National Bereavement Alliance

Commissioning for Compassionate Community Bereavement Support

The impact, risks & costs of bereavement

This guidance forms part of a suite of resources for commissioners and providers of bereavement services. These resources are intended to build on the opportunities in the Health and Care Act 2022 and the UK Commission on Bereavement. These provide new structures and ways of working for local people, communities and services to collaborate to set out a vision for bereavement support in the local area, and to work together to make this vision a reality.

Overall, these will help communities, providers and commissioners collaborate to ensure that the full range of bereavement support is in place and integrated, following expected and unexpected deaths across an Integrated Care System or place-based partnerships.

The resources are available at
https://nationalbereavementalliance.org.uk/ourpublications/commissioning/

Introduction: The need for bereavement support

Grief is a normal reaction to bereavement and many people find that their inner resources, combined with support from family and friends, are enough to help them manage their distress and the life changes and adjustments triggered by loss. However, public awareness and understanding of grief is often lacking, and many bereaved people report feeling lost and misunderstood. Additionally, bereavement is associated with risks to health and wellbeing and can give rise to a wide range of needs.

The tragic and widespread loss of life during the COVID-19pandemic has led to a greater awareness of the suffering that grief can bring, the importance of support, and of inequities in facing bereavement and getting support. At the same time, the pandemic exacerbated this suffering, increasing and prolonging bereaved people's need for support, and widening disparities in access to it.

Support that helps people manage their grief range from information about grief and what it is like, through health promoting community-based resources to more intensive, specialist help for those whose reactions are complex or prolonged, and affect their ability to manage everyday life.

Many people and organisations have a role to play in providing bereavement support. Everyday networks of families, friends and neighbours, and the places where bereaved people have to function, including work and school, provide the lion's share of support. Some people will need additional support to help them through their experience. This might be general support which

helps meet the needs and gaps that the bereavement brings, such as welfare rights advice, or befriending support; or it might be specific to bereavement, such as a bereavement group or one to one support. The number of bereaved people is growing. The annual number of deaths in England is increasing and is predicted to rise by 20% over the next 20 years (ONS, 2015), alongside increases in the population and a dramatic rise in the proportion of elderly people (Calanzani et al, 2013). As numbers of deaths rise, so do the number of bereavements, so this issue is growing in urgency.

What is the impact of bereavement?

Grief is a normal reaction to the death of someone close including partners, babies and children, parents, siblings, other relatives and friends. Grief is often seen as primarily an emotional response, but it has many facets with physical, cognitive, spiritual and behavioural dimensions, and it may begin before the death.

Many people experience intense loneliness when they are grieving, even if they have friends and family close by. Some experience traumatic stress reactions, for example when the circumstances of the death are particularly distressing.

For many people, bereavement also brings life changes and practical challenges, including dealing with the administration of the death and taking on new responsibilities, just at the time when they may be feeling vulnerable and overwhelmed. These are the common and disruptive challenges of adjusting to and building a new life without the person who died.

Common grief reactions in adults (Adapted from Relf, 2002)

- Emotional
    - Depression, sadness, sorrow, despair
    - Guilt and remorse re events surrounding loss or past behaviour toward deceased
    - Anger re health and social care providers, the deceased, family members, friends, God
    - Aloneness – feeling emotionally isolated
    - Loss of enjoyment - believing that to experience enjoyment is impossible or wrong
    - Relief - that suffering has ended / that role of carer has ended
    - Low self-esteem and feelings of inadequacy, failure, incompetence, worthlessness
- Behavioural
    - Agitation, restlessness, over-activity, 'searching' for deceased
    - Fatigue - apathy, poor concentration
    - Expressions of sadness
    - Changes to patterns of life – e.g. sleeping, eating, libido
    - Avoiding or seeking situations that may trigger grief
- Cognitive
    - Yearning/pining for deceased, pre-occupation, hallucinations, idealisation
    - Hopelessness - loss of purpose, loss of hope for the future
    - Anxiety – difficulty making decisions, fear re own health, fear re future

    - Low self-esteem – feelings of inadequacy, worthlessness
    - Sense of unreality and feeling removed from current events
- Social
    - Relationship difficulties - feeling misunderstood and unsupported
    - Feeling lonely
    - Managing different grief reactions with family and social network
- Physiological
    - Loss of appetite, weight change
    - Physical complaints - tension, muscular pains, indigestion, shortness of breath, lump in throat, palpitations, panic attacks
    - Increased use of antidepressants and other medicines, alcohol, tobacco
    - Lowered resistance to infections.

Common grief reactions in children (Dyregrov, 2008)

- Emotional
- Anxiety
- Vivid memories
- Sleep difficulties
- Sadness and longing
- Anger and acting out behavior
- Guilt, self-reproach and shame
- School problems

Some children might show regressive behaviour, social isolation, fantasies, personality changes, pessimism about the future, preoccupation with cause and meaning, and a sense of maturity and growth as a result of being bereaved.

Over time, most people's grief follows one of three patterns (Bonnano et al, 2011; Melhem et al 2011, Mancini et al, 2015; Lenferink et al 2020).

- Resilience with a return to functioning after some months (often, but not always, after an initial period of intense disturbance).
- Gradual recovery over a year or more.
- Prolonged distress, which may pre-date the death and last for years.

While many people are resilient and regain their equilibrium, a minority experience persistent high levels of distress and chronic grief symptoms that impact on their physical and mental health and on their functioning for a substantial period of time (Shear, 2015; Prigerson et al 2009). There is debate about the exact nature of these difficulties, which have been described as prolonged, persistent, complicated or complex. Prolonged Grief Disorder, now recognised as a distinct diagnostic category in the World Health Organisation's Inventory of Classifiable Diseases ICD-11 is a collection of difficulties, which is distinct from, but often found alongside, other mental health disorders such as depression, anxiety and post-traumatic stress disorder. Before the pandemic, around 10% of bereaved people experience these difficulties (Lundorff et al 2017), with higher rates among specific groups such as parents whose child has died, and those bereaved in sudden and traumatic circumstances (Djelantik et al 2020).

Some people will experience traumatic stress symptoms, with around 12% of widowed people meeting their criteria for Post Traumatic Stress Disorder (PTSD) in the first year after their bereavement (Onrust and Cuijpers, 2006). Across countries, around 5.2% of people who experienced the unexpected death of someone close to them at some point in their lives will currently meet the criteria for PTSD (Atwoli et al 2017), with the highest odds among women, those bereaved of a spouse or child, those who believe they could have done something to prevent the death, and those who had prior exposure to trauma or a history of mental disorders.

Other bereaved people may experience high levels of distress for a shorter period. For example, they may have disturbing memories of the events leading up to the death, blame others for the death or have feelings of guilt.

Following the death of a parent, around one third of children will have clinical levels of emotional or behavioural difficulties at some point over the first two years (Worden, 1996).

The impact of the pandemic on people's experiences of grief

The COVID-19 virus, and the social restrictions imposed to control it, had a profound impact on people's experiences of grief. Families and friends were bereaved in sudden and shocking ways; many were unable to be with their loved ones as they died, and to gather to support one another in their grief. People experienced grief at a time of general fear and economic pressure, and while access to usual networks at school and work, as well as referral routes to formal bereavement services, were severely disrupted. These losses were felt particularly heavily by those from disadvantaged and deprived communities. Health and care workers on the frontline were impacted by death on an unprecedented scale (Penny and Nibloe 2021).

These disruptions had a significant impact on the support that people received, and on their levels of grief and their struggles with everday functioning (Neimeyer & Lee, 2022). Half of respondents to a UK survey about grief experiences during the pandemic reported high/severe vulnerability in grief (51%) but nearly three quarters of these people had not accessed bereavement or mental health services (Harrop et al 2021). Of those that had tried to access support, more than half had experienced difficulties in getting support from a bereavement service (56%) or their GP (52%) with barriers including limited availability, lack of appropriate support, discomfort asking for help and not knowing how to access services. About 39% also experienced difficulties in getting support from friends and family.

The risks and costs of bereavement

Even in pre-pandemic times, bereavement was associated with an increased risk of mortality, physical and mental health problems (such as anxiety and depression), relationship difficulties and difficulties coping with everyday life. We have mapped these risks against some of the key outcomes frameworks for health and wellbeing.

These risks are associated with factors including

- the bereaved person's history, health and sociodemographic variables;
- the situation and circumstances of the death;
- the meaning of the relationship with the person who died;
- how well supported the bereaved person feels and
- other stressors that pre-date the death or are precipitated by it, such as caring for others, and housing or financial problems (Stroebe et al, 2007).

Bereaved people make greater use of healthcare services (Stroebe et al, 2007) including GP services, mental health services, acute and psychiatric hospitals, and consumption of medicines.

These increases begin before the death, spike immediately after it, and may last for months or years. Some services are used twice as much in the year following the death (Guldin et al, 2013). Bereaved children (Lloyd-Williams et al, 1998) and adults visit GPs more frequently but studies suggest that those with complex or prolonged grief may be less likely to do so (Stroebe et al, 2007; Prigerson et al 2001).

In Scotland, there is evidence that shows that the death of a spouse is associated with increased mortality and also with longer hospital stays. These longer hospital stays cost NHS Scotland around £20 million each year (Corden, 2013). In England, with over eight times the number of deaths, this figure would be very much higher. It would be even greater if it included the impact of non-spousal deaths such as the death of a child or parent, and if it included the costs of using other health and social care services, and the costs of time off work.

It is estimated that at any one time, bereavement impacts on one in ten of the workforce (McGuinness, 2009), affecting sickness absence, morale, productivity and retention. Grief experienced by employees is estimated to cost the UK economy £23bn per year and costs HM Treasury nearly £8bn per year, through reduced tax revenues and increased use of NHS and social care resources (Sue Ryder, 2020).

Cost	Key findings
Social care use	• The death of a spouse is associated with increased use of domiciliary care services over the age of 70, even when other factors including health status are taken into account (Glaser et al, 2006, UK).
Use of GP services	• Increased before the loss and peaked at the time of loss (Guldin et al 2013) • Increased over the period from 1 year before the loss to up to 5 years after the death of a spouse (Oksuzyan et al 2010, Denmark) • Use of out of hours GP service: rose by 20% among bereaved spouses (Guldin et al 2013, Denmark)
Use of medications	• Use of all-cause and major system-specific medications: increased over the period fomr 1 year before the death and up to 5 years after (Oksuzyan et al 2011) • Use of sedatives and anxiolotics: increase preceded the loss during caregiving, with a distinct and acute increase at the time of the loss, and consumption only decreeing slowly in the first year after the loss (Guldin et al 2013) • Use of antidepressants: number of prescriptions increased steadily during the two years following bereavement (Guldin et al 2013)
Referral to mental health professionals	• Referral to psychologist: increased probability of referral to a psychologist in the acute phased following a loss (Guldin et al 2013) • Referral to psychiatrist: grew a year after the loss (Guldin et al 2013)

Hospital admission and length of hospital stay	• A study of almost 100,000 married couples in Scotland found that bereaved spouses found that bereaved spouses who survive (see below) are both more likely to be admitted and to stay longer in hospital than a comparable non-bereaved cohort. The death of a spouse is estimated to lead to an average of 0.24 hospital inpatient days per year among adults of all ages (Tseng et al, 2018, Scotland). Greater increases were found among those over 75, and among those living in smaller households who are more likely to be living alone after the death. • Death of a spouse was associated with a markedly increased risk of admission to a somatic or psychiatric hospital ward (Guldin et al 2013, Denmark) • Bereaved spouses had an average stay that was twice as long as their non-bereaved peers (Guldin et al 2013, Denmark)
Overall health spend	• Among all Danish citizens over 65, the increase in men's healthcare spend in the year after their partner's death was an average of 42 euros per week more than their non-bereaved peeers, with women's corresponding increase being 35 euros (Katsiferis et al 2023). • In the US, surviving female spouses had a $3,500 increase in Medicare expenditure over the two years following their partner's death, regardless of their caregiving status, the cause of death, or length of terminal illness. There was no corresponding increase in spending for bereaved men (Ornstein et al 2019).

The benefits of bereavement support

High quality bereavement support can help to achieve the outcomes identified in the frameworks in the appendices.

Organised bereavement support can reduce the use of health care services, including GP consultations (Relf, 2000). Full cost benefit analyses of bereavement services are underdeveloped, and this is a priority area for research. The limited number of available studies suggest that bereavement support can deliver healthcare savings.

- A community-based crisis intervention service for people bereaved by suicide showed a cost saving of AUS $803 and an increase in quality-adjusted life years of 0.02 over usual care (Comans et al 2013).
- An un-targeted visiting service for older widowed people found slightly better results against slightly higher costs compared to treatment as usual, and recommended in depth analyses to identify who benefits most from this kind of interventions, and in what subgroups the incremental cost-utility is best (Onrust et al 2008).
- Specialist counselling after baby loss was found to deliver a return of £2.71 for every £1 invested, focusing exclusively on the specific costs to government in terms of benefit payments, health care and social services (O'Shea, 2019).

Conclusion

This guidance has set out the risks and costs of bereavement. For suggestions of what needs to be in place to mitigate these risks, and how to set out a vision for bereavement support in a local area, visit our wider resources at https://nationalbereavementalliance.org.uk/ourpublications/commissioning/

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