

Briefing for Adjournment Debate on Bereavement Counselling

26 March 2019

Executive summary

- Around 600,000 people die in the UK each year, with their families and friends having to cope with bereavement. 72% of people say they have been bereaved at least once in the last five years. Key dates such as Mother's Day, birthdays, and anniversaries often reawaken painful feelings.
- Many bereaved people find that their own inner resources, combined with the support of family and friends, are enough to see them through.
- However, many people are uncomfortable talking to someone who has been bereaved, and people can be left feeling lonely and overwhelmed.
- The practical and economic challenges of bereavement can make emotional distress even worse: finding the money to give someone a proper funeral, dealing with an inquest, going back to work, learning to live alone. There are simple steps that the Government could take to ease the practical pressures on bereaved people, which would in turn ease their emotional distress.
- It is generally accepted that people do not need routine referral for bereavement counselling simply because they have been bereaved. However, services should be made available – and accessible – to those that need this type of support.
- We recommend a stepped care approach, with proactive information about grief and compassionate communities available to everyone, opportunities to meet other bereaved people and reflect on the loss, and specialist support to those who need it.
- There is currently a gap in provision of support, with less than half of the people who want support being able to access it. Those who need support the most may be reluctant to ask for help.
- The National Bereavement Alliance's report *Life after death*¹, highlighted the challenges faced by bereaved people of all ages. The report set out six recommendations for better bereavement support:
 - A named Minister with responsibility for bereavement
 - A national review of the impact of financial, administrative and economic changes on those who have been bereaved
 - Clarity about who is responsible locally for commissioning and providing bereavement support, with better coordination and information about services in each area
 - Better support at work
 - Training in bereavement for all those coming into contact with bereaved people, at a level appropriate to their role
 - More compassionate communities where everyone knows enough about grief to play their part in supporting people around a death.

This briefing has been prepared by the [National Bereavement Alliance](#) (NBA), a group of over 40 national and regional organisations working with bereaved people including the major bereavement care providers, and the [Childhood Bereavement Network](#) (CBN), the national hub for those working with bereaved children and young people across the UK. **For more information on the work of NBA or CBN, or this response, please contact Alison Penny work apenny@ncb.org.uk | 07894 390 736.**

The experience of bereavement

1. Each year in the UK, around 600,000 people die, leaving bereaved families and friends to deal with the aftermath of lossⁱ. 72% of people say they have been bereaved at least once in the last five yearsⁱⁱⁱ.
2. Many of those bereaved people are already depleted by the strain of caring for someone at the end of their life. 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.
3. 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). This will have implications for the profile of bereaved people.
4. The Childhood Bereavement Network estimates that around 24,000 parents die each year leaving over 40,000 newly bereaved children under 18^{iv}. Many others have been bereaved of a sibling, grandparent or someone else close.

Bereavement and health

5. Grief is a normal reaction to bereavement and many people find that their inner resources, combined with support from family and friends, are sufficient to help them manage their distress and the life changes and adjustments that are brought about by the death in the family. However, general awareness and understanding of grief is often lacking, which can leave bereaved people feeling lost and overwhelmed.
6. Bereavement brings significant risks to health and other outcomes. Across types of bereavement it increases the risk of mortality, physical health problems, physical disability, use of medication and hospitalisation^v. Widow(er)s^{vi} and children bereaved of a parent^{vii} are more likely to visit their GP. Children bereaved of a parent or sibling are more likely to have clinical rates of mental health difficulty, may underachieve at GCSE and have a greater risk of poor health behaviours^{viii} – all outcomes with life-long significance.
7. Around 11% of people are likely to suffer ‘complicated’ or ‘prolonged’ grief following a death from natural causes (these collections of difficulties are distinct from, but often found alongside, other mental health disorders such as depression, anxiety and PTSD): rates are likely to be higher among those bereaved of a child, or following a traumatic death^{ix}.
8. In Scotland, the death of a spouse is associated with increased mortality and also with longer hospital stays, costing the NHS around £20 million each year^x. In England, with over eight times the number of deaths, this figure could be between £150 and £190 million. It would be even greater if it included the impact of the death of someone else close, such as a child or parent, and took into account the costs of increased use of other health and social care services^{xi} and days off work.

