you while this is all going on and then all of a sudden, you're struck with the bereavement. There's no preparation there because they've just, they're absolutely exhausted.
>
> Bereavement support worker

> Support…may incorporate practical, educational, psychological, spiritual, financial or social strategies (based on unmet needs and a desire by the caregiver(s) for assistance) with the intention of enhancing the caregiver's capacity to undertake their role, respond to its challenges and maintain their own health (including the bereavement period
>
> Hudson and Payne (2009)

Carers are people who provide unpaid care to an ill, disabled or older family member or friend. The amount and type of care varies hugely, from a couple of hours a week doing the shopping or making phone calls on someone's behalf, to being with the person all day and through the night, every day of the week. The care that carers provide helps those they are caring for to live healthier, safer and more satisfying lives. Collectively, their care also makes a huge social and economic contribution to society, worth an estimated £132 billion each year (Yeandle and Buckner 2015).

Looking after someone close is part of what it means to live in relationship with others. Caring can bring a sense of fulfilment, growth, meaning and pride. But it can also come at significant personal cost, with carers facing health, social and financial difficulties. Despite policy initiatives intended to ease the strain, many carers have needs that go unmet, and struggle to carry on (Carers UK 2018).

Facing bereavement

Each year in England, over 500,000 carers face the death of the person they were caring for. They have been described as 'ex-carers' or 'former carers'[1]. Despite the catch-all terms, their experiences vary hugely, in terms of the caring responsibilities that led up to the death, the cause of death, and the bereavement afterwards.

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.

Carers who have given up work and seen their friendships and hobbies dwindle while they were caring often feel lonely and lost after the death. Social, financial and practical challenges have to be faced alongside grief. The loss of the person can be compounded by the loss of role, identity and meaning in life, and the loss of relationships with professionals who had been involved in care. Carers may feel a sense of relief at the end of suffering and strain, and be glad to have some more time for themselves, but at the same time they may be exhausted and depleted by the strain of caring, and sorry to see their role and identity changed so profoundly.

Many carers will find that their inner resources, family and friends help them adjust to changed life, but many will need more support to help them through this change. Often different members of the family or social network react in different ways and this can leave bereaved carers feeling lost and misunderstood. Some carers' social networks will have strengthened as they drew on other's help to care, and this can be a comfort into bereavement, but others will have become more isolated. Ironically, just at the time when former carers might have more time and energy to make use of organised carers' support services, and might need them most, these services may be less available. Health and social care services, employers, businesses and communities all have a role to play in helping carers to find their feet again and to start to rebuild their lives.

About this report

This report aims to share good practice and ideas to improve outcomes for bereaved carers. Some of these are things that can be put in place before the death, to improve outcomes in bereavement. Others are ways of improving support after the death to make it more sensitive to the 'legacies of caring' (Larkin and Milne 2017).

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.

Methods

- A scoping review of national policy in relation to carers, end of life care and bereavement care.
- A scoping review of literature on carers, former carers and bereavement, searching electronic databases (Pubmed, Medline, ASSIA and ProQuest) and sending out a call for grey literature across members of the National Bereavement Alliance and their constituent networks.
- A call for examples of good practice, circulated among members of the National Bereavement Alliance and their members.
- Desk research and follow-up telephone calls with a random sample of 45 carers' organisations. Organisations were asked how long they are able to continue to support carers once the person they are caring for has died, the nature of this support, links with other organisations providing bereavement support, and specific issues for bereaved former carers.
- Four focus groups with carers and bereaved former carers. Participants had cared for parents, partners and children, were men and women, and ranged from their 20s to their 70s. Their time of caring ranged from a few months to several decades. They had cared for people with a range of conditions and circumstances including terminal illness, life-limiting illness, drug and alcohol use, disability and frailty.

- A study day for 61 researchers and practitioners in the field of bereavement and carers. This included presentations and discussion on the needs and experiences of bereaved people who identify as LGBT, young carers facing bereavement, carers for those with palliative care needs, and carers of people with dementia.
- Telephone interviews and visits with 12 case studies. These included discussion of the context and rationale for the approach to supporting carers facing and following bereavement, the nature of the offer, and the impact on those using the service.

A note about terms

In this report, we use the term 'carers' to describe people who provide care to an ill, disabled or older family member or friend. This report looks specifically at the needs of adult carers.

'Family' is used to mean people bound together by 'a whole range of relationships of blood, care, commitments, duty, friendship and of love' (Monroe and Oliviere 2009).

In this report we sometimes refer to 'former carers' or 'ex-carers' to describe those who have been bereaved by the death of the person they were caring for. These terms are not intended to suggest that the person no longer 'cares about' the person who died, simply that they no longer actively 'care for' them.

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. Together, the economic value of their caring is around £132 billion per year (Yeandle and Buckner 2015).

Who is caring for whom?

Age and relationship

- 8% are caring for disabled children under 18
- 50% are caring for someone aged 75 or more
- 40% are caring for a parent or parent-in-law
- 26% are caring for a spouse
- 13% are caring for a child
- 9% are caring for a friend or neighbour

Why the person needs care

37% of cared-for people have a long-standing illness

17% have problems connected with ageing

13% have a mental health problem

10% have dementia

4% have terminal illness

1% have drug or alcohol dependency.

Figure 2: Characteristics of carers' circumstances. Taken from NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

Those providing more intense care (20 or more hours a week) are more likely than low-intensity carers to be caring for those with long-standing illness or disability, mental health problem or terminal illness. Those providing less intense care are more likely to be caring for someone with dementia or problems connected with ageing.

When caring ends

Each year, around 2.1million people's caring role comes to an end (Carers UK 2014, Hirst 2014). For some, this will be because the person they cared for has recovered, or their care arrangements have changed, but for many it will be because the person has died (Larkin and Milne 2007).

In what circumstances are carers bereaved?

Around half a million carers will be involved in some type of end of life care provision each year (National Council for Palliative Care 2012, Payne and Morbey 2013). Given population projections, mortality trends, policy influences and public wishes, the number of people caring for someone at the end of their lives is likely to increase (Payne and Morbey 2013, Calanzani et al 2013).

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. Carers may have begun their caring role hoping that the person would recover, and have had to deal with high levels of uncertainty about how a disease would progress. They may have had several crisis moments when they thought that death was imminent, but the person went on to recover temporarily. The tasks of caring are likely to have been particularly intense at the end of life (Carers UK 2018) and have to be done in the face of impending loss (Candy et al 2009).

Two thirds of people who die each year are aged 75 or over, and over half are over 85. Most older people die from chronic health problems and are more likely to have complex needs and problems and more than one health problem. As most caregivers of older people are spouses, they are often older themselves, with their own health issues (Davidson and Gentry 2013, Marie Curie NI and Carers NI 2018).

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 (Together for Short Lives 2016). Their parent carers are faced with the particularly difficult experience of a death that is outside the usual order of family life.

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 many of these will have needed the care of family members for enduring mental illness.

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.

> I think often with a death in this context [drug or alcohol use], it's not anticipated. Even if it might be somebody's worst fear, it still fits into that category of being a shock or being unexpected.
>
> Bereavement support worker

The strain of caring in these circumstances, including living with the possibility that the person may put their own safety at risk and die, can have serious mental and physical health implications (Turnbull and Standing 2016, Templeton et al 2016, Vermeulen et al 2015). Alongside difficulties in family relationships, many carers' experiences are made worse by stigma (Valentine et al 2016).

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).

Bereavement after caring for someone has been seen as part of an overall 'caregiving career' (Orzeck and Silverman 2008), with this phase described as 'taking the next step' (Brown and Stetz 1999), 'new horizons' (Cavaye 2006) or the 'post-caring transition' (Ume and Evans 2011).

A limited number of studies – all with adult carers - have explored these transitions. Larkin (2009) described this as a trajectory with three distinct phases: the 'post-caring void', 'closing down the caring time' and 'constructing life post-caring'. Cronin et al (2016) describe former carers as being 'worldless' or 'caught between worlds'. Again 'loss of the caring world' was a key theme, but many of the former carers they interviewed continued 'living in loss', with abiding and complex painful feelings of guilt, relief and anger, and practical as well as emotional challenges. Some had begun to 'move on', constructing a life post-caring with the help of families, interests, friends and work.

Some had taken on new responsibilities for caring for someone else. Most (91%) of people who have cared for someone at the end of life would be willing to do so again in similar circumstances (Johnson et al 2016). Larkin (2009) found this experience of 'serial caring' among 70% of the former carers in her study, and this group seemed particularly vulnerable to poor health and being out of work. Some may have been caring for more than one person at the same time, and so in their bereavement they are both a current and a former carer (Kelleher and O'Riordan 2017). Bereaved former carers say that having had to juggle care at the end of life with other caring responsibilities is one of the things that makes their grief harder (Stajduhar et al 2010).

More and more people are likely to experience this caring/post-caring/caring cycle or simultaneous caring and post-caring as the need for informal care grows. We know little about how people's caring responsibilities fluctuate and overlap: the research literature tends to look at the impact of a single episode of caring on the outcomes in bereavement.

> I looked after my grandmother-in-law too…we nursed her at home and I was with her and looked after her until she died. She was my apprenticeship: my mum was my full-blown certification.
>
> Bereaved former carer

Simply dividing experiences into 'active caring' and 'post-caring' suggests that being a former carer is a 'single fixed state' of 'formerality'. This does not tally with people's descriptions of the life changes and challenges they continue to face after they have been bereaved (Larkin and Milne 2017).

Carers: individuals, families, networks?

The caring relationships and responsibilities described above relate to individual carers. Yet for most, the intense caring relationship happens within a wider set of relationships and networks.

In practice, the daily responsibilities of caring at the end of life are often shared between several people, who might take turns or divide specific tasks up: the 'caregiver shift' (Waldrop 2006). These primary carers, whether parents, spouses or children or others, may be supported by a wider group of secondary carers who provide emotional support as well as backup and practical help with shopping, meals and transport. A wider network may provide social rather than practical support through keeping in touch and calling in (Waldrop 2006).

Much of the research literature on caring for adults focuses on the experiences and needs of individual carers - often the spouse or next of kin – rather than the wider family or social network (Stroebe and Boerner 2015, Stroebe and Schut 2015, Naef et al 2016, Waldrop 2006). Less is known about the experiences of extended family members and friends whose contributions and needs are much less visible (Pleschberger and Wosko 2017, Burns et al 2013, Abel et al 2011).

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). Yet coordinating roles and negotiating who will do what is a responsibility in itself, and can be a tension. While sharing decisions about treatment and care can reduce the isolating feeling of sole responsibility, it can also bring conflict between couples, siblings, family members who have different views about the best thing to do.

> We kind of like realised that she wasn't just ours, she was everybody's, our friends that knew her and that kind of like helped us to come through it and it helped us when she died.
>
> Bereaved former carer

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). For example, if one parent is overwhelmed by grief following their child's death, the other parent and relatives may have to take on more responsibility for caring the siblings. If an adult child has to give up work to care for a dying parent, their siblings may have to bear more financial responsibility for paying for the funeral.

Whether wider support is present or absent, consensual or conflicting, the social context makes a profound difference to individuals' experiences of caring and of bereavement. Keeping the social context in mind, and considering how family dynamics and individual experiences influence one another, provides a richer and more accurate picture of the challenges which caring and bereavement bring (Stroebe and Schut 2015, Breen et al 2018).

What caring means for bereavement

While some aspects of bereavement (such as organising the funeral and adjusting to the physical loss of the person) are common whether or not there were caring responsibilities before the death, other aspects are unique to former carers, such as returning equipment and ending benefit claims related to the illness or caring role. Caring often brings extra dimensions to the bereavement experience (Larkin 2009), particularly secondary losses such as the role of carer, and the social network of health and other professionals involved with the person who died, and who provided information, comfort and support.

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 key negative legacies:

- **finance:** the depletion of savings, care-related costs, withdrawal of carer-related benefits, leaving work early compromising pension contributions
- **social networks:** social isolation and loneliness through lacking time and energy to see friends and family, drifting apart as experiences differ and not feeling able to talk about the caring role, having less money to spend on social activities, not feeling able to leave the house (Carers UK, 2017)
- **persistence of physical health challenges associated with long-term caregiving**: including back problems, exhaustion, skin disorders, infections, arthritis, high blood pressure and cardiac problems. Among carers, those providing palliative or end of life care are most likely to report a negative impact of caring on their physical health (Carers UK 2018)
- **psychological health:** many carers experience significant distress following the death of the person they cared for, especially around loss of self-esteem, role and purpose and negative feelings such as anger, guilt or a sense of failure. Some, however, may experience a gain in well-being after the death, perhaps because of a sense of relief, a feeling of being in greater control of life or a feeling that they did a good job of caring (Schulz et al 1997, 2003 and Seltzer and Li 2000, in Larkin and Milne 2017; Skaff et al 1996).

How does caring influence bereavement?

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 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. Much research in this area has been carried out outside the UK, particularly in Australia and the US.

Different carers show different patterns in their bereavement (Aneshensel et al 2004). Understanding some of the ways in which the caring role influences grief helps to consider who might need what type of support. There are three main (and conflicting) theories (Schulz et al 2008; Boerner and Schulz 2009).

> The caring role is such a big part of the bereavement…the before is as much part of the bereavement as the actual death itself.
>
> Bereavement support worker

- **Wear and tear**: the cumulative and chronic stress of caring for someone depletes the carer's personal and social resources and leads to negative outcomes in bereavement
- **Stress reduction**: the carer's burden is relieved and the patient's suffering is over, leading to a reduction in distress following the death
- **Anticipatory grief**: because the death is expected, some of the 'grief work' happens before the death, leading to less distress after the death. There is a trade-off between pre- and post-bereavement outcomes: the caregiving period is very intense, but distress is alleviated afterwards.

An individual 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'.

Within a family or social network, individual members might be associated more strongly with one effect than another: for example, one parent may have felt more able to prepare for their child's death than the other, or one adult child might be very relieved from the burden of caring while others feel guilty about not having done more. It is common for these differences to be a source of misunderstanding and stress in themselves.

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.

Influences on carers' bereavement outcomes

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). Understanding these factors can help to inform how family, friends, communities and organised services could respond most helpfully, both before and after the death (Schulz and Boerner 2008).

Figure 3 provides a summary of the risk factors that increase the risk of carers experiencing complicated grief in bereavement, which may take a variety of forms including prolonged grief (Rando 2013). Some of these factors are stable demographic factors or prior experiences. While they can help to identify carers who might be at particular risk, many are not possible to influence or modify through support and services. The influence of cultural understandings of family responsibility, attitudes to illness and healthcare are under-researched and need more exploration.

Predictors of bereavement outcomes among carers

(Schulz et al 2008)

Researchers have looked at the literature on the risk factors associated with worse bereavement outcomes among former carers.

Factors before the death

- High levels of pre-death distress (eg depression and anxiety)
- High levels of burden, feeling exhausted and overloaded, lacking support
- Reporting more benefit from the experience of caring
- Not being prepared for the death

Factors after the death

- Depression
- Poor physical health

Demographic characteristics

- Being female
- Low levels of self-esteem
- Low socio-emotional support
- Lower income

Figure 3: Predictors of worse bereavement outcomes among carers (Schulz et al 2008)

The factors of most relevance to this report are those that are modifiable and can be influenced through support networks and organised services. These are discussed below.

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.

Following caring for someone with palliative care needs, bereaved carers' recollections of poor symptom management (Kreicbergs et al 2005, van der Geest et al 2014, McLean et al

2017), the patient's fear of death (Kramer et al 2010) and poor quality of life (McCarthy et al 2010) are associated with greater difficulties in medium to long term grief. Memories of good communication and continuity with the healthcare team (van der Geest et al 2014) and perceptions of good quality of care (Kramer et al 2010, McCarthy et al 2010), better patient quality of life (Wright et al 2008) or quality of death (Garrido and Prigerson 2014) are associated with fewer difficulties and/or higher quality of life. Lingering regrets or concerns - about the person's death and whether carers made the right decisions and did all they could - make bereavement harder to bear (Stajduhar et al 2010, Harrop et al 2016, Holtslander et al 2017).

> We knew exactly when she was going to die. We were all prepared for that. What they didn't tell us was the traumatic way that…the actual way that she did pass…Afterwards we said 'does that normally happen?' 'Yes, with this type of cancer'. We weren't told what to expect…That's traumatised.
>
> Bereaved former carer

Some studies have found that a hospital death is associated with worse bereavement outcomes, or a home or nursing home death is associated with better outcomes (Bernard and Guarnaccia 2002, Goodenough et al 2004, Gomes et al 2015, McLean et al 2017, Brazil et al 2002). Others have found a more complex or no relationship between place of death and bereavement outcomes (Jaaniste et al 2017, Roulston et al 2017). The patient's completion of a Do Not Resuscitate (DNR) order makes it more likely that the carer's mental health improves after the death (Garrido and Prigerson 2004). Carers who used palliative care services while caring at the end of life are more likely to feel willing to care again in similar circumstances (Johnson et al 2016).

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 (Kelly et al 1999, Aneshensel et al 2004, Kurtz et al 1997, Boerner et al 2004, Thomas et al 2014, Nielsen et al 2017). These findings challenge the concept of 'anticipatory grief' as a protective factor which had been thought to lead to better outcomes in bereavement because of the 'grief work' done before the death (Coelho et al 2018). Carers' anticipation of death - a core concept of anticipatory grief – fluctuates as they hold on to hope and deal with uncertainty (Coelho et al 2017).'Pre-loss grief' may be a better way of describing the complex reactions to multiple losses that carers face before the death, and which are a risk for poor outcomes after the death (Nielsen et al 2016).

> When there was nothing else [to be done] I asked 'could I have some counselling?' That was through the hospital and I went, and I went for a session and the woman said that she wasn't used to people in my situation.
>
> Bereaved former carer

Strain and exhaustion

The challenges of caring are related directly and indirectly (through pre-bereavement distress) to grief after the death. Some carers of adults experiencing a heavy burden of care do show fewer difficulties after the death, probably because of a sense of relief (Li 2005, Tsai et al 2015). Other studies have found carers who felt overloaded and unsupported (Anenshel 2004), in poor physical health (Brazil et el 2002) or were caring for someone with more difficulties (Schulz et al 2006) are more likely to experience difficulties after the death, including ongoing social isolation (Burton et al 2006 among older carers). Among carers of adults who died from cancer, the amount of time spent caring for the person is a more important predictor of adverse bereavement outcomes for adult children than spousal carers (Mclean et al 2016).

Difficulties in the family

Families who are supportive and resolve conflicts well during a family member's terminal illness experience less intense grief and adjust better to the death than families who have low to some cohesiveness and moderate to high conflict (Kissane et al 1996). Bereaved fathers' memory of talking with the child's mother about the impending death is a significant factor in feeling they have worked through their grief several years later (Kreicbergs et al 2007). Fathers do better following their child's death if their partner grieves in a similar way to them (Wijngaards-de Meij et al 2007).

Social support

Carers who have good social support while they are caring are more likely to do better when they are bereaved (Aneshensel 2004, Brazil et al 2002, Kurtz et al 1997, Tsai et al 2015, Kreicbergs et al 2007). This may be because of a general benefit of social support on health and wellbeing, rather than an effect that is specific to bereavement (Stroebe et al 2005). Parents who recall not having someone to share their problems with during their child's illness are more likely to be troubled several years later by thoughts that their child had a difficult death (Kreicbergs et al 2005) and less likely to have worked through their grief (Kreicbergs et al 2007). There is some evidence that a shorter illness is associated with higher grief intensity for adult children (but not spouses) who are caring. This may be because a shorter illness means less time for support networks to form for these carers (Mclean et al 2015). When asked about advice for others in their situation, bereaved carers of palliative care patients recommend making use of social networks (Breen et al 2017).

Benefit from caregiving

While finding meaning and value in their role may help carers carry on, some studies have found that those who report more benefit from caring for adults seem to be at greater risk of poor outcomes after the death (Schulz et al 2006). This may be because the death deprives them of an important part of their identity and feelings of fulfilment. Alternatively, finding benefit in caring may be associated with the quality of the relationship: the death is a greater blow to those who were particularly close (Schulz et al 2008).

In contrast, other studies have shown that a difficult relationship with or difficult behaviours from the cared-for person (Li 2005) increases the risk of poor outcomes.

Preparedness

It might be expected that caring for someone with a terminal illness or an increased risk of dying would mean that the carer was forewarned of the death. Yet 16-23% bereaved former carers report that they were unprepared for the death (Hebert et al 2006, Hauksdottir et al 2010). Feeling unprepared for the death increases the risk of post-bereavement difficulties such as anxiety, depression and grief among carers of adults (Schulz 2006, Tsai 2016, Nielsen et al 2017) and of children with cancer (McCarthy et al 2010, Valdimarsdottir et al 2010, Rosenberg et al 2012).

Carers say that being prepared includes being aware of the symptoms and prognosis, being emotionally prepared for the death, and doing necessary tasks such as will-writing and sorting finances (Hebert et al 2009). These do not necessarily go hand-in-hand: carers find emotional preparedness more challenging than cognitive and behavioural preparations (Breen et al 2018a).

> I feel guilty, very guilty because I went home and left her when I should have been there…I expected her to be okay, to be feeling much better when I came in the following day, that was in my mind.
>
> Bereaved former carer

Supporting carers' preparedness for the death may have benefits for bereavement outcomes (Caserta et al 2017). Accurate and timely information from the healthcare team can help carers prepare for the death and increase the likelihood of being there when it happens which, if missed, can give rise to lasting feelings of guilt and regret for some carers (Holtslander et al 2017, Stajduhar et al 2010). Examples of effective interventions that improve carers' preparedness include the patient's engagement in Advance Care Planning (Schulz et al 2015) and a psychoeducational programme for carers (Hudson et al 2013), but there is a gap in studies on interventions to support the emotional dimension of preparedness (Nielsen et al 2016).

Household finances and work

Lower income or economic hardship is associated with greater distress while caring at the end of life (Götze et al 2014) and with worse bereavement outcomes for those who cared for adults (Li 2005, Schulz et al 2005) and children with cancer (McCarthy 2010). Carers of lower socio-economic status and those who stop work before or after their bereavement are at greater risk of poor bereavement outcomes, with employment seeming to offer some protection (Roulston et al 2017).

What does this mean for how support should be provided?

There is a lack of evidence for preventative interventions in supporting carers facing bereavement (Schulz et al 2008; Nielsen et al 2016, Coelho et al 2018). The evidence that exists is often based on experimental studies which need adjusting to meet the practical 'real world' needs of social networks and organisations supporting carers. Many recommendations are based on specialist palliative care settings, to which not all carers have access.

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, this support should aim to

- Ensure that **the death is as good as possible**, which will also benefit the dying person's carers (Kreicbergs et al 2005, McCarthy et al 2010, van der Geest et al 2014, Jalmsell et al 2010, Wright et al 2008)
- **reduce the burden of care** (Ghesquiere et al 2011, Li et al 2005)
- support carers to maintain a **life outside caring** (Roulston et al 2017) and to think ahead to a **life after caring** and what they need now to help them achieve those goals (Larkin 2009)
- support carers to **prepare for the death and for their own life afterwards** emotionally as well as cognitively and practically (Boerner & Schulz 2009, McCarthy et al 2010, Schulz et al 2015, Nielsen et al 2016, Breen et al 2018)
- **provide welfare advice and financial assistance** (Cronin et al 2015, McCarthy et al 2010, Roulston et al 2017).

Formal organised carers' support services, end of life care organisations 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 (Burns et al 2013, Breen et al 2018c) and how these can be enhanced (Kreicbergs et al 2005, Kreicbergs et al 2007, Ghesquiere et al 2011), for example through public education aimed at carers' friends and families about how to help
- support **good communication** within the family and social network (Stroebe and Schut 2015, Kissane et al 2016) and with the healthcare team, including about the prognosis and the death itself (McCarthy et al 2010, van der Geest et al 2014, Kreicbergs et al 2007, Harrop et al 2016)
- **explore carers' individual and family needs for practical and emotional support** before and after the death and **identify how these might best be met** (Schulz et al 2006, Holtslander et al 2017, Nielsen et al 2017, Kissane et al 2016, Ghesquiere et al 2011, Ewing and Grande 2018, Aoun et al 2018b)

- **collaborate with other community and professional organisations** to improve signposting, share skills and knowledge and improve links e.g. between carers' organisations and bereavement services (Kelleher and O'Riordan 2017)
- provide **emotional support at appropriate levels** to help carers develop coping strategies to deal with their pre-loss grief and other mental health difficulties (Schulz et al 2006, Boerner and Schulz 2009, Ghesquiere et al 2011). This could include information about what grief is like, group opportunities and one-to one support. It should include appropriate assessment and targeting of support
- promote **continuity of care** where possible before and after the death so that carers do not feel abandoned when the person dies (Larkin 2009, Johansson and Grimby 2012, Masterson et al 2015, Kelleher and O'Riordan 2017, Kreicbergs et al 2007, Harrop et al 2016)
- **build on the experiences of bereaved carers** in developing resources and training (Breen et al 2017)
- be **accessible** and **respectful** to carers with varying levels of (health) literacy, facing different levels of stigma around the illness or circumstances of the person they are caring for, and constrained from accessing support in different ways by their caring role.

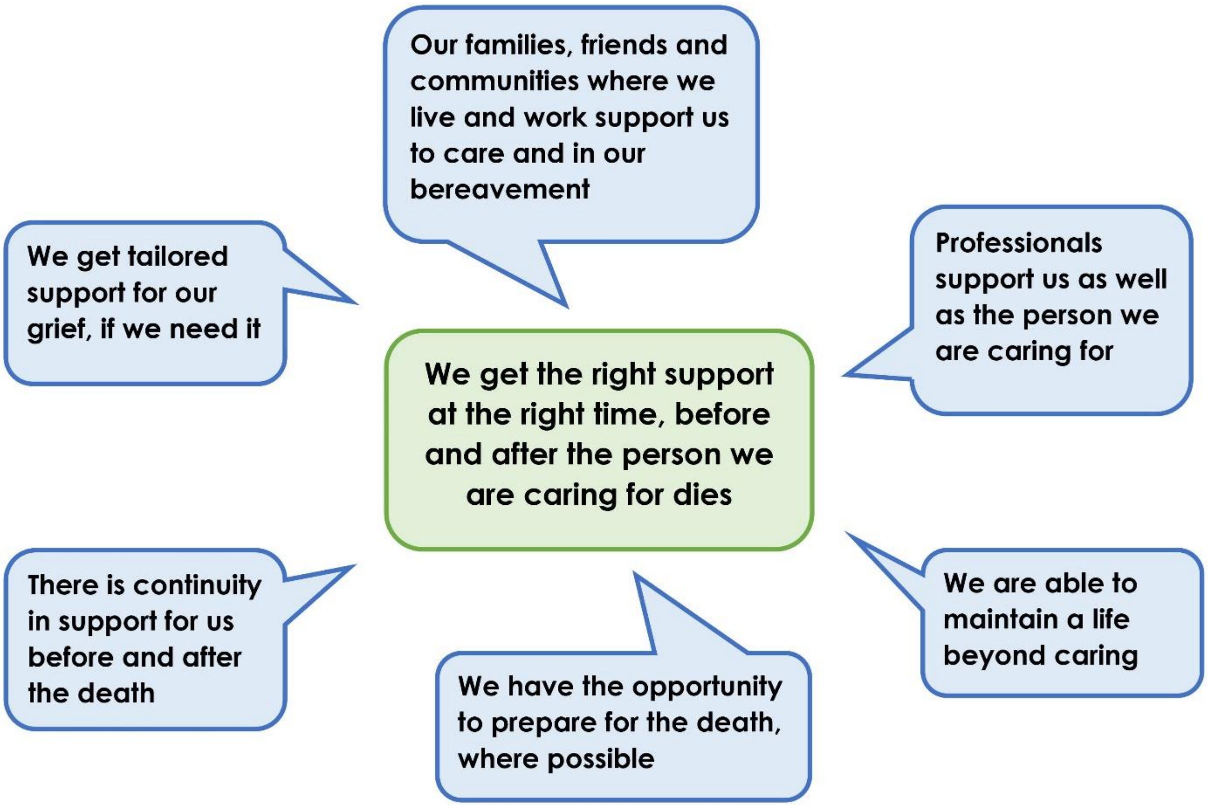
Our aspirations

If the support outlined above is in place, we can aspire to a situation where all carers get the right support at the right time, before and after the person they are caring for dies.

‘We’ statements

These aspirations are expressed as ‘we’ statements rather than ‘I’ statements, to emphasize that

- we want them for all carers, whatever their circumstances and needs
- caring for someone often involves more than one carer, and this social network has collective as well as individual needs.



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

Our families, friends and communities where we live and work support us to care and in our bereavement

Professionals support us as well as the person we are caring for

We are able to maintain a life beyond caring

We have the opportunity to prepare for the death, where possible

There is continuity in support for us before and after the death

We get tailored support for our grief, if we need it

Figure 4: What needs to be in place for carers to get the right support before and after the person they are caring for dies

The policy context

There is a significant gap for many carers between these aspirations and the reality of the support they get.

This is despite a wide-ranging policy context. Policy responsibility for carers facing and following bereavement sits across a number of government departments. Various key policy initiatives include important opportunities to meet carers’ needs before and after the death of the person they are caring for, although these opportunities are often implicit and generic rather than addressing these needs specifically. These are set out in detail in Appendix 1. In summary, they include

- **overarching strategies** such as the Loneliness Strategy, the NHS Long Term Plan and outcomes frameworks for the NHS, Clinical Commissioning Groups and Public Health
- policies supporting **carers** including the Care Act (2014), Children and Families Act (2014) and the Carers Action Plan
- policies around **end of life care** including the Ambitions for End of Life Care, NICE guidance on end of life care, response to the review of Choice in End of Life Care and NHS England's information for commissioners on specialist level palliative care
- policies on **bereavement care** including the National Bereavement Alliance's guide for commissioners and the NICE guidance on supportive and palliative care
- policies around **support after a death** including When a Person Dies, National Guidance on Learning from Deaths, Child Death Review statutory and operational guidance.

The next section of this report explores some of the key barriers to these aspirations. It signposts to resources and examples of good practice that can help communities, networks and professionals to ensure that this support is in place.

We get the right support at the right time, when we are caring and if the person we care 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).

Hudson and Payne (2009) have set out a definition of support for family carers who are assisting a relative or friend requiring palliative care. This is adaptable to other situations where someone is being supported and there is a possibility they will die:

> Support…may incorporate practical, educational, psychological, spiritual, financial or social strategies (based on unmet needs and a desire by the caregiver(s) for assistance) with the intention of enhancing the caregiver's capacity to undertake their role, respond to its challenges and maintain their own health (including the bereavement period).
>
> Hudson and Payne (2009)

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).

Bereaved people themselves report that the support they draw on most frequently, and find most helpful, is that from their family and friends, closely followed by that from funeral directors (Aoun et al 2018a).

Offering counselling routinely may encourage people to use services rather than turning to family and friends or allowing their grief to follow its natural course. It could encourage people to view grief as a mental health problem per se, rather than a normal reaction to loss which can increase vulnerability. It could lead to the unnecessary over-professionalization of bereavement care (Rumbold and Aoun 2014), reducing services' capacity to respond to those who do need them.

However, it is important that people are given information about the support that is available to them: without knowing about it, they cannot choose to access it for themselves.

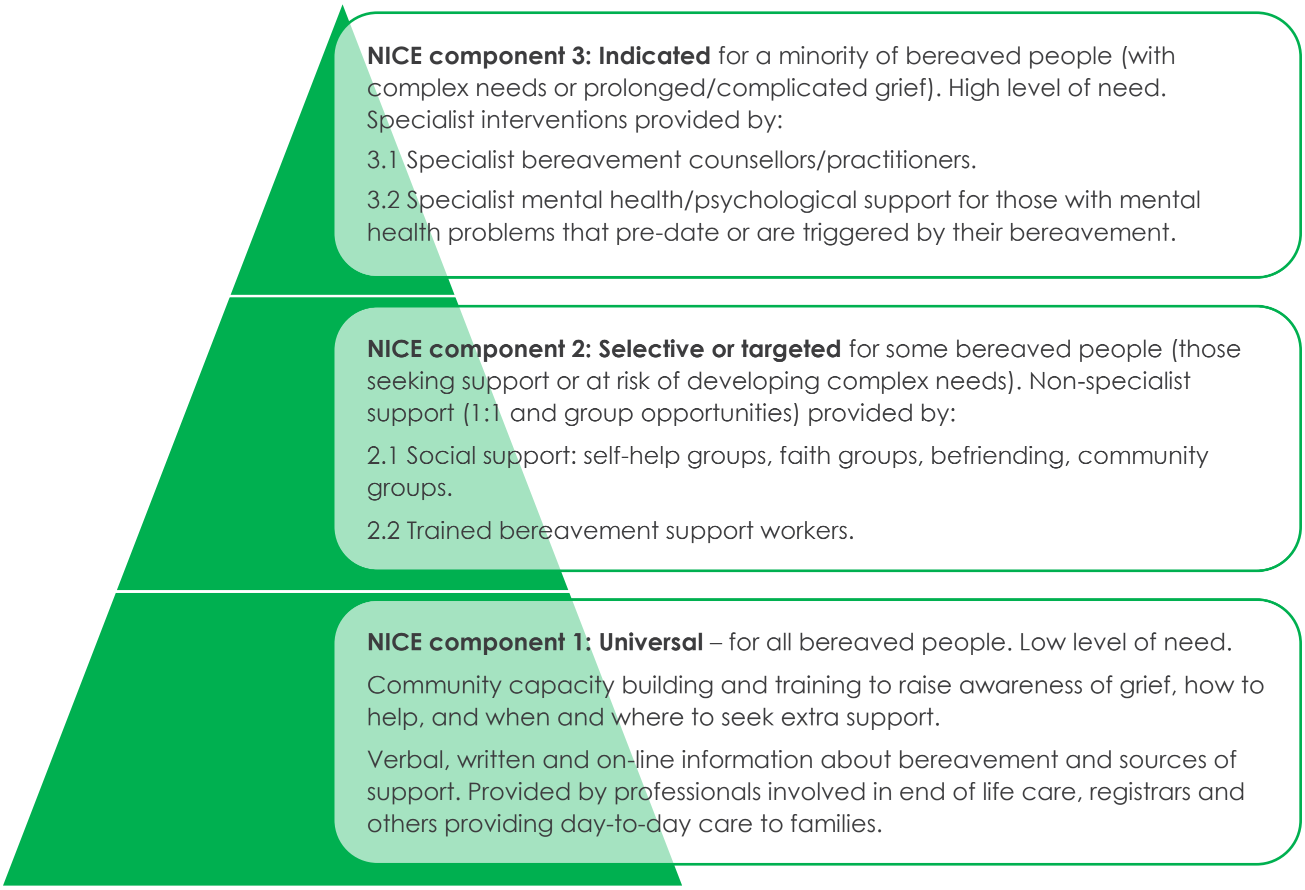
The role of informal networks and communities in supporting dying people and those caring for them – and ways these can be enhanced - has been set out helpfully in public health approaches to palliative care (Kellehear 1999, Kellehear 2005, Abel et al 2011, Abel et al 2016). There is some acknowledgement of how these networks can continue to support carers into bereavement (Abel 2018, Aoun et al 2019) but generally these approaches are much less developed in relation to supporting bereaved people (Rumbold and Aoun 2014).

Researchers in Australia have set out a public health approach to bereavement and tested this in a population-based survey looking at levels of risk and need (Aoun et al 2015). This 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, Aoun et al 2019) or if the carer is experiencing an otherwise complex response to bereavement. As already shown, difficulties in the family and a lack of social support complicate the bereavement experience of former carers.

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.



NICE component 3: Indicated for a minority of bereaved people (with complex needs or prolonged/complicated grief). High level of need. Specialist interventions provided by:

3.1 Specialist bereavement counsellors/practitioners.

3.2 Specialist mental health/psychological support for those with mental health problems that pre-date or are triggered by their bereavement.

NICE component 2: Selective or targeted for some bereaved people (those seeking support or at risk of developing complex needs). Non-specialist support (1:1 and group opportunities) provided by:

2.1 Social support: self-help groups, faith groups, befriending, community groups.

2.2 Trained bereavement support workers.

NICE component 1: Universal – for all bereaved people. Low level of need.

Community capacity building and training to raise awareness of grief, how to help, and when and where to seek extra support.

Verbal, written and on-line information about bereavement and sources of support. Provided by professionals involved in end of life care, registrars and others providing day-to-day care to families.

Figure 5: summary of the three-component model of bereavement care

Our families, friends and communities where we live and work support us to care and in our bereavement

Social support and isolation

Some former carers in our focus groups spoke warmly of the support they had received from family and friends while they had been caring.

Others had clearly not had the social support they needed or wanted while they were caring. Some groups are particularly isolated because of the circumstances in which they are caring, for example for a family member using drugs or alcohol or with mental health difficulties, where fear of stigma or worry about betraying the person inhibits them from seeking support.

> I wouldn't have sought outside help because of the secret nature of it.

Bereaved former carer

Others had found that their families and networks were not able to meet their needs, particularly as time went on.

> The children don't have the same sense of concern as I have. I find it very difficult to get it out of my mind.

Bereaved former carer

Awareness of what grief is like

Former carers found it difficult when their grief did not meet the expectations of those around them, especially when people expressed (either explicitly or implicitly) an assumption that the person should be over it.

> I had a colleague say to me the other week when it was near my daughter's anniversary, he said I should go and have counselling because I seem to think about, mention her quite a bit and that. He said that I need to put it behind me, that kind of thing.

Bereaved former carer

They also encountered a general taboo about talking about these topics and offering everyday support. Expectations about grief and how to mourn appropriately are heavily influenced by culture (Rosenblatt 2013) and falling short of other's expectations can be a source of additional stress for bereaved people.

> You see, people don't want to talk about death, do they? They want to speak about life, most people.

Bereaved former carer

Although some had found that family members and friends shared hidden stories after the death.

> During this journey like people have said to me that they lost a baby that I didn't know that they had and that and people have been very generous with their stories. It's almost like a sisterhood, almost.

Bereaved former carer

These opportunities for informal peer support were welcomed. While most of the peer support opportunities mentioned by carers were those organised by health, social care and bereavement organisations, some mentioned initiatives they had been involved with to set these up.

> The undertaker shared my views about it, and we were going to start a support group. A discussion group for anybody that wanted just to call in and talk about death, just so that we tried to make the community aware of ‘this is a thing that’s going to happen to all of us, and it’s just ok to mention the word’.

Bereaved former carer

As well as support from family and friends, practitioners mentioned other resources in the community including companion services, faith groups and Hospice Neighbour schemes. They described how some carers’ social isolation persists into bereavement. Particular worries were raised about those with housing difficulties and learning disabilities.

> The starting point has to be that most people will get by on their native resilience, the support of family and friends – always have done and always will do. But there remain those more marginalised and vulnerable people who are hard to reach for all manner of reasons – socially excluded or psychologically unable to access help.

Bereavement support worker

Hospices and bereavement support organisations can help build community capacity through public education and closer liaison with existing voluntary groups.

Resources

- Dying Matters produces leaflets to help people know what to say when someone close to them has been bereaved.
- Walter (2010) published a checklist to help bereavement practitioners consider the cultural influences on grief and mourning
- The National Council for Palliative Care published guidance on ‘Each Community is Prepared to Help’ in palliative care.

Case studies

- The Cruse Bereavement Supporter project trains residents in ExtraCare retirement and sheltered housing to act as Bereavement Supporters for their neighbours.
- Leeds Bereavement Forum helps educate the public about dying and bereavement.
- Parent Voices Count brings together parents who are currently caring for a child with life-limiting or life-threatening illness and those whose child has died.

Professionals support us as well as the person we are caring for

Strain and distress while caring have an enduring impact, as they are also associated with worse outcomes in bereavement.

The needs of someone at the end of life and their carer are intertwined and mutually reinforcing: lack of support for the carer may have negative implications for the patient (Hudson and Payne 2009) and poor care for the patient can affect the carer's grief.

Carers are seen as both providers and recipients of care, and there can be competing demands between their own health and well-being and that of the person they are caring for (Payne and Morbey 2013). In palliative care settings, the family is understood to the 'unit of care' although in practice, this may mean support for the main carer, with the needs of the wider social network not receiving the same attention. The degree to which this philosophy of family support is lived out varies as a result of resource constraints and organisational barriers, as well as carers' reluctance to consider their own needs (especially in front of the person they are caring for) (Hudson and Payne 2009, Payne and Morbey 2013).

Some groups may be less likely to recognise themselves as carers, including those caring for someone diagnosed a fairly short time before their death, and those who are caring for someone with drug, alcohol or mental health issues. Some carers will choose to avoid the involvement of professionals.

Former carers whose family member had received health and social care services gave examples of how these professionals had addressed their own practical and emotional concerns as carers.

> She could tell that him coming home [to die] was going to be really tough. I wanted him to come home, but…

Bereaved former carer

Assessment to support caring

Under the Care Act 2014 and the Children and Families Act 2014, carers are entitled to an assessment of their needs and for eligible needs to be met. However, almost a quarter of carers providing palliative or end of life care report having waited longer than six months for an assessment (Carers UK 2018).

The strength of an assessment lies in its capacity to identify or lever sources of support for carers. Even if an assessment has been thorough, this support may not be forthcoming, or it may be offered in a way which does not fit with carers' lives.

> Professionals then go back and don't offer everyone the services that are available. They will pick and choose – it's gatekeeping and I understand that they're gatekeeping because there's not enough services for everybody but how do people choose?

Bereaved former carer

> The carers' assessments are a tick box signposting exercise. Cares are usually very busy people, often trying to juggle a job, families and their caring role which does not facilitate them time or energy to be contacting the organisations that they have been signposted to.

Bereavement support worker

Barriers included services not being available or a long way away (especially for those caring for someone with non-cancer diagnoses), a reluctance to seek out support, previous unhelpful experiences with services, and not conforming to professionals' expectations of someone in need of help.

> We probably came across as quite middle class almost. They probably made assumptions that we didn't need it [support] as well.
>
> Bereaved former carer

Within palliative care services, data are weak on who carers are, what support they need and what support they have received. Assessments of carers are ad-hoc and largely professionally led rather than person centred (Ewing and Grande 2018). Ten recommendations for achieving organisational chance have been set out to remedy this (see figure 6), and while these have been developed for hospice care, they can be applied to all care settings (Ewing and Grande 2018).

The Carers Support Needs Assessment Tool is a promising approach to the systematic consideration of carers' needs in palliative and end of life care. It includes a dual focus on the support the carer needs to maintain their caring role and the support they need for themselves. As a screening tool it allows the carer to consider the areas in which they might need additional support, for further discussion with health professionals. These areas address many of the areas identified in this report as priorities for care, and which carers themselves have identified as being of most concern.

In relation to the support needed to provide care for the patient, areas include understanding the patient's illness, knowing what to expect in the future, and knowing who to contact. In relation to the carers' own needs, this includes

- looking after their physical health
- dealing with feelings and worries
- financial, legal or work issues
- practical help in the home
- support with beliefs and spiritual concerns
- time for themselves in the day and overnight respite.

This holistic, carer-led approach has been shown to reduce carer's strain while they are caring in community palliative care (Aoun et al 2015b), to increase the likelihood of death at home and to improve mental and physical health into bereavement (Grande et al 2015).

Ten recommendations for achieving organisational change

- Comprehensive identification of carers within the care setting.
- Demographic and contextual data on who the carer is and their situation.
- A protocol for assessing carers and responding to the assessment.
- A recording system for carer information, separate from patient data.
- A process for training practitioners about carer assessment and support
- Available time/workload capacity for carer assessment and support.
- Role models/champions for carer assessment and support
- Pathways for communication about carer assessment and support
- Procedures for monitoring/auditing processes and outcomes of carer assessment and support.

Figure 6: Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change (Ewing and Grande 2018)

Assessment of risk in bereavement

Assessment before the death can also help to identify those carers who are more likely to need targeted or specialist support following the death (Sealey et al, 2015b). At the last survey, around 40% of UK palliative care services were using a formal bereavement risk assessment (Field et al 2004).

Guidance for bereavement needs assessment in palliative care (Relf et al, 2010) outlines approaches to exploring people's resources and needs. It includes measures that can be used by nurses and other health care staff to assess the needs of people before and around the time of their bereavement. The Range of Response to Loss Matrix is based on the theoretical underpinnings of the nine-item Adult Attitude to Grief Scale (Machin, 2007) and explores coping responses, and factors relating to vulnerability and resilience.

Other bereavement needs assessment tools have been reviewed for use in specialist palliative care settings (Agnew et al, 2010; Sealey et al 2015a) and many are equally appropriate for use in community settings with other bereaved carers.

Resources

- The Carers Support Needs Assessment Tool is a structured way of helping carers to identify the support they need when caring for someone with a life-limiting condition.
- Hospice UK has published Guidance for bereavement needs assessment in palliative care (2010).

Case studies

- Giffard Drive Surgery in Hampshire makes particular efforts to identify and support carers.
- University Hospitals Birmingham have a bereavement care pathway for carers.

We are able to maintain a life beyond caring

Carers, particularly those who had been caring for many years, gave examples of how their life had been consumed by the caring role. Some did not question this, but other could see the risks and costs that this brought, particularly in bereavement. Those who had been caring for a shorter, more intense time, generally saw less disruption to their ongoing lives.

Maintaining a life beyond caring is of benefit both in providing respite while caring, but also in helping with the transition into bereavement and lessening the void that can be felt. Larkin (2009) suggests using the rights under the Care Act not only to support carers while they are caring, but also to address post-caring needs, using some of the resources in the care package to invest in their future lives. This would free them to spend time during caring keeping up with their interests, taking up education and training, and developing skills.

While friendships and interests were mentioned, work was a key area that had been disrupted. Carers for people at the end of life are one of the groups most likely to reduce their working hours because they are caring (Carers UK, 2018). For those that had given up work, this had allowed them to focus on the caring role, but had come at a cost, both financially and in terms of the support, distraction and identity that work could bring.

> I had to pack in work. I just so adored my job.

Current carer

Being able to hold on to a job and return to work following the bereavement was recognised as a protective factor, as long as the employer and colleagues were sensitive and flexible and this did not add extra pressure. A recent study in Northern Ireland found that a high proportion of people who registered a death had stopped working before (39%) or after (42%) the death, and this was associated with greater grief. Professionals raised particular concerns about carers under retirement age who had given up work to care.

> So many people are struggling to maintain a job and then after the bereavement to continue within that role, but in a way, with maybe a phased return to work or some very simple adjustments or even just a kind word, a listen here.

Bereaved former carer

> A lot of people have said that actually what was really difficult was actually the workplace really and how to re-engage with it. Wanting to, because that gives you a purpose and sense and something to get up to do, but then when you find yourself there it’s a very difficult place.

Bereavement support worker

Additional challenges were faced by some carers returning to work.

> Some bereaved people are client-facing. They’re actually, they might be caring, might be a nurse…there needs to be options really and phased return to different roles and different exposure.

Bereavement support worker

> There’s just no way, even now, that I could contemplate going to work on her birthday or anniversary, you know, I’d have it unpaid. I just couldn’t.

Bereaved former carer

More broadly, financial strain curtailed some carers’ opportunities to maintain life outside caring as well as adding greatly to the stress of caring. Carers providing palliative care are one of the groups of carers most likely to report that they are struggling to make ends meet (Carers UK, 2018).

> You also have the loneliness, the deprivation if you haven't got any money. You're stuck in hospital, how are you going to pay the bills? I see so many families destroyed by this like if the husband walks away or the wife walks away. Get thrown out of housing, there's all that.
>
> Bereaved former carer

> Your life isn't normal and you're worrying about bills, you're worrying about losing your house, you're worried about your child dying.
>
> Bereaved former carer

Resources

- Carers UK has a guide for carers on taking a break, including how to arrange and pay for care
- ACAS has a good practice guide on bereavement in the workplace.

Case studies

- St Giles Hospice's Bereavement Help Points support former carers and other bereaved people to rekindle social relationships and interests.

We have the opportunity to prepare for the death, where possible

Preparation for the death

For some carers, including those who would not recognise themselves as such, there was no opportunity to prepare for the death as it was experienced as sudden. For others it was only a fairly short time before the death that they realised what was happening.

> At the time I didn't really believe he was dying – he was just in [the hospice] for pain management. It wasn't until two weeks before he died that it really hit me.

Bereaved former carer

> Whilst they're alive, you've got hope, so you don't, it would be difficult to approach, well actually, this person may die or they're killing themselves.

Bereaved former carer

Sometimes this was because carers didn't get information or misunderstood what they were told. They expressed bitterness about poor communication and gratitude when conversations went well, although these were acknowledged to be difficult.

> I almost had to stand there and say 'I'm his wife, you have to share some information with me'.

Bereaved former carer

Lack of preparation about specific aspects of the death could lead to painful memories, lingering concerns and regret for carers.

> We knew exactly when she was going to die…We were all prepared for that. What they didn't tell us was the traumatic way that…she did pass…Afterwards we said 'Does that normally happen? 'Yes, with this type of cancer'. We weren't told what to expect…That's traumatised.

Bereaved former carer

Some carers described the ambivalence of holding on to hope while preparing for the death, and the complexity of dealing with different views in the family about information and how it should be shared. For health and social care organisations, there are times when the patient has rights over and above those of their carers, for example around treatment decisions, and choices about who receives information and can make medical decisions on their behalf (Hudson and Payne 2009).

> He would not talk about death. He said 'I talk about life, I don't talk about death'.

Bereaved former carer

For some carers, discussion or encouragement about how to talk in the family would have been helpful.

> I read her discharge notes, so I understood – I watch Holby City so I know everything. I understood how bad it was, but I kept that to me…It was such an elephant in the room, that is my regret, but it was just too raw. Had I been able to have a conversation with somebody that sort of put the perspective from someone different, and said 'Maybe there's things that she might want to say to you, to your dad, to your daughter'.

Bereaved former carer

Preparation for bereavement

As well as preparing for the death, former carers discussed how difficult it was to prepare for grief and bereavement, although some had chosen to confront this.

> I also find it's given me permission in a way to ask other people questions like 'What's it like to lose your child, for them to die? How does it feel?'. I know we'll all feel different but that was a question I've always wanted to ask people and that is something we all feel.

Current carer

After the death, they reported struggling particularly when they were surprised how grief had manifested itself. Some had made specific efforts to understand more,

> I didn't know what to expect. I thought 'I've been a sportsman all my life, I'm tough, I'm going to be alright'.

Bereaved former carer

> I've read a lot of books on grief and that works for me.

Bereaved former carer

Challenges were practical as well as emotional,

> Whether you're a married couple and your partner or husband, wife, whatever, controlled all your finances and then they're gone and then you're just left in this mess because you just haven't got a clue how to deal with it all, or what kind of benefits that you could be entitled to as well. Sometimes those are really hard things to find out and you're not in that right space in your head to know where to go or what to do with it. It can be very hard finding out all the information as well.

Bereaved former carer

Greater public understanding of bereavement could help families and social networks to support grieving carers better, but could also help carers themselves to prepare for this experience.

Resources

- The NHS produces information on planning ahead for the end of life, including advance care planning.
- Hospice UK has information about what to expect when someone is dying.
- The Royal College of Physicians has produced a guide to talking about dying and beginning honest conversations about what lies ahead.

Case studies

- Carers Network supports carers when someone is at the end of life.
- Cambridgeshire and Peterborough CCG's End of Life Care Dashboard helps GPs and other clinicians keep track of conversations about caring at the end of life and bereavement support.

There is continuity in support for us before and after the death

Some carers noted a tailing off of support from family and friends over time.

> You learn to adapt but it never diminishes really but then time passes, and everybody's life has moved on, so you feel kind of like, a kind of pressure almost to conform.

Bereaved former carer

Repeatedly, former carers report feeling abandoned after the death by the health and social care professionals they had encountered while caring (Larkin et al 2009, Harrop et al 2016, Holtslander et al 2017).

> Once the person has died, often, I think, again it varies, but often people, family members no longer have contact, access, support.

Bereaved former carer

Professionals raised particular concerns about the withdrawal of support after the death from carers who were socially isolated, including those with learning difficulties and precarious housing situations, including those who had been caring for elderly parents or siblings and living in their social housing.

Hospice and palliative care services

In relation to hospice care, bereaved carers welcome continuity of support before and after the death (Field et al 2007). Hospices have a variety of mechanisms for ensuring this happens, including multidisciplinary team meetings, and regular visits by the bereavement service staff to the patient care unit (Field et al 2007).

3-9 months after a death in palliative care, around half of bereaved carers reported that they would like a bereavement follow up. Typically they wanted this to be in their own home, to be a meeting with the person most involved in the patient's care, and to involve discussion about what had happened during the terminal phase, their present situation, loneliness and the future (Millberg et al 2008). A recent population-based survey in Australia also led to recommendations to enable continuity of relationship as well as continuity of service. Bereavement follow-ups were most helpful when they were tailored to carer's own needs rather than generic, and the assessment of these needs should begin before the death (Aoun et al 2017).

When support does come to an end, carers in our focus groups appreciated careful management and reassurance.

> I had counselling for 18 months. It was pre-bereavement counselling, it started while we were [at the hospice]…I suddenly sort of went 'I've noticed you've separated our visits to every three weeks' and then it was every four weeks. Then he gave me lots of warning that we're going to finish. I just know that, yes, I can't keep going on with this.

Bereaved former carer

> The thing is I am now left with a contact and I think that is brilliant. It doesn't matter how long it is, if I need to I can have somebody to talk to again.

Bereaved former carer

Carers' organisations

The majority of carers' organisations we surveyed can continue working with former carers after the death, although this may be for a time limited period (from 13 weeks to 'indefinitely', with a year being the most frequently mentioned length). Sometimes this was only available to carers who had registered for support prior to the death.

> We realise carers are at their most vulnerable and needy after losing their focus. In some cases they have lots of time freed up by the person dying. It's important that any social networks they've built up through us remain in place.
>
> Carers support worker

For some carers this continuity is welcome but others find that the type of support they had been receiving no longer met their needs.

> I did carry on going to a group for a little while, but they would moan about their person. but they've got a hope that I never have any more and I found that quite painful.
>
> Bereaved former carer

This may be to do with the nature of the group support on offer. If the focus of the group is mutual support around the caring role, then former carers may not feel it is for them, unless they are able to offer suggestions and support from their own experiences. If the group has a more social or activity-based content, such as exercise classes or mindfulness, then the difference in circumstances between current and former carers may not matter so much.

Other forms of continued support included counselling, 1:1 support with a carers' support worker or therapeutic listener, telephone befriending, phone support or advice. One service had a carer-to-carer mentor scheme which could continue into bereavement, and another could occasionally extend respite sessions so that the bereaved carer didn't immediately lose the support of the carers who had been coming into their home.

Some carers' organisations organised post-bereavement support in a different way or signposted or referred on to other support. This included

- former carers' groups (which included those carers whose relative had moved into a residential home)
- specialist bereavement counselling (in-house)
- 1:1 support
- drop-in bereavement groups
- structured groups to support former carers to think about their future.
- support around finding work
- support around claiming benefits including bereavement benefits
- sending a letter of condolence with useful information
- providing information and support to organise the funeral
- self-help courses/training in managing grief and loss.

Many organisations also talked about support for carers provided by other organisations, including bereavement groups, bereavement counselling, former carers' groups and specialist support. Specific organisations mentioned included Cruse Bereavement Care, Age UK and local hospices. Some carers organisations signposted to these services and activities, while others made an active referral.

Case studies

- Carers Leeds has a dedicated bereavement support worker
- St Nicholas Hospice builds community capacity and supports carers before and after the death.

We get tailored support for our grief, if we need it

Many carers will find that their inner resources, family and friends help them adjust to changed life after the death, but others will need more support to help them build up their coping strategies, reflect on the meaning of their loss and start to rebuild their lives. This is particularly the case for those carers who are socially isolated before or as a result of caring.

Not everyone who wants it gets to access this additional support. Around 20% of people who register a death report that would have liked to talk to someone from health, social care or a bereavement service about their feelings about the illness and death, but they did not get the chance (Office of National Statistics, 2016. There are a number of barriers to accessing this type of support, including availability and accessibility, appropriateness, awareness of services, and willingness to seek help.

Availability and accessibility of services

A major problem is simply the availability of services.

> Our dog died at the vets and I was given a cup of tea and the vet said did I want to chat? This is a few years ago. Our daughter died, and we didn't get anything at all, you know.
>
> Bereaved former carer

Even where services do exist, they may be organised in a way that is not accessible to carers, and need to be sensitive to the barriers carers may face.

> [Services need to be] culturally sensitive to people who have not found what they need in their own cultural community but who would be ashamed to demonstrate that publicly.
>
> Bereaved support worker

Awareness of services

Many former carers report it taking a long time for them to hear about the support that is available to them. They recommend better information this is publically available, as well as professionals having a better understanding of the support that is out there. They also appreciated clear messages with an offer of support from the health and social care organisations that had been supporting them before the death.

> If I hadn't had that letter from [the hospice] with that little bit at the bottom saying 'Would you like some help' I wouldn't have had a clue where to go. In fact I delayed for six months before I needed some help…I kept the letter just in case.
>
> Bereaved former carer

Some carers may need extra support to help them access services. There is some indication that people with higher bereavement-related distress are less likely to use support services (Lichtental et al 2011) possibly because of their beliefs and feelings about grief support, including anxiety about stigma (Breen et al 2018b).

Appropriateness of services

As outlined in the three-component model of support (see page 25), different types of support will be appropriate for particular carers. Some may want opportunities to meet other bereaved people, to be among those who 'get it' and to seek and provide mutual reassurance and guidance; others will want 1:1 support either in person, over the telephone or the internet.

> There are websites and forums and all these things. It's not practical for everyone to travel.
>
> Bereaved former carer

Some may benefit more from support that focuses on emotions; others on support that focuses on behavioural and cognitive difficulties following the death (Schut et al 1997). Carers will need support that is sensitive to their particular experiences, for example following a short but intense period of caring which gave them little time to prepare, or following a death from drug or alcohol use where they experienced stigma before the death.

> I know I could go to the mainstream bereavement services but it's a specialist service that I would want, you know, a specialist service.
>
> Bereaved former carers

> The one thing I felt I've not had help with is you've had a life with your partner, or your mother, your father for numerous years, that was one life. Now how do you start a new life for yourself?...I'm getting there, but there's not - there's the grieving help, which is fine. Then actually you've got to live your life and you need help doing that.
>
> Bereaved former carer

Meeting these varied needs requires careful assessment which takes account of people's resilience and strengths alongside their needs and risks, and helps them to understand and choose the support that is right for them at that time

> We have the time to talk to them for 45 minutes and work out that actually, they don't need counselling and that we can give them support that's appropriate to them, but the GP hasn't had that time.
>
> Bereavement support worker

> That was my initial contact. I was amazed, he gave me at least 20 minutes going through everything and I felt I could keep on talking. That made a huge difference, his approach to me around talking about it.
>
> Bereaved former carer

As well as appropriate content and structure, support also needs to be at an appropriate time, matched to its purpose. For example, conversations about how to manage the funeral will be relevant in the early days, while support that is focused on building a new life may be more useful further down the line.

> About six or seven weeks [after the death, someone] contacted me 'did I need some counselling?'. Yes I did. This is going to sound bad, but I ended that counselling session because I wasn't getting anything from it. Then the first of everything occurred and I went into the darkest place you can imagine. On our first anniversary of our marriage, I ended up talking to my GP, who then put me under the mental health team.
>
> Bereaved former carer

Resources

- The National Bereavement Alliance has a guide to commissioning bereavement support services.
- Cruse and the Bereavement Services Association produced the Bereavement Care Service Standards as a framework for good practice.

Case studies:

- Rotherham Social Prescribing Service links bereaved former carers to local support, including a peer support group.
- Waltham Forest Social Prescribing Service connects supports and social opportunities to those that need them.

Case studies

The case studies that follow have been gathered as examples of good practice in supporting carers before and after the death of the person they are caring from. Contact details are given for each.

Bereavement Supporter Project

Cruse Bereavement Care

Context and rationale

The Bereavement Supporter Project is a partnership between Cruse Bereavement Care and The ExtraCare Charitable Trust. This project addresses a gap in bereavement care to older people by taking a preventative approach to ensuring that older bereaved people, including those with early stage dementia, have the support they need at the time they need it in order to stay active, engaged and involved with their communities.

This project builds on the success of a six year Big Lottery Funded project, Beyond Words, in Northern Ireland which commenced in 2012. This partnership project between Cruse Bereavement Care and the Stroke Association in Northern Ireland delivered a project to improve bereavement support for older people focusing on stroke survivors, their carers and residents in sheltered housing.

The Bereavement Supporter project aims to expand this project which has evidenced a reduction in the levels of loneliness and isolation through development of neighbourhood approaches, improved outcomes for those with social care needs alongside interventions which promote the longer term mental health and wellbeing of older people.

Cruse Bereavement Care is the leading national charity for bereaved people in England, Wales and Northern Ireland. The organisation offers support, advice and information to children, young people and adults when someone dies and strives to enhance society’s care of bereaved people. Cruse offers face-to-face, group, telephone, email and website support to nearly half a million bereaved children, young people and adults each year. Five thousand skilled and trained volunteers provide support through a Freephone national helpline and a network of 76 locally based areas.

ExtraCare operates 19 retirement villages and housing schemes and supports 4,400 older people including those living with dementia.

The project aims to improve bereavement support for older people, including those living with dementia, in ExtraCare retirement villages and housing schemes, by:

- Raising awareness of how bereavement affects older people’s mental and physical health
- Improving access to support for bereaved older people in sheltered and retirement accommodation
- Encouraging self-help and peer support in order to reduce loneliness and social isolation
- Contributing to safeguarding and promotion of long term mental and physical health.

Background

The project is funded by the Big Lottery Fund, began in January 2017 and will run for 5 years. Advised by a Project Reference Group, made up of residents and staff, the project was initiated in Pannel Croft village, adapted in two other sites and is being expanded into all other ExtraCare villages and schemes over the five years. At each village, the project tailors the elements below to specific local needs and the ethos of the particular community. For example, the third project village had opened recently and there were still residents moving in. In some cases, this will be as a result of bereavement or other losses which may have triggered their move, so the level of recent bereavement in that community is likely to be relatively high, influencing how the project is developed and delivered.

The project is taking a multi-tier approach to improving support for bereaved residents:

- Tier 1 – getting the community talking about bereavement and being more aware of its impact
- Tier 2 – residents offering each other informal support through existing relationships
- Tier 3 – peer support – residents accessing a resident Bereavement Supporter volunteer
- Tier 4 - accessing Cruse and other specialist support.

Key elements to the project

Bereavement information and awareness sessions for ExtraCare residents and staff.

These informal, one-hour sessions provide information about the project and help raise awareness of the impact of bereavement. The sessions are delivered within the village environment and include information about grief and what it is like, with activities to help bust myths about grief and how it 'should' be. For example, participants are given a selection of cards featuring reactions such as physical symptoms, emotions such as jealousy, anger etc, and asked to discuss whether they think this is a common feature of grief. The sessions make residents and staff aware of support in their community and beyond, and talk through ways they can support themselves or someone else (e.g. family, friend or neighbour) following a bereavement.

Bereavement Supporters

Building on the strong ethos of volunteering in ExtraCare, residents can apply to become a Bereavement Supporter in their community. They complete an application form and undergo a DBS check. Once it has been established that they are potentially suitable and not recently bereaved themselves, they are given a day's Cruse Loss and Bereavement awareness training. After this, they have a discussion with staff to agree whether the role is right for them. This includes a discussion of the boundaries of the role to make sure that volunteers feel confident in what is being asked of them

Once volunteering, they provide listening support, information and signposting to bereaved former carers and residents. Residents can access support in three ways:

- Responding via a poster displayed in the village, with photos and names of the Bereavement Supporters
- Through ExtraCare staff who can match them with a Supporter
- By filling out a form and leaving it at a collection point in the village.

Supporters don't have to commit to a certain amount of time. They complete a simple form to record their activity, tallying up the support they have provided that week. They have a regular face-to-face catch up with the project leads from Cruse and ExtraCare. They also have access to a member of ExtraCare staff who supervises all the volunteers. Supporters provide listening support, reducing social isolation.

Loss and Bereavement awareness training for ExtraCare staff members.

To enhance the support they offer bereaved former carers and other residents, staff are also accessing Cruse training to understand how to communicate compassionately with bereaved people and increase understanding of bereavement models and theories and factors affecting the grieving process.

Cruse Bereavement Volunteers

The project also recruits, trains and deploys new Cruse Bereavement Volunteers in order to provide specialist longer term support to residents who are assessed as needing it. Discussions are happening about how the support fits with specialist input from the local Cruse branch and other providers. An outreach post has been established in a village, benefiting both ExtraCare residents and the local community.

The project complements existing provision, including support groups for carers run by ExtraCare. Pre-bereavement support is acknowledged to be an important component of support for this group, particularly those who are supporting someone living with dementia.

Evaluation methods and plans

Bereavement Supporters keep a record of any contact they have made with former carers and other residents who have been bereaved. On occasion they have also provided listening support to relatives of residents who have died, e.g. when they have come to empty the apartment.

Project activities are being fully evaluated against the intended outcomes across the project life course. Initial feedback from residents, Bereavement Supporters and ExtraCare staff is encouraging. Residents who have received support can complete a feedback form to evidence how the impact the support has made. Cruse is also collaborating with Aston University who will be evaluating the project and this model of working.

As well as providing immediate support and reducing isolation, Bereavement Supporters have been able to signpost bereaved former carers and other residents to appropriate sources of further support. For example, a Bereavement Supporter recognised that a bereaved resident’s symptoms went beyond an expected grief reaction, and encouraged them to book a GP appointment which revealed an undiagnosed condition. Volunteers have said they have found the role rewarding.

> Living in a village with over 55 year olds means that bereavement, and how people cope with it, can’t be ignored. You always sympathise with the person and give your condolences, but you don’t always know how the person is feeling. I don’t want to tread on toes and say the wrong thing so when the Cruse project started and they were recruiting Bereavement Supporter volunteers in the village I applied.
>
> The training was very good. It helped with knowing the right things to say and it helped learning to support the person and not take over. The volunteers have also found that bereavement isn’t just about the death, it’s the knock-on effect that brings up wider issues like finance, relationships.
>
> The training helps with this as it provides a network of signposting so the volunteer can point the bereaved person in the right direction.
>
> Bereavement is part of life. It’s not going away. Death is still a taboo subject but is something that has to be talked about. Death knows no age so you need to talk about it now.
>
> Millie

> Over the years I’ve had close friends and well-loved family members die. These experiences have motivated me to give support in a manner that can ease distress. Panel Croft is my home – a place that offers me quality care and shelter.
>
> Cruse training has given me what I regard as added value to enable me to deliver and become a more informed bereavement supporter in my village.
>
> George

Tailoring the project

Interestingly, the size and culture of the village seems to make a difference to how people access the service. In the pilot village where most people know each other, the majority of bereaved people access support through seeing a poster and approaching a Bereavement Supporter direct. In villages where fewer people know one another, being able to complete a self-referral form or speak to staff first is a key way of residents accessing support. Ongoing engagement with residents has been essential to ensure that the support delivered meets their needs.

Future development plans

In year one, the focus was on delivering Cruse loss and bereavement awareness one-day courses. Year two had a specific focus on developing training and resources on dementia and bereavement, for Cruse staff and volunteers and ExtraCare staff.

Whilst preparing this project we learnt that often a partner of a person living with dementia can experience pre-bereavement and ambiguous loss. Many people living with dementia experience changes to their cognition which affect their personality and preferences, this can be exceptionally difficult for a loved one to cope with and may leave them feeling that they have lost aspects of their partner and lead to a sense of loss. We have learned that many people bereaved by dementia are offered support following the death of their partner. In some cases we have found that people experienced a greater sense of loss at an earlier stage in the dementia journey. This has taught us the importance of pre-bereavement and ambiguous loss and that many people may require this nature of support long before they experience the actual bereavement. Workshops have been held with carers to coproduce 'Carers' stories' – a printed guide for carers who care for someone with dementia, written by carers. This focuses on their personal experiences of caring and losses along the carer journey. The guide will be a combination of the carers own words, and illustrations that are being produced by a Cruse Bereavement Volunteer. The finalised guide will be disseminated throughout 2019, and will be a useful resource to support carers/families experiencing pre-bereavement and ambiguous loss.

Additionally we aim to build on existing knowledge of how a person living with dementia experiences bereavement. A person living with dementia may go through a period of anticipatory loss as they come to terms with their diagnosis of dementia and how the progression of the disease may affect their thinking and behaviour, and change their plans.

We would also like to explore existing best practice and any new approaches to supporting a person living with dementia following a loss. As dementia impacts our thinking abilities such as our memories of a person, their death or the timeline of their death, a person living with dementia may be at a higher risk of experiencing a complicated grief process. People involved in the care and support of people living with dementia need support to know what works best and this project has the potential to develop useful examples for a range of professionals to draw upon.

Contact

Eve Wilson, Bereavement Supporter Project Manager
eve.wilson@cruse.org.uk

Leeds Bereavement Forum

Context and rationale

Established in 1996, Leeds Bereavement Forum (LBF) is a small charity which works to develop and improve bereavement services in the city. The Forum works collaboratively with partners across the city who include public, private and third sector organisations. The Forum is funded by Leeds Clinical Commissioning Group.

Run by three part-time staff, LBF has a trustee board bringing experience of the funeral industry, bereavement support, bereavement training, NHS acute care services and condition-specific support organisations.

LBF helps to create the conditions throughout Leeds for compassionate support for carers and bereaved people, through a range of activities.

Signposting

LBF signposts bereaved people and professionals to the most appropriate service either locally or nationally. People can contact the Forum directly – no referral is needed. The Forum maintains a themed Directory of Bereavement Services available online at www.lbforum.org.uk, and published in hard copy. Containing over 80 local and national support services, 1,000 copies are distributed each year across the city, including copies to every GP practice.

Training, events and information

Each year, LBF puts on training courses, events and conferences for people who work in the area of bereavement to support their professional development.

Recent events include a conference on Men and Grief in June 2018, looking at the ways in which men face bereavement and how professionals can support them better.

Free monthly Special Interest Groups talks have run over lunchtimes in the city centre. 2018 topics included loss across the life course for LGBTQ+ people and communities, tissue donation after death, and celebrity death and public grieving.

Bereavement Skills training is available to a wide range of groups and individuals working with bereaved people in general settings such as health and social care, housing support, adult care, volunteer bereavement workers, faith and community groups. The three-hour session, run quarterly, covers to some of the basic theories about the grieving process and coming to terms with loss. It provides an opportunity for attendees to explore these ideas and develop their skills and awareness in a small group.

The LBF also offers Bereavement Skills training to those who work with children and young people, and an intermediate bereavement skills training.

Each month, LBF sends out an email bulletin to members sharing news, initiatives and resources, helping those with an interest in bereavement care to keep in touch and up to date.

Improving provision

LBF campaigns and advocates for improved bereavement support in Leeds, working in partnership with organisations across the city. It has been instrumental in securing better support for bereaved children, through developing a pathway for those working in universal services, publishing a charter for bereaved children, and supporting Leeds City Council in commissioning a brand new bereavement service for children across the city.

The Leeds Citywide Bereavement Meetings are chaired quarterly by the LBF, with partners including St Gemma's Hospice, Sue Ryder Wheatfields Hospice, Carers Leeds and Cruse Bereavement Care.

Campaigning to help people talk and prepare

Helping people talk more openly about dying, death and bereavement and make plans for the end of life are key objectives for LBF.

Partnerships with Dying Matters nationally and locally have seen lots of activity, for example with Leeds City Museum. Last year LBF ran a small grants programme on behalf of the Dying Matter Leeds Partnership to encourage organisations and groups to run events during Dying Matters Week. Later this year they will support the delivery of a training course devised by Sue Ryder Wheatfields Hospice to help staff and volunteers, who work with people approaching end of life, improve their confidence and communication skills around death, dying and bereavement. It will give participants an opportunity to practise holding sensitive conversations in a safe, secure space.

Throughout the year, LBF run Death Cafes in partnership with Leeds Libraries, community centres and other places, to help people get more comfortable with these conversations.

Contact

Jane Robinson, Manager
jane.robinson@lbforum.org.uk

Parent Voices Count

Rainbow Trust Children's Charity

Context and rationale

Parent Voices Count is a group of parents who have experience of caring for their child with a life threatening or life limiting illness. The group works alongside the North West Children's Palliative Care Network (NWCPCN) and the Rainbow Trust Children's Charity, with the aim to improve children's services across the region.

The NWPCN is committed to involving parents and carers in meaningful engagement and the group encourage involvement and participation in the design, implementation and evaluation of children's services. Rainbow Trust Children's Charity recognises that parents are the experts on what it is like to have a child with a life threatening or terminal illness.

How the group works

The group has been meeting monthly at the North West offices of Rainbow Trust Children's Charity. It includes parents who are currently caring for their children, and those who have been bereaved. A spirit of supportiveness, empathy and openness means that parents can recognise the shared experiences they have, and work together.

> I was wondering what it was going to be like when I first came but I found we have got a really good camaraderie.

Group member (current carer)

> Even though other parents have been parents of children and teenagers, even though they might have had more on-hand to help in a nice way, at the end of the day when we've been talking, our stories are very, very similar with the nuts and bolts that having to fight for dignity and basic, basic things that we shouldn't have to fight for.

Group member (bereaved parent)

The group is not a support group: it exists to improve children and young people's services. But through working on activities and projects, inevitably the group has got to know one another and support each other through the challenges of caring, the pain of grief and the building of a new life.

> I also find it's given me the permission in a way to ask other people questions like, 'What's it like to lose your child, for them to die? How does it feel?' I know we'll all feel different but that was a question I've always wanted to ask people and that is something we all feel so - with regards to each other, we can ask those sorts of questions.

Group member (current carer)

The group has been facilitated by the Rainbow Trust Family Support Manager.

Principles for gathering parent's feedback

The group has used Together for Short Lives' Core Care Pathway to identify specific ways of gathering feedback from families at each stage of a child's journey. The Pathway includes diagnosis or recognition, ongoing care, and end of life including an end of life care plan and bereavement support. Examples of the principles which the group felt were important are:

- Ask straight out for an honest opinion.

- Give the family time to reflect.
- Offer a choice of professional to ask for feedback.
- Anonymous feedback.
- Questionnaires should be easy to respond to.
- “Please tell us about your experiences today” poster at clinic.
- Feedback opportunities should be offered straight away and shouldn’t be a ‘one off’.
- Professionals should do the ‘chasing’.
- No ‘one-size-fits-all’ approach.

An A-Z guide

Hints and tips from one parent to another were gathered by the group in consultation with other parents in their network. The group ran a series of open meetings and also distributed feedback cards to garner suggestions, which were then published into a small booklet to be given to parents when their child receives a diagnosis or their condition is recognised, or when the parents could do with some extra support.

Overcoming challenges

Individual members of the group face challenges in getting to meetings because of long travel times, but feel it is worth it for the benefits of coming together, sharing experiences and working together. The group increasingly work by email to overcome this.

It can be a struggle to encourage new parents to join the group, but the group is determined to be open to new members.

> Because our commonality is having a very sick child or [being] a bereaved parent, we don't know who's going to come through the door.

Advice for other groups wanting to set up something similar include

- ‘Keep at it’
- ‘Be open, transparent, honest, trustworthy’
- ‘Communicate with each other’
- Be clear that it isn’t a support group – although it will hopefully be supportive
- Focus on tasks.

Shared projects can help to sustain parent’s engagement, and when there is a particular issue to work on or influence this can be helpful.

> We started off with a to-do list as well and we work through that. Everything's done by consensus of what we want to do next, isn't it?

The group members are now part of Rainbow Trust’s national parent participation activities. This has meant getting their voices heard from working on literature that reaches parents when they first start working with us to informing the charity’s national policy work on topics such as carers’ support and paid statutory compassionate leave for bereaved parents.

Contact

Hannah Petheram, National Manager
hannah.petheram@rainbowtrust.org.uk

Support for carers at the end of life

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, Debbie Payne, 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. For example, all clinical staff take their coffee break at the same time, which brings informal opportunities for case management.

Identifying carers

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.

- When new patients register with the practice, they are asked if they are caring for anyone, or if they have a carer.
- The active Patients’ Group is often aware of carers in the community, and can make the practice staff aware.
- A carers’ noticeboard in reception raises awareness of the benefits of registering as a carer.
- Registration forms and carer information packs were publicised on reception during Carers Week.
- All new registrations include information about carers and carer registration.
- The Carers Coordinator has a physical presence in the surgery on monthly clinic dates which encourages some carers to come forward. The surgery’s Carers’ Champion actively invites new carers for 60 minute appointments at the Carers’ Clinic.
- Doctors have personal lists: supporting patients over the years mean they are aware when someone takes on caring responsibilities.
- When reception staff scan information into a patient’s record, such as a cancer diagnosis, they are alerted to a household where caring is likely to increase.
- Health visitors let the practice know about other siblings when a child is seriously ill.
- The practice makes particular efforts to identify young carers.

Helping people to recognise they are a carer can be challenging and some can even be a little offended by the term, saying they are just doing what a husband/daughter/neighbour should do. Talking about ‘the care you give’ or ‘your caring role’ rather than ‘being a carer’ can help.

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.

Making contact

Once a carer has been identified, Debbie Payne, the Carers Champion and 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 complete two registration forms: one to go to the Princess Royal Trust for Carers to register themselves formally and be eligible for a Carers Assessment and support, and one to register as a carer with the practice. This is scanned and added to both their notes and the patient's notes.

Supporting carers, including at end of life

- Carers Clinic. This monthly surgery has hour long appointments for carers to book and meet with a Carers' Support Worker from the Princess Royal Trust for Carers. This can be used for emotional or practical support or a simple chat. Appointments are popular and tend to be booked up several months ahead.
- When GPs go on leave they leave a list of the patients they are particularly concerned about, so that their colleagues are aware of the situation.
- Poorly patients list – the board is visible to all reception staff (not to the public), and patients on this list (many of whom are at the end of life) and their carers get priority when they contact the surgery.
- When someone is known to be seriously ill or a carer is thought to be in need of particular help, the practice makes proactive contact with the carer to offer support.
- The practice has a new paramedic service team who carry out many home visits, but doctors make visits themselves when the patient is thought to be at the end of life. They check on the carer's needs and wellbeing at the same time.
- The wider community health team are a crucial asset in supporting carers, particularly the district nurses and named health visitors.
- The surgery is actively supported by a locality based Integrated Care Team (ICT) which consists of a multi-disciplinary team of health and social care professionals to whom the GPs or other practice staff can refer patients. This team can co-ordinate many aspects of patient's care and provide valuable assistance for the carers.
- Young carers can be put in touch with local young carers groups for support and respite.
- A retired patient volunteers for the practice by driving patients and carers to appointments, helping with brief respite care and other 'good neighbour' tasks.
- The practice has good and growing links with the local hospice, including sharing volunteering opportunities with staff and patients, such as promoting the hospice's home visiting scheme and actively supporting their fund raising efforts.

When a patient dies

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, but this often arrives rather later.

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. Christina Firmin, Practice Business Manager holds the register of patients who have died, and Debbie and colleagues then do any necessary paperwork such as cancelling hospital appointments.

Christina sends a condolence card to the patient's next of kin and/or registered carer. The practice's electronic patient record (EMIS) has a field for 'known as' if someone goes by a different name from their first name. This means Christina can be confident she has used right name for the patient when writing to their family.

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.

Supporting the Nepalese community

The practice has a significant Nepalese community, and sometimes patients travel to Nepal to die or their body is taken there after death. The practice sometimes learns about these deaths much later when a family member returns to the UK or when a relative travels here from Nepal. In these cases the practice will telephone the family, and a member of the reception team who is Nepali will write a special condolence card.

Contact

Christina Firmin, Practice Business Manager & Debbie Payne, Carers' Champion
christina.firmin@nhs.net debbie.payne@nhs.net

Bereavement Care and Pathway

University Hospitals Birmingham NHS Foundation Trust

What is offered

Lead nurse for bereavement

The Trust has a lead nurse for bereavement, and End of Life Care Champions, giving carers and bereavement visibility and priority across the trust.

Education and training

Throughout the trust, staff are provided with training on end of life care and bereavement. These topics are included in the induction training for junior doctors, consultants and nursing staff of all grades.

Visiting and caring

The trust has introduced a number of initiatives to make it easier and more comfortable for relatives.

- Comfort care packs are available for carers if they have come in with a relative who has been admitted as an emergency/ or have been called in to hospital if someone is nearing end of life. These include deodorant, toothpaste, pen, paper and snacks.
- Open visiting means that visitors can come and go when it is convenient for them, and can also spend long days with their relative if they wish, for example if they are caring for someone with dementia/ learning difficulties and who may be very dependent on them to explain care and be their advocate. This allows relatives and carers to be updated on care and involved in discharge planning.
- glideaway beds have been purchased so that these are available on every ward for carers who would like to stay overnight with their relative (for example at end of life).
- Car Parking – passes are available at a reduced rate for relatives or carers that are visiting daily (e.g. in oncology).

Care of the dying, and after death

Each ward has End of Life Care boxes with essential equipment at hand to enable staff to undertake last offices for the patients in their care.

Bespoke on line training has been devised for porters.

The mortuary team also provide training for staff about care of a person after death including the rapid release of people for cultural and religious reasons.

End of life and bereavement champions are being trained on wards and departments and receive regular updates to cascade to colleagues relating to the provision of gold standard end of life and bereavement care.

Medical Examiner

The trust is an early adopter of the new Medical Examiner role, which is going well at all four sites. Following the Learning from Deaths, all care at the end of life is scrutinised. The Medical Examiners speak to all relatives, and collate causes of death and other themes to provide audits of end of life care.

Time taken to discuss care provided and explain the cause of death has provided the opportunity for the families to ask questions, raise concerns and also express grateful thanks for the care provided. Although hard to quantify, this proactive approach has reduced the number of complaints regarding causes of death and the death certification. It has also stream lined the escalation of concerns, if any are raised, so that they can be dealt with appropriately.

Rapid release for funeral

On the basis of individual need, the Trust can also arrange for the rapid release of the body of the person who has died for burial. Most often arranged for Muslim or Orthodox Jewish families, this can happen only if a doctor who saw the patient in the last 14 days is available; the cause of death is known and natural and there is no need for a referral to the coroner.

Bereavement meetings and packs

When families come in to collect the death certificate, they are seen in a dedicated bereavement room and have an individual 1:1 appointment with the bereavement officer who talks through what will happen next with regards to registration and funeral arrangements. The relative is given a bereavement pack which includes a condolence card, their copy of the medical certificate of cause of death, useful telephone numbers (registrar's office, local funeral directors, HM Coroner etc), details of local and national bereavement organisations, and a copy of a bereavement questionnaire about the quality of the care their relative had at the end of life.

They are also given their relative's belongings in a discreet canvas bag. Any jewellery is returned in a special pochette.

Car parking is free of charge for relatives visiting the bereavement office.

Bereavement leaflets that may be helpful for relatives are also available for them to take away with them.

Referral for bereavement support

The trust has an SLA in place with the local Cruse Bereavement Care area. Relatives are asked if they, or someone else affected by the death, would like some extra support. If they take this up, the bereavement officer passes their name to Cruse who then follow up with a series of three telephone calls to find out how they are doing. If they are struggling, and would like further support, they can then access 1:1 support from Cruse. Cruse report back to the Trust quarterly on the take-up of and feedback on the service. This facility is being extended to all staff in the Trust, who can also be affected profoundly by their experiences of the death of patients in their care or when they suffer a personal bereavement themselves.

Child bereavement

The Trust also has a midwife-led pregnancy and baby bereavement service, which is a pilot site for the new National Bereavement Care Pathway for Pregnancy and Baby Loss led by SANDS and other charities.

Impact of the project

The Trust cares for the families / carers of approximately 100 deceased patients a week.

Families are appreciative of the conversations with the Medical Examiner about the care provided and of the explanation of the cause of death.

Responses to the bereavement questionnaires are reviewed quarterly. Overall the responses are overwhelmingly positive. Positive feedback is relayed to the relevant ward or team. The Head Nurse responds in person to the family if the feedback is negative.

Around 4-5 relatives take up the offer of referral to Cruse Bereavement Care each week.

The training provided helps to equip staff with the skills and insight to support people at their most vulnerable times – patients approaching end of life and acutely bereaved relatives.

The rapid release service and collaborative working with the Trust's multi-cultural communities provides reassurance to patients and relatives that their individual needs will be sensitively respected and supported at end of life and bereavement.

Contact

Dr Dawn Chaplin, Divisional Head of Nursing for Patient Experience and Bereavement
dawn.chaplin@heartofengland.nhs.uk

Bereavement Help Points

St Giles Hospice

St Giles Hospice is working to engage communities in thinking about dying, death and bereavement, and to develop community initiatives that help support people at times of crisis and loss. It provides light touch support to schemes already supporting patients and carers, and has set up an innovative project to provide peer support in bereavement that is easy to access.

Whittington and Fisherwick Good Neighbour scheme

This scheme offers practical, low level support with the things that can help people live independently: transport to hospital, picking up prescriptions, doing odd jobs. For people whose family live far away, or who are socially isolated, the scheme helps make sure they stay safe and well and have some friendly social contact. Volunteers can give as little or as much time as they like to their neighbours, helping strengthen social networks.

St Giles Hospice has supported the scheme with pragmatic, practical help including doing DBS checks for the volunteers, providing training on understanding bereavement, moving and handling, and dementia friends.

Bereavement Help Points

Several years ago, St Giles had an ongoing bereavement group, Monday Club, which provided transport to bring former carers in to the hospice once a week to meet together. The group was very much a service, rather than an enabler, and it was not clear how it was helping people in their bereavement.

But with pressure on the 1:1 bereavement service, knowledge that this level of support wasn't needed by all bereaved families, and a desire to meet the needs of bereaved people not already in contact with the hospice, St Giles needed to think creatively about how to support people to help one another.

Helen Chetwynd, counselling and bereavement lead, had the original idea for the Bereavement Help Points service. She said

> "The original idea behind the project was to reach as many people in the community as possible, to provide the place and the dedicated bereavement support volunteers for just a few hours a week, for people to meet, talk, grieve and take care of each other, so we didn't have to turn distressed and grieving people away."

Where and when

Since the first Help Point opened in Lichfield, the scheme has gradually expanded so that it is now offered in 10 different places and times during the week. This means that anyone getting in touch can be offered support somewhere across St Giles' catchment area within 48 hours. Working in partnership with Age UK, Cruse Bereavement Care, the Dove Service, Uttoxeter Cares and other agencies, the help points have around 850 visit each quarter.

The Help Points run in a range of venues at different times of day. For example, the Lichfield Help Point runs in the community room at the local Tesco superstore on a Wednesday afternoon. With tables, chairs, mugs and an urn, and crucially a window in the door so that new attendees can look into the room before venturing in, the room has everything needed to run the group. Being based in a supermarket, people can combine coming to the group with doing their shopping. Having something else to do alongside can make it more possible to come into the group. 'It's so public, it's anonymous' say Ian Leech, who has overseen the expansion and development of the scheme.

The Cannock group meets in the early evening so is easier to get to for those who are working. Following the success of a daytime group in Tamworth, a second group has recently opened there in the evening.

Coming to the group

People come to the help points from a range of sources. They are referred in by the hospice itself, and also by the local Cruse Bereavement Care and the Dove Service, especially if they are wanting to offer something to those on their waiting list. GPs also make some referrals, having been leafleted. Increasingly, people are self-referring through word of mouth. Although there's no need to say they will be coming in advance, a phone number is available on the website if people would like to hear more about the Help Points before deciding if it's for them.

When a new person comes for the first time, one of the volunteers welcomes them, makes them a drink and then sits with them before gently introducing them to other members of the group. Members tend to gravitate towards those with similar interests.

The groups have a psycho-educational as well as a social aspect: at each session, there is information on coping with both the practical and emotional aspects of losing a relative or friend, as well as a chance to chat over a cup of tea.

People are welcome to come to the groups however long ago they were bereaved, and whatever the circumstances of the death. Often, once people have been along to one Help Point and understand more about what it's like, they are often willing to go along to a different group.

There is no pressure to 'move on' from attending the help point – people can keep coming for as long as they find it helpful. Ian's response if they started to reach the capacity of the room would be 'to find a bigger room'.

For some attendees, the challenge is coming in to the group each week. For others, it is leaving at the end of the session and going back into the wider world. Regular attendance can help attendees feel more confident about managing beginnings and endings.

Staffing the help points

Overall the scheme involves around 50 volunteers who have had training and get support from the Community Engagement team. At each session, there is always a member of staff or a volunteer who has been on St Giles' Working with Loss training.

Occasionally, the group needs help in managing further change and dynamics, for example if friendships or romantic relationships develop between members. Some group members feel able to celebrate others building a new life, while for others it can be a challenge and remind them of what they have lost. Staff and trained volunteers can help the group come through these difficult times.

The impact on carers

Between April 2017 and January 2018, the help points had 2,933 visits. Men and women tend to come in equal numbers to the groups, which is unusual for bereavement groups. On average, the scheme costs £1.63 per visit to run (it is free to attendees).

A short evaluation form is given out which asks attendees what they were expecting, how they found the group to be, and any suggestions. Comments include about having initial reservations but finding the group very helpful, and the comfort of being with others in the same situation, realising 'I'm not on my own'.

> I come here because it's safe. I can talk about anything and people understand.

Bereavement Help Point visitor

The help points have helped local bereavement services to offer alternative support to those on their waiting lists, some of whom realise that what they need is to get together with others, rather than the 1:1 support for which they are waiting. This means that services are freer to offer therapeutic support to those that need it most.

> We see it as a safety net for the community. Sometimes it just takes the opportunity to speak to someone who can empathise and understand.

Nikki Archer, Supportive Care Director

Visiting a help point, there was a palpable sense of growth in the group. Attendees shared recent examples of the first time they had done something since their bereavement, which in some cases was several years prior. There was a welcoming and inclusive atmosphere, with a natural flow of conversation towards and away from the direct subject of loss and bereavement. People were able - but under no pressure - to talk about their experiences.

Following the death of his wife, Ken attended the Lichfield Help Point.

> It's a brilliant place to spend time as everyone understands where I am coming from and knows what I've been through. I can be honest, share how I feel and cry if I want to and at the same time I can enjoy a laugh with the group if that's how I feel too. The group has been a lifesaver for me over the last year and I'm so grateful I found it.

The Help Point is also attended by Vera. Following the death of her husband of 25 years, St Giles Supportive Care team suggested she might like to go along.

> It was really hard at first but the difficult part wasn't walking into the room, it was leaving at the end, because I felt so safe and supported at the help point. When I left I had to go back into the big world and back into this big bubble of grief. I honestly don't know what I would have done without the group and I can't praise them enough, they are just so kind and caring.

Nearly three years on and Vera is now an active part of the group, organising get-togethers and meals out and continuing to benefit from the support the help point volunteers and members provide.

> We joke the group is like a magnet because we are all drawn together and we can sit and laugh or cry together, we could be the happiest sad people in the world. It's been a brilliant support for me and now when a new person comes in, I offer them a cup of tea and a warm welcome.

Contact

Ian Leech, Community Engagement Officer
Ian.leech@stgileshospice.com

End of life carers project

Carers Network

Context and rationale for the project

The project was initiated by a Former Carers Network CEO who, in her work as a death doula, saw the need for carers to be better prepared for the end of the life of the person they were caring for. The aims of the project are to make the carers' experience more positive and fulfilling; and make it more likely for the cared-for person to achieve their wishes such as their preferred place of care.

Funding was sought from City Bridge Trust for the first three years of the project, which operated across the City of Westminster and the London Borough of Hammersmith & Fulham. Now in its fourth year, the project, which has expended into the Royal borough of Kensington & Chelsea and the City of London, is now funded by a range of sources.

Once he was in post, Project Manager Francis Ngale refined the groups of carers the project would target, recognising the need to put support in place as early as possible, before someone was actively dying. The targeted groups are carers of

- people with a terminal diagnosis
- people aged 80 or over, who have general frailty and co-existing conditions **-** Death usually occurs in old age: in 2008, 62.6% of all women who died were over 80 years and 43.2% of all men. In 2008, over half of all deaths were in people aged 81 years and over
- people who are in a residential or nursing home - Almost a quarter of all deaths are now in a residential or nursing home. People are typically already frail by the time they move into registered 24-hour care and on average die within 18 months of admission.

What the project offers

The project aims to facilitate a conversation and activity around advance planning. This could include setting up Lasting Powers of Attorney, settling financial matters, writing wills, thinking about organ donation, setting out advance wishes.

Tailored 1:1 support

Many referrals come from Chelsea and Westminster Hospital (Francis had excellent prior links through his work with the hospital discharge team). Others come from GPs, social services, the wider Carers Network team, and self-referrals.

Once a referral comes in, Francis does a home visit, and uses an assessment tool he has developed to open up conversations. This is a useful entry point, helping him to find out what matters to the carer.

This usually provokes two sets of actions: one around the things the carer has identified as being important to them, and one around the things that Francis picks up during the conversation, for example making carers of people with dementia aware that they can apply for a reduction in their Council Tax. His rule of thumb is 'to know the things that might be useful to them, but to work with what matters to them'. The priorities have to be the carer's, not his.

Once he and the carer have agreed next steps, he continues to check in with them and to give them a chance to return to talk about issues that might have felt too difficult to begin with. Sometimes, carers engage with him because they want help with one specific aspect of planning, but later want to take more action. There is no set number of sessions: he continues to work with a carer while they still need him: the longest time he has been supporting a carer is 2 ½ years. Ideally he wants to start working with them as early as possible.

Because he works face to face with carers, he can see if people are finding it upsetting to talk about some aspects of end-of-life planning, and tailor his approach accordingly. Sometimes it is the cared-for person that is particularly enthusiastic about the project, encouraging their carer to take up the help, anticipating that it will be needed when they die.

Part of the support is being a trusted contact who carers can rely on to help them navigate the system. Carers will sometimes contact him and say they have been visited by a professional but weren't sure who they were: Francis can help them find out and feel more in control of coordinating the support available.

Workshops and training

The project also offers workshops and training on specific aspects of future planning. This has included two workshops on funeral poverty, delivered by Quaker Social Action's Down to Earth project which helps people arrange affordable, meaningful funerals.

Support after the cared-for person has died

The support that Francis developed for his end-of-life carers once they have been bereaved has influenced how the whole organisation supports former carers. This includes a system for recording when Carers Network are told that the cared-for person has died. The carer's support worker is informed, and they telephone the carer within five working days to find out how the carer is doing, and to make a note of the date of the death and of the funeral. This is followed up by a letter of condolence explaining the support they can continue to access from Carers Network.

They carry on working with bereaved carers for at least a year but find that most don't need it for that long. If the support worker is aware of specific bereavement support needs beyond contact, checking and accessing existing programmes, they signpost the carers on to local support. Carers Network tried to run a bereaved carers' group themselves but it was decided to stop the support group because of a lack of sufficient interest.

Moving on from caring

Carers Network also runs a Former Carers project which is dedicated to supporting those whose caring role has come to an end and who are looking to move into active life beyond caring. It is open to all former carers, regardless of the reason behind the end of their caring role. It offers 1:1 casework to former carers who are looking to get into employment, volunteering or other opportunities.

If the bereaved carer already has a caseworker, he or she will continue to receive support, including bereavement support from their caseworker during the initial phase. The caseworker will then be able to explore with the bereaved carer when it may be appropriate to link them into the Former Carers project. Some are ready to move along quickly: others take longer to decide how they want to organise and live their lives.

The impact on carers

In that first three years, the project worked 1:1 with 289 carers. Some of these would have refused Carers Assessments and so had casework focused on specific issues. Of these numbers, 62% have a disability. 63% are aged 75 or older. Of these, 69% are female and 31% male. Including those who came to workshops as well, the project supported 374 carers as primary beneficiaries during that time.

98 attendees took part 13 End of Life workshops covering topics including will writing, Advance Care Planning & funeral costs, talking about death and planning the last years of life, benefits for carers of older people and 5 Barclays-run workshops to help older carers build their confidence and make the most of their smart phones, tablets and iPad. 56% of the attendees were carers aged 65 or over.

Through their End of Life Stall at local carers community events, the End of Life Carers Project has tried to broaden the reach of the project and highlight the benefit and importance of a community where people are having conversation about death, dying and bereavement.

> Talking about death is not taboo. From my encounters with the carers I work and the members of the community I have discussions with during our community events, talking about death and dying is about what to say, how to say it, who to discuss it with and where to find help.

Francis, Project Manager

The project seems to be reaching even those carers who choose not to access any other support, such as respite or a sitting service. Francis acknowledges that for people who have not been sociable in their earlier lives, these types of support can be difficult to accept. The practical suggestions he is making are more palatable to some carers. However, through supporting these carers, he can often arrange more practical support for them including from other agencies. He is able to help people acknowledge that they are struggling.

References

National End of Life Intelligence Network (2010), Deaths in Older Adults in England, Page 9, See www.endoflifecare-intelligence.org.uk for copy of report

The National Council for Palliative Care (2014), Identifying end of life patients http://www.dyingmatters.org/gp_page/identifying-end-life-patients

Contact

Francis Ngale, Carers Project Manager – End of Life, City Carers and Former Carers
francis@carers-network.org.uk

Cambridgeshire and Peterborough End of Life Care data sharing and dashboard

Cambridgeshire and Peterborough CCG

Background

The Cambridgeshire and Peterborough End of Life Care data sharing and dashboard project was developed to support GP practices, Community Nursing teams and Palliative Care teams to record key information and share data across the healthcare system in order to improve the care of patients at the end of life and their carers.

Started in 2012, it is the Electronic Palliative Care Coordination System (EPaCCS) for Cambridgeshire and Peterborough CCG (C&P CCG) area. The Health Innovation and Education Cluster at Cambridge University Health Partners initially funded the project with Ian Merrick as the original Project Manager and Dr Stephen Barclay as Clinical Lead. It is currently one of the Vanguard work streams within the C&P CCG and is led by Dr Stephen Barclay, a local GP and University Senior Lecturer in Palliative Care.

There are four components:

- A) Structured template for entry of clinical information that is then shared with patient consent
- B) Summary view of the data entered that can be viewed by 111, out-of-hours, ambulance services and emergency admissions units
- C) Clinical dashboard that presents patient data to individual GP practice teams to facilitate clinical review
- D) Business Intelligence dashboard of aggregated data at practice level that permits benchmarking of practice performance on key process measures across the CCG

The Dashboard is currently used by over 85% of the 93 practices in the CCG, and was included in the CCG Quality and Engagement Framework for 2018/19, supporting its mainstream use.

The Clinical Dashboard

This displays a list of a practice’s patients who are on their end of life care register. It shows key pieces of information such as each patient’s preferences for care, their CPR status, Gold Standards Framework (GSF) status, and the prescription of ‘just in case’ medications. It incorporates urgent care data, so that practices can see quickly who are currently inpatients or have had recent unscheduled care attendances. It is increasingly widely used to support practices’ GSF or palliative care review meetings.

Recording and promoting support for carers

Data is entered through templates (longer version for GPs, shorter version for district nurses). As well as fields about the patient’s clinical status, preferences and care plans, it includes several fields relevant to carers, including

- the carer's contact details
- documentation of discussions about the care plan with the carer
- carer awareness of the patient's prognosis
- whether the patient has appointed someone with a personal welfare LPA
- whether the team has considered bereavement support after the patient's death.

The template also includes web-links and has embedded documents to print and give to patients and their carers, including:

- a weblink to information about setting up a Lasting Power of Attorney
- a weblink to information about setting up an Advance Decision to Refuse Treatment (living will)
- a leaflet about what to expect during the final days of life
- a leaflet about local and national bereavement support. This includes contact details for the local hospital and hospice bereavement care services, bereavement support offered by healthcare services and the voluntary sector, and local and national bereavement support services for children, those bereaved by suicide, etc.

Copies of the leaflet have been widely distributed, to funeral directors, Registrars of Deaths, GP practices and other clinical settings across the CCG area. Bereaved carers have reported this to be a very helpful resource, either shortly after the death or some time later.

Training videos have been produced for GPs and District Nurses concerning the templates and summary view and for GP practices concerning the Clinical and Business Intelligence Dashboards and are available online. This web link also gives details of a University of Cambridge research study concerning the project and data sharing more broadly.

The team would be very happy to share the tools developed with interested colleagues.

Contact

Clinically-related issues: Dr Stephen Barclay sigb2@medschl.cam.ac.uk
IT and technical questions: Bill Wilson bill.wilson@nhs.net

Support for bereaved carers

Carers Leeds

Context and rationale

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 the core funding provided to Carers Leeds by Leeds City Council.

What is offered

The CCG grant allowed Carers Leeds to appoint staff with counselling skills to provide tailored 1:1 support to bereaved carers. Sue Sutton was appointed in 2014: she now works in this role 28 hours per week with her colleague on the project working 14 hours per week.

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.

1:1 support

The offer is of 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). Not everyone needs the full six sessions: it can be enough just to make sense of the story by telling it.

Sue and her colleague tend to visit former carers at home, particularly for the early sessions. This can be helpful in quickly building a good relationship, and also getting a picture of how the carer is managing at home after the bereavement. For some carers who are very isolated and lacking in confidence, coming into the city to meet Sue would be too outfacing.

Emotional support

The tailored support Sue and her colleague offer includes support with the emotional aspects of loss. When helping carers to understand more about grief, she tends to talk about 'common' reactions rather than 'normal' reactions. She doesn't want to minimise the enormity of the feelings and changes that former carers are going through. She explains to them 'You have a unique relationship with everyone in your life, so when you lose someone close to you, it's unique for you.'

Some of the carers she supports didn't have a good relationship with the person they cared for, and their overwhelming feeling may be of relief. Sue can support carers with feelings and emotions that feel confusing, painful or less possible to share.

Practical and social support

Emotional support is accompanied with practical support, such as help completing forms and explaining about probate. The project has a strong ethos of supporting carers to re-enter society and lessening their isolation. This can include Sue working with a carer to find some groups they would like to join, and then accompanying them the first couple of times until they feel confident to go along alone.

Sue says 'As a bereaved carer, their grief is different. They've lost the person, and at the same time lost their job, their purpose, often their home'. She highlights particular difficulties for those who were caring for elderly parents in the parent's council home, who may be having to adjust to living independently very quickly.

Group support

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

> Members really appreciate the dips and highs. They can be bobbing along for a long time and then something happens and the grief really hits them. It's helpful to have that peer support from people at different points in their grief, and to observing others in the group having down times and then coming back up. They can celebrate with you, and be with you when you're down.
>
> Sue Sutton

Sue would like to see professionals better able to have a conversation about grief, which is why she is so supportive of the Leeds Bereavement Forum training and education activities.

Impact on former carers

The work is evaluated using Core-10 in the first sessions and then again at the end of a piece of work. Clients enjoy being able to see their scores and how they change over time.

An evaluation form is also completed once the sessions have been completed. This gives the bereaved carer the opportunity to reflect on how they are feeling now and whether or not bereavement support has been helpful. Feedback is extremely positive, as can be seen from the examples below:

> The opportunity to talk about how I felt – the length of time available allowed for this. Non-judgemental.
>
> 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.

Contact

Sue Sutton, Bereaved Carer Support and Development Worker
susan.sutton@carersleeds.org.uk

Building a compassionate community: hospice neighbours, carers and bereavement services

St Nicholas Hospice

Context and rationale

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. Though this approach, the hospice hopes to raise awareness and information as well as mutual support.

As we have developed the way we deliver our services at St Nicholas Hospice Care, we have learnt to question the artificial boundaries between 'us and them' We have learnt to question the labels that can be so tempting to give people in order to make them 'fit' with an organisational structure of service delivery.

> Hospices need to take risks to liberate the skills of groups and individuals in order to better serve their communities. We believe that the future of hospice care must encompass a new model of mutuality.

Jacqueline Saunders and David Rushton in e-hospice
https://www.ehospice.com/uk/Home/tabid/1030/tabid/10697/ArticleId/9730/language/en-GB/Default.aspx

Hospice Neighbours

A service that epitomises St Nicholas' ethos of humanity, compassion and community empowerment is its flagship volunteering scheme: Hospice Neighbours.

When families are living with a terminal condition, the world doesn't stop, and all the household tasks still need doing. People living with dying can become even more distressed by seeing their garden overgrown or their dog not walked, and providing practical solutions to these simple problems can have a big impact. This unmet need to provide practical support to patients and families has been identified through discussions with local partners and individuals.

> Hospice Neighbours is a fantastic way of helping to connect communities and reverting back to neighbours helping neighbours, which we believe not only helps people when they need it most but makes the world a nicer place to live in.

St Nicholas Hospice website

Hospice Neighbours aims to empower communities to care for those affected by life shortening illness. 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.

The scheme provides patients and carers with a source of companionship, practical support and a link in to their local community where those links had diminished for whatever reason. At times they may very well continue to support bereaved people whose needs are more for companionship than anything else, especially where a relationship has built up.

The scheme was launched in 2010 in two pilot areas (Haverhill and Stanton) and then rolled out to each of the eight main population centres in catchment area, covering all communities in West Suffolk and South Norfolk. Around 150 volunteers each support an average of four patients and/or carers per year.

Volunteers' feedback is used to improve the service. The intention has always been for the service to become a sustainable, community led scheme with the hospice's support. The scheme is moving more into a community development mode, with the aim of mobilizing existing community resources on behalf of people and enabling the development of a 'compassionate community'. Hospice staff's input has gradually reduced as more management responsibility is handed to volunteer coordinators in each area. The service is very light on bureaucracy.

> In a recent evaluation of the project, one thing that stood out from the results was that the word 'friendship' was used by every respondent – a concept often avoided in the professional world. They are often the most consistent person in a process that involves many different professionals from a range of organisations.
>
> Jacqueline Saunders and David Rushton

> What I find refreshing is the hands-off approach, where we are trusted to visit our people, build a relationship and use our common sense and initiative to help in whatever way we think fit within the hospice guidelines. It's not just companionship or just having a chat. A few of my colleagues do where possible go out with the patient for a couple of hours, just to give them a change of scenery and some fresh air. You are there for the relatives and carers as well. They obviously need a break and a change of scenery and use the opportunity of our visits to go out for the afternoon, visit friends or just do something different from their normal routine.
>
> Steve Smith, Hospice Neighbour

Support for carers

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
- A weekly Mindful Movement group
- A 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.

Bereavement support

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.

Structured, closed groups

The Bereavement Support Group meets weekly for six weeks and is organised twice a year. Facilitated by the Family Support Team, it offers a safe setting in which to explore feelings, share information and simply be with others in similar situations. Sometimes participants continue to meet and support each other after the group has finished. The closed group idea is now being replaced by a stronger emphasis on peer support groups like the weekly café.

Nicky's Way is for children and young people who have been bereaved. It starts on a Saturday, followed by four after-school sessions and finishing with another whole Saturday. It takes six weeks overall. Activities include making things, asking an adult or doctor questions, throwing things at an anger wall, remembering the good times, having a treasure hunt.

Nicky's Way is open to any bereaved child in the local area, not just those in families already known to the hospice. Adults can come along with their children and meet in a separate group, where they can share information and feelings with other parents.

Open groups

Walking group: the Stepping Forward walking group meets once a month on a Thursday evening for an hour's walk. Open to all who are bereaved, the group includes trained bereavement volunteers. No appointment is necessary as this is an informal event, members just turn up and enjoy the company.

Activity groups: the hospice also runs occasional bereavement activity groups, such as cooking, DIY and arts and crafts, which consist of four sessions over three to four months.

Café-style groups: there are now two more cafe-style groups which are very popular, the most recent in a public space in a big arts and entertainment centre which also has a community support role. People access these services freely, without any appointment or fuss.

These can be effectively run mostly by trained volunteers but professional staff (eg. a psychologist for the most recent cafe) are needed to maintain the 'safe space', knowing when to get involved closely and when to get out of the way - of course, it's not just a case of providing space and refreshments! As any bereaved person can walk through the door, some people accessing these services may have complex grief issues, mental health concerns or be coping pretty well.

Information is available on the other services the hospice offers. Some group members use them as a means of accessing 1:1 help later on - others use them as a way of weaning off 1:1 and redeveloping a social life.

> When I first came along I think most of all I expected it to be uncomfortable and lots of people talking about the loved ones they have lost, but it wasn't like that at all. It is very inspirational listening to people talk about their experiences and having the chance to

> talk to people who are in similar situations to yourself is very useful. You find that you are able to teach each other certain things, help each other, and you are able to get to know each other.
>
> Group member Bob Brough

In bereavement cafes people who feel they want to move on but don't want to leave the group or naturally start to take a facilitator type role can become co-facilitators in any way they feel confident to do, e.g. meet and greet new people or have even have a more formalised role such as hospice neighbour or other volunteer positions in the hospice.

With the bereavement café they, like the bereavement volunteers, can also sit within the circle again if they feel they need the peer support rather than giving it. This makes a holistic and person-centred approach that enables people to negate what they need and when on their bereavement journey, whilst engaging with and enhancing their sense of agency, self-identity and resilience and promoting the notion that suffering that comes with bereavement can be tolerated and survived.

1:1 bereavement support

The 'traditional' or core bereavement services provided by the hospice are now open to any bereaved adult or child in our area, not just focussed exclusively on the hospice population. Other people tend to be referred through their GP or refer themselves. We find that in the wider community we encounter more bereaved people who have not had the benefit of the support offered by palliative care services. Their needs often encompass more complex issues involving sudden or traumatic death and may overlap with mental health issues including suicidality.

The adult service uses the Adult Attitude to Grief scale (AAG) as a means of enabling practitioners to assess the most appropriate level of need, and as a tool in the working relationship. 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. Meetings can either take place in the Hospice's private counselling rooms or the person's own home. Bereavement workers regularly review needs and work towards a mutually agreed ending.

In summary, peer support and community-based groups are now the most popular bereavement service the hospice offers. The volume of contacts over the last 6 months in peer support compares with contacts in one-to-one casework as follows:

- Peer support 568 contacts;
- One-to-one casework 206 contacts.

In peer support this only represents minimum of contacts encouraged by the hospice – there are more, as people organise further contact for themselves. Some of these are completely informal and others the hospice has learned about, eg. a holiday group, lunch club, quiz group and so on. This represents a significant shift in focus and takes place without hospice 'ownership'.

Contact

Bianca Neumann-May, Family Support Team Leader
Bianca.Neumann-May@stnh.org.uk

Rotherham Social Prescribing Service

Voluntary Action Rotherham and Mind Rotherham and Barnsley

Context and rationale

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.

Voluntary Action Rotherham, in partnership was commissioned in 2012 to provide a service with two main elements: a team of advisors providing a single gateway to voluntary and community sector support, and a grant funding programme through which support to meet service users' needs could be micro-commissioned.

Funded by the CCG (including through the Better Care Fund, a partnership between health and social care), initially the project covered 10 of the GP practices; it now covers all 31 practices.

In 2015, the service targeting patients with long term conditions was supplemented by a sister project for patients with mental health difficulties, commissioned by Rotherham CCG. Working in partnership with Doncaster and South Humber NHS Foundation Trust (RDaSH), the scheme diverts referrals to psychological therapies when social and practical support could make a significant difference to people's lives.

In total, the two services comprise nine advisors, one of whom is a full-time Team Leader.

What is offered

Social prescribing advisers

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. Eligible patients and their carers cannot self-refer to the service – they would need to approach their GP Practice first.

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 advisors provide feedback to GPs and other practice staff about the patients referred to Social Prescribing, as part of the Integrated Case Management teams.

Grant funding programme

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.

VAR uses this fund to micro-commission services to meet the needs that advisors are finding when they talk to clients. There is a particular focus on those activities which will help people re-enter society, including enabling services delivered by organisations including the British Red Cross, Royal Voluntary Service and Age UK. For those that need more intensive support, VAR has commissioned Rotherham and Barnsley MIND to provide six weeks of individual counselling.

All services and activities funded through the grant programme are time limited, with the intention of supporting people to move into sustainable activities and services. The diagram below shows this time-limited pathway to support.

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 of those referred to the service.

Bereavement workshops

Following discussion with VAR, Mind was commissioned to run three eight-week bereavement workshops. These are structured, closed groups with around eight participants. There are no specific criteria for the groups, so they often include participants with a range of different types of bereavement (eg cancer death, suicide), relationship to the person who died (spouse, parent, child) and length of time since the bereavement. Despite this diversity, the groups are able to find common ground and offer mutual support. Participants are not obliged to talk about the person who died and their own experiences, but many choose to do so and value the opportunity to practice telling their story and sharing memories in a supportive space.

The emphasis is on normalising grief, understanding bereavement, and beginning to think about the future. At the end of the series of workshops, participants are invited to write a plan of the things they would like to do, and this is posted to them around six months later.

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.

Peer support group

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 session begins with a structured check-in and ends with a check out. Participants have said

> 'I feel lighter'
>
> 'It was tough getting here but I'm glad I did'

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.

Evaluating support

Participants who are referred through Rotherham SPS have already completed assessment and evaluation measures. Those who join the group from other sources complete the depression PHQ-9 which measures symptoms of depression, before they join the group and after taking part.

Impact on service users

Between September 2013 and March 2016 the Rotherham Social Prescribing Service supported more than 3,000 local people with long-term health conditions and their carers, the majority of whom did not have access to opportunities to engage and become active in their local community.

Evaluations of the long-term conditions service, carried out by the Centre for Regional Economic and Social Research at Sheffield University, have shown its effectiveness in several areas important to carers and to the health service.

Use of health services

The evaluation looked at inpatient admissions and visits to A and E in the 12 months before and after taking part in the service

- Among those referred in 2012/13 and 2013/14, inpatient admissions fell by 11% and A and E use by 17%. Among those referred in 2014/15, the drops were 6 and 11% respectively as more elderly patients accessed the scheme.
- Those who made the most use of secondary health services (3+ visits) in the 12 months before being given a social prescription saw the biggest improvements afterwards: a 46% drop in inpatient stays and 42% fall in visits to A and E.
- Over the first four years of the service these reductions equate to estimated NHS costs avoided of £647,000: an initial return on investment of 35 pence for each pound (£1) invested. If these reductions were sustained for three years following engagement with Social Prescribing the cost of delivering the Service would be recouped.

Well-being

Between September 2012 and 2014

- 82 per cent of service users experienced positive change in at least one outcome area
- improvements were recorded for each measure

- patients who had the lowest well-being when they were referred to the service made the most progress.

In 2014/15, progress was strongest in the outcomes of work, volunteering and social groups; feeling positive; and money.

Between 2012 and 2015, the social value of these improvements in wellbeing experienced by service users in the first year following their prescription is estimated at around £2 million, a return on investment of £1.11 for each pound (£1) invested in the service.

Impact on the local voluntary and community sector (VCS)

Wider benefits to the Rotherham's VCS include

- an investment of £2.1 million since 2012 in frontline services through the grants programme
- development and promotion of volunteering and social action among service users
- new model of commissioning
- recognition of Rotherham's good practice in Asset and Place-based approaches

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Contact

Barry Knowles, Service Manager – Rotherham Social Prescribing Service, Voluntary Action Rotherham
barry.knowles@varotherham.org.uk

Rachel Siddall, CEO, Mind Rotherham & Barnsley
rachel@rbmind.co.uk

Social prescribing service

London Borough of Waltham Forest

Context and rationale

Waltham Forest's Social Prescribing pilot scheme was set up in 2016 to link residents struggling with issues such as loneliness, social isolation, unemployment and welfare debt issues. The service is part funded by the local authority Public Health, and part funded by the Waltham Forest Clinical Commissioning Group (Better Care Together Fund), and is based in the Council's Adult Social Care Wellbeing and Prevention Scheme.

The pilot scheme began working in 2016 as a telephone only signposting service, responding to 700 referrals between July 2016 and September 2017.

The service has recently been successful in a partnership proposal to Public Health England with Waltham Forest Citizen's Advice (WFCA) as the lead partner. This will bring £250k per year for three years, allowing a significant expansion for the voluntary and community sector to develop social prescribing activities.

What is offered

How the service is structured

The service works closely with the public health and adult social care teams in the Council which has brought spin-off benefits – the wider teams inevitably get to know about some of the services to which the social prescribing team are referring, and so these become more widely accessible.

Referrals

One of the aims of the service is to free up capacity among specialist health and social care professionals, so that they can focus on people with the most intense needs. Senior Social Prescriber Sharon Hanooman says

> 'GPs tell us that a big proportion of consultations with patients are about non-medical issues. We need to release them to do what they are trained to do, and do best.'

For that reason, referrals come in to the social prescribing service from those professionals, rather than via self-referral. 86% of these referrals come from GP practices, and of the 42 practices in the borough, 75% of them are referring in to the service. Sharon worries about the patients on the lists of those practices who aren't referring in – as they can't benefit from the service. The next largest referrals come from the Community health services (NELFT) and adult social care.

How the service works

Health and social care professionals explain the social prescribing service to clients, and ask if they would like to be referred. If they agree, the referrer completes a simple form with the main presenting issue, and passes it to the team.

The team then arranges to telephone the client. During this call, they discuss the person's experiences, needs and the kind of support or information they would be interested in. The underlying question informing the discussion is 'Where can I connect you?'. The service was envisaged as a high volume, low contact type of service, with the team researching suitable opportunities and developing a package of non-clinical support. They let the client know about these opportunities in a second phone call, and then follow up with a third call after some weeks to find out how they were getting on.

The service is primarily offered over the telephone. Although there was some early scepticism about how well a telephone service would work, some service users have said that they wouldn't have felt able to access a face to face service, either because of the strength of feelings including suicidality, or because their social isolation would have meant having a visitor or going out to meet someone would have been too big a step.

In practice, some patients do need more support to access the opportunities that could help them. The service has identified a gap in befriending and advocacy services for vulnerable and isolated residents. It is important too that referrers give clients an accurate picture of what the social prescribing service is able to provide.

The service is viewed by many healthcare professionals as the single point of access to suitable support in the community. Alongside the Social Prescribing Service, WFCA has placed a welfare advisor for one day per week in the three GP hubs across the borough. The social prescriber can make direct appointments for patients needing welfare advice at one of these GP surgeries.

Why people are referred

The most frequent reason for referral is low mood and anxiety – or rather, that is the reason that people have sought help from their GP. Once they are contacted by the social prescribing team, it often emerges that there is an underlying issue: most often, housing followed by social isolation and loneliness. This includes older people, but also younger people such as 30-40 year olds who are may be out of work, estranged from their family or living in hostel accommodation. As time has gone on, Sharon has noticed an increasing number of referrals of men in their 50s or 60s whose long-term relationships have broken down.

Supporting carers and bereaved people.

Between July and December 2016, around 4% of clients were referred to the service specifically because of bereavement. However, bereavement often emerged as an underlying issue.

Among carers, Sharon has noticed an increase in older former carers being referred to the service. She has also identified particular difficulties for those who had been caring for elderly parents in council accommodation, who then have to leave the home after their parent's death because they are not on the tenancy.

> 'These people have put their life on hold, lost skills and so on.'

Bereaved former carers can be referred to a local bereavement group or to talking therapies. Families where there is a cancer diagnosis are referred to the specialist Macmillan Social Prescribing Service from Bromley-by-Bow. For families bereaved in specific circumstances, the team will try and find specialist support, such as that from Support after Murder and Manslaughter (SAMM).

Impact on service users

Colleagues at the Institute for Health and Human Development (IHHD), University of East London were commissioned to evaluate the Social Prescribing Service. This included an evaluation of the health and well-being outcomes of clients, the process of developing the service, and the social return on investment between July 2016 and May 2017.

Outcomes evaluation

48 services users were followed up. 63% were women, and only 21% were aged 65 or over, unlike many other social prescribing schemes targeted at older people. Respondents were from ethnically mixed backgrounds (44% white). Almost four out of ten lived alone (38%), two thirds (65%) were not in paid employment, and one third (33%) unable to work because of sickness.

They were asked to rate their top two concerns before and after using the service. The biggest reductions in their first concerns were in housing and practical support, and the biggest reductions in their second concerns were in practical support followed by mental health.

Respondents showed improvements in all standardized indicators. Improvements in the last three indicators were statistically significant:

- Mental wellbeing (Warwick Edinburgh Mental Wellbeing Scale
- General health (very bad to very good)
- Wellbeing (Measure Yourself Concerns and Wellbeing)
- Quality of Life (EQ-5D-3L)
- Patient Activation (Patient Activation Measure).

Improvements in quality of life were particularly strong in terms of respondents' increased abilities to carry out their usual activities, and decreased feelings of anxiety and depression. Health outcomes improved from a very low starting point.

Respondents showed a statistically significant drop in GP visits, but slightly increased their visits to A and E.

Qualitative interviews with nine users were not so positive but this was mainly related to a lack of (or long wait for) services to meet the needs which the social prescribing service had identified, rather than an inherent problem with the rationale for social prescribing.

Social Return on Investment

The Social Return on Investment [SROI] showed that for each £1 invested on the service, there was an expected return to society ranging from £1.09 to £1.92. This is low than the average reported by other studies of £1: £2.30 (Kimberlee et al 2017) but is considered acceptable for a pilot project.

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Contact

Sharon Hanooman, Senior Social Prescriber
sharon.hanooman@walthamforest.gov.uk social.prescribing@walthamforest.gov.uk

Appendix 1: The policy context

Support for carers of people at the end of life straddles several policy areas, including general support for carers, end of life care, and bereavement care. This chapter looks at each of these policy areas in turn, highlighting key legislation and documents that are relevant to carers in this situation.

Overarching policies

The NHS Long Term Plan sets out a range of ambitions for the NHS, some of which are directly aimed at improving the identification of and support for carers. Others will have an impact on carer health and wellbeing through better support for the person they are or have been caring for. These commitments include

- introduce Quality Markers for primary care that highlight best practice in carer identification and support (para 1.19)
- increase the number of trained Social Prescriber link workers (para 1.40)
- introduce proactive and personalised care planning for everyone identified as being in their last year of life (para 1.42)
- improve the identification of and support for carers from vulnerable communities (para 2.33)
- encourage the national adoption of carer's passports which identify someone as a carer, and enable staff to involve them in a patient's care (para 2.33)
- introduce developments to electronic health records that allow people to share their caring status with healthcare professionals wherever they present (para 2.33)
- more carers to have back-up support in place, including conversations about 'contingency plans' to be included in Summary Care Records (para 2.34)
- roll out 'top tips' for general practice which have been developed by Young Carers, which include access to preventive health and social prescribing, and timely referral to local support services (para 2.35)
- expand access to IAPT services for adults and older adults with common mental health problems, with a focus on those with long-term conditions (para 3.91)
- put in place suicide bereavement support for families in every area of the country (para 3.106)
- encourage volunteering initiatives (para 4.54).

The NHS Mandate 2018-19 sets out objectives to 2020, underpinned by specific plans for 2018-19. It details that NHS England should ensure the NHS empowers people to manage their own health and care, especially people with long term conditions and at the end of life. It also states that carers should routinely be identified and given access to information and advice about the support available.

The NHS Outcomes Framework includes several domains and outcomes relevant to carers of people at the end of life

- 1.1 Reducing premature mortality – bereaved people have an increased risk of mortality
- 1.2 Reducing premature mortality in people with mental illness – while bereavement is not a mental illness itself, it does increase the risk of a range of difficulties
- 2.4 Enhancing quality of life for carers
- 4.6 Improving the experience of care for people at the end of their lives

- 4.7 Improving experience of healthcare for people with mental illness
- 4.9 Improving people's experience of integrated care.

The Clinical Commissioning Group Outcomes Indicator Set also includes domains relevant to these carers

- 1.2-1.9 Reducing under 75 mortality
- 2.15 Health-related quality of life for carers, aged 18 and above
- 2.16 Health-related quality of life for people with a long-term condition
- 4.3 Family and friends test
- 4.8 Patient experience of community mental health services
- 4.9 Bereaved carers' views on the quality of care in the last three months of life.

The Loneliness Strategy (2018) identifies carers and recently bereaved people as two key groups at risk of loneliness and looks at solutions for strengthening social relationships in an era of change.

- An expansion of social prescribing connector schemes across the country
- Improving the evidence base on social prescribing
- Piloting postal workers putting lonely older people in touch with services
- Integrating advice into the Tell Us Once service for recently bereaved people
- Encouraging greater use of community spaces and better transport links
- Building a national conversation to raise awareness and reduce stigma
- Embedding consideration of loneliness in the policy-making process, including in the government's Family Test.

Support for carers

The Care Act (2014) and the Children and Families Act (2014) set out the legislative framework for local authorities' responsibilities towards carers. Other key documents are NHS England's Commitment to Carers (2014) and the cross-government Carers Action Plan 2018-20 (2018).

Care Act (2014) and Children and Families Act (2014)

Support for carers in different circumstances is set out in the Care Act 2014 (England) and the Children and Families Act 2014 (England). Statutory guidance sets out more detail behind the Acts. The two Acts should work together to make sure that the needs of the whole family are met when someone in the family has care needs.

Table 2: Legislation on support for carers in different circumstances

Who is caring for whom?	Relevant legislation
Adult caring for an adult	Care Act 2014
Parent caring for a disabled child	Children and Families Act 2014, section 97
Parent caring for a disabled child preparing for adulthood	Care Act 2014, section 60
Young person caring for an adult or child	Children and Families Act 2014, Section 96

Young person preparing for adulthood caring for an adult or child	Care Act 2014, section 63

Together, these pieces of legislation set out key rights for carers. Local authorities must promote carers' **well-being**. This is a broad concept including:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal
- suitability of living accommodation.

Some of these aspects are particularly relevant to carers as the person they are caring for approaches the end of their life.

Under the Care Act 2014, local authorities have a duty to **prevent, reduce and delay the need for support for carers.** This could include approaches that prevent difficulties arising or worsening for carers as the person they are caring for approaches the end of life, even if they don't currently have support needs. Local authorities should have arrangements to identify and target those who might benefit from preventative support, and the statutory guidance gives bereavement as an example of a point in a person's life when these approaches might be particularly appropriate.

> For example, at the end of life in relation to carers, prevention services could include the provision of pre-bereavement support.
>
> Care Act Statutory Guidance para 2.11

Table 3: Approaches to preventing, reducing and delaying support needs (adapted from Care Act Statutory Guidance)

Approach	Examples
Primary prevention / promoting wellbeing Generally universal	Promoting healthy and active lifestyles Reducing loneliness or isolation Encouraging early discussions about the future (eg advance care planning, lasting power of attorney)
Secondary prevention / early intervention Generally targeted	Identifying carers, including new carers A few hours support to help carers
Tertiary prevention / formal intervention	Enabling carers to have a life of their own alongside caring, eg respite care, peer support groups, emotional support, stress management classes

Local authorities are also required to provide **information and advice** to carers in relation to their caring role and their own needs, including their own health and well-being, their wider family relationships, financial and legal issues, employment, education and need for advocacy (3.17).

The statutory guidance recognises that there are key triggers in a person's life which might mean they have a particular need for information and advice: these include the diagnosis of health conditions, application for or review of certain benefits including attendance allowance and carer's allowance, and bereavement (3.26). In providing information and advice, local authorities should have particular concern for people who are socially isolated (3.30).

Carers also have a right to a **carer's assessment** based on the appearance of need, and for their **eligible needs to be met.** Importantly, the carer's assessment must also consider the carer's future needs for support (Care and Support Statutory Guidance 6.18). The primary reason for this is to consider whether the caring role and relationship is sustainable, but this could also be an opportunity to consider the likely future support needs of the carer if the person they are caring for dies.

> 6.19 The carer's assessment must also consider the outcomes that the carer wants to achieve in their daily life, their activities beyond their caring responsibilities, and the impact of caring upon those activities. This includes considering the impact of caring responsibilities on a carer's desire and ability to work and to partake in education, training or recreational activities, such as having time to themselves. This impact should be considered in both a short-term immediate sense but also the impact of caring responsibilities over a longer term, cumulative sense.

Carers' assessments should take a **whole family approach**, looking at how support needs impact on other family members, including children, and others in their support network. They should also look at **fluctuating needs**, recognising that carer's needs may change if the condition of the person they are caring for changes, or if other circumstances in the carer's life change such as their responsibilities for children.

> 2.16 Carers play a significant role in preventing the needs for care and support for the people they care for, which is why it is important that local authorities consider preventing carers from developing needs for care and support themselves.

Care and Support Statutory Guidance

More specifically in relation to carers, the NHS Commitment to Carers (2014) includes 37 high level commitments, including mention of bereaved former carers.

Carers Action Plan

The cross-government Carers Action Plan 2018-20 (2018) sets out the activities the government intends to carry out for the next two years. Most will have an impact on carers of people at the end of their life and bereaved former carers, but some have particular relevance for this group.

Services and systems that work for carers

- 1.1 carer-friendly GP practices
- 1.2 Bereavement care pathways
- 1.4 Exemplar models for older carers and carers of people with dementia
- 1.5 implementation of the Dementia 2020 challenge
- 1.6 Public Health England 'productive healthy ageing' action plan.

Employment and financial well-being

- 2.3 BEIS consideration of dedicated employment rights for carers
- 2.10 Carers UK development of e-learning resource to help carers recognise the skills developed through caring and how they could use these skills
- 2.11 Government Equalities Office (GEO) new returner programmes in the public sector
- 2.12 GEO working with employers to improve support and opportunities for returners in the private sector
- 2.16 Analysis and research on barriers for carers in remaining in and returning to employment
- 2.18 Department for Work and Pensions reviewing and improving information and signposting for carers visiting Jobcentres.

Support for young carers

- 3.5 Review of Children in Need
- 3.8 Improving the offer of mental health support for young carers through the Green Paper *Transforming Children and Young People's Mental Health.*

Recognising and supporting carers in the wider community and society

- 4.1 *Carer Innovations Fund* to develop carer-friendly communities
- 4.3 Ageing Grand Challenge to support society to age better and improve quality of life
- 4.4 Industrial Strategy to invest £98 million in innovations aimed at supporting people to age well
- 4.5 Continued promotion of Carer Passport project
- 4.8 Office for Civil Society supporting an *End of Life Social Action Toolkit* to support more social action and volunteering at end of life
- 4.9 Office for Civil Society looking to use social action to encourage better self-care for people living with long term conditions
- 4.11 DHSC Citizens Engagement Programme to improve the lives of people with dementia and their carers
- 4.13 Public Health England running national campaign to help people become better informed about public health
- 4.14 DCMS to consider carers in the development of the cross-government loneliness strategy.

Building research and evidence to improve outcomes for carers

End of Life care policy

The Ambitions for End of Life Care (National Palliative and End of Life Care Partnership, 2015) state that good end of life care includes bereavement and pre-bereavement care, including for those affected by deaths caused by sudden illness or trauma, including suicide. Support should be provided for bereaved children and young people as well as adults. Although the Ambitions focus on the needs of the dying person, the document states that they should also be read as ambitions for carers, families, those important to the dying person, and where appropriate for people who have been bereaved. The relevant ambitions for people facing and following bereavement are:

> **Ambition 1: Each person is seen as an individual: Good End of Life Care includes bereavement**
> Caring for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and bereavement.
>
> **Ambition 2: Each person gets fair access to care - Community partnerships**

> Dying, death and bereavement affects everyone, so everyone must be able to get care that works for them personally, for their family and carers and for their communities. Local plans should include the development of community partnerships between different faith groups and cultural communities, as well as the diverse organisations that support children and young adults, people living with different life shortening illnesses, and those managing the difficulties of older age.
>
> **Ambition 6: Each community is prepared to help**
> "I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Ambitions Partnership for Palliative and End of Life Care (2015)

Each Community is Prepared to Help (National Council for Palliative Care, 2016) expands the public health approach outlined in ambition 6, setting out ways in which professional organisations can actively participate in helping to build supportive communities.

Every Moment Counts (National Voices, 2015) underlines the central importance of bereavement care to achieving a good death. A set of 'I statements' provide a narrative for person-centred, coordinated care near the end of life:

> I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).
>
> I am confident that the people who are important to me will have the opportunity to get support with bereavement before and after my death.
>
> Taken together, the information, care and support I receive helps me feel 'at peace' about what will happen in the future, including how the people who are important to me will cope after I die, and be supported to do so.

NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) provides a model for local bereavement support and the End of Life Care Strategy (Department of Health, 2008) subsequently applied this model to bereavement following all expected deaths.

This guideline will be retained alongside End of Life Care for Adults in the Last Year of Life: service delivery (NICE, forthcoming). A parallel set of guidance on End of Life Care for Infants, Children and Young People (NICE, 2016) includes the provision of care and support for parents, carers and families including siblings.

Together for Short Lives' Perinatal Pathway for Babies with Palliative Care Needs (2017) includes a focus on high quality end of life and bereavement care.

Priorities for Care of the Dying Person: Once Chance to Get it Right (Leadership Alliance for the Care of Dying People, 2014) describes care in the last days and hours of life. The fourth priority states that

> 'The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.'

Response to the Review of Choice in End of Life Care (Department of Health, 2016c) sets out how the government will respond to the review's recommendations. These includes that carers should be formally identified and supported in line with the Care Act 2014, and supported following bereavement, and that family members, carers and/or those important to the individual should be involved in discussions about care preferences where the dying person has said they should be.

The End of Life Care Commissioning Toolkit (NHS England, 2016e) states that commissioning plans must encompass bereavement and pre-bereavement care, including care for children and young people.

NHS England Specialist Level Palliative Care: Information for commissioners (NHS England, 2016f) identifies that specialist palliative care includes providing care and support to those important to the person receiving care, including facilitating bereavement care. The sample specification includes the strand:

> Identify and assess the needs of those important to the person, including psychological and social needs, and provide support, preparation for the caring role at whatever level is required to be undertaken, and facilitate access and signposting to other services, including pre-bereavement and bereavement.

Bereavement care policy

The National Institute for Clinical Excellence set out a three-component model of bereavement support in its Supportive and Palliative Care for Adults with Cancer (2004), based on a systematic review of the evidence available at the time. The End of Life Care Strategy (Department of Health, 2008) applied this model to all expected deaths. No similar model exists for sudden deaths.

The National Bereavement Alliance's Guide to commissioning bereavement services in England builds on the three-component model and the public health approach to bereavement which maps the components on to a universal/targeted/indicated model of tiered support. This emphasizes the capacity of social networks and communities to respond to bereaved people, and positions bereavement care as a shared responsibility between communities and healthcare services (Rumbold and Aoun, 2014).

Table 3: summary of the three-component model of bereavement care

Component	Support
NICE component 1 **Universal** – for all bereaved people. Low level of need.	Verbal, written and on-line information about bereavement and sources of support. Provided by professionals involved in end of life care, registrars and others providing day to day care to families. Community capacity building and training to raise awareness of grief, how to help, and when and where to seek extra support.
NICE component 2 **Selective or targeted** for some bereaved people (those seeking support or at risk of developing complex needs).	Non-specialist support (1:1 and group opportunities). 2.1 Social support: self-help groups, faith groups, befriending and community groups. 2.2 Trained bereavement support workers.
NICE component 3 **Indicated** for a minority of bereaved people (those with complex needs or prolonged/complicated grief). High level of need.	Specialist interventions. 3.1 Specialist bereavement counsellors/practitioners. 3.2 Specialist mental health/psychological support for those with mental health problems which pre-date or are triggered by their bereavement.

The three-component model is supported by public education about grief and bereavement, and assessment, which takes account of people's needs and risks alongside their resilience and strengths, so that they can have help that is appropriate to their level of need.

Support after a death

When a person dies (National End of Life Care Programme, 2011) identifies good practice in bereavement care around the time of death and shortly afterwards, setting out provision in detail, with a particular focus on acute settings. The National Paediatric Hospitals Bereavement Network is developing standards and guidance for bereavement care following the death of a child in an acute setting.

National Guidance on Learning from Deaths (National Quality Board, 2017) sets out a framework for NHS Trusts and NHS Foundation Trusts on identifying, reporting, investigating and learning from deaths in care. Chapter two focuses on bereaved families. Providers should have a clear policy for engagement with bereaved families and carers, and should offer a bereavement service for families and carers of people who die under their management and care. NHS England, led by the Chief Nursing Officer, will develop guidance in 2017-18 for bereaved families and carers which will cover how families should be engaged in investigations.

Working together to safeguard children (Department for Education, 2018) sets out the statutory responsibilities for investigating sudden or unexpected child deaths, including providing support to the bereaved family, involving them in meetings as appropriate, referring to specialist bereavement services where necessary and keeping them up to date with information about the child's death. This is supplemented by the Child Death Review statutory and operational guidance (Department of Health and Social Care and Department for Education, 2018).

The Royal College of Pathologists and the Royal College of Paediatrics and Child Health's Sudden and Unexpected Death in Infancy and Childhood (2016) sets out multi-agency guidance for care and investigation. A key component is ongoing consideration of the psychological and emotional needs of the family, including referral for bereavement support.

Sands is leading a group of baby loss charities to develop a National Bereavement Care Pathway with a focus on pregnancy loss and the death of a baby.

Guide to Coroners Service (Ministry of Justice, 2014) gives statutory guidance that the coroner's office will provide information on the main local and national voluntary bodies, support groups and faith groups which help bereaved people, including as a result of particular types of incidents or circumstances, or specific medical conditions.

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