Practical support – what government can do

9. The provision of emotional support is only part of the picture of improving support for bereaved families. For many bereaved people, seeking emotional support is secondary to all the practical and administrative challenges that bereavement brings.

10. Money worries are one of the biggest reported concerns for bereaved people. In recent years, Government has helped to address some of these difficulties by
- rolling out the Tell Us Once scheme, simplifying the information that people have to give when registering a death
 - establishing the Children’s Funeral Fund to cover the costs of burying or cremating a child
 - enacting the Parental Bereavement Leave and Pay Bill which will introduce two week’s paid leave for those bereaved of a child under 18.
11. However, we are deeply concerned that changes to the benefits system, funeral costs rising much faster than inflation, changes to bereavement benefits, hardship for unmarried partners, availability of Legal Aid for inquests following a state-related death, the introduction of Universal Credit and the earlier application of the under-occupancy charge on bereaved families will lead to increased levels of poverty and distress in this group. **We recommend a cross-departmental review of the financial impact of current welfare, administrative and economic changes on those who have been bereaved.**
12. There are simple actions which Government could take that would reduce the pressure on bereaved families at a time of major stress and anxiety. These actions would likely reduce the need for emotional support services to deal with the fallout of practical challenges. These include
- Conduct the review it has promised into the impact of Bereavement Support Payment (BSP) introduced in April 2017 which replaced Widowed Parent’s Allowance. 91% of families with children are now supported for a shorter time, and 75% are worse off in cash terms, meaning that parents will have to go back to work or increase their hours before their grieving children are ready.
 - Bring forward legislation to make unmarried, cohabiting parents eligible for bereavement benefits in line with the Supreme Court ruling of 30 August 2018. Each day of delay, another four to five families fall foul of the outdated eligibility criteria, denying them support for their children despite their partner’s National Insurance contributions.
 - Increase the discretionary element of the Social Fund Funeral Payment which has been capped at £700 since 2003. The SFFP now covers on average just 35% of the cost of the average funeral.
 - Review the impact of the introduction of Universal Credit and the availability of transitional protection for those making a new claim because their partner has died, and the application of the under-occupancy charge on bereaved families.

What employers and schools can do

13. We also have concerns about the support available at work to bereaved employees. According to a survey published by Dying Matters, almost a third of people who had been bereaved in the last five years while they were in a job said they were not treated with compassion by their employer^{xii}. ACAS has produced guidance for employers on supporting bereaved employees^{xiii}. **We recommend that this guidance is rolled out to employers of all sizes, and that training is provided to help employers meet their statutory and moral responsibilities.**
14. Schools have a major part to play both in supporting bereaved pupils, and providing opportunities for children and young people to learn about how to cope with change, loss and bereavement and to support one another. **We recommend that flexible pastoral support systems and staff training are included in the implementation of the Children’s Mental Health Green Paper, and that the curricula for Health Education and Relationships Education are enhanced to include these topics.**

Emotional support – a stepped care approach

15. It is generally accepted that people do not need routine referral for bereavement counselling simply because they have been bereaved (Stroebe et al, 2017). 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, which in turn creates demand and increases waiting lists for those who do need support.

16. However, multiple recent surveys have revealed how uncomfortable people are in supporting one another following bereavement, and some bereaved people will need more support than their families and friends can currently provide.
17. Flexible, non-stigmatising, commissioned support at multiple levels helps communities to respond adequately, and provides more intensive help to those who need it. This support may be commissioned across a range of services including end of life care, carers' support, maternity services, mental health services, suicide prevention, emotional wellbeing and services for specific groups. Commissioners also need to plan to respond at every level to meet the needs of communities affected by local emergencies.
18. The National Bereavement Alliance has built on NICE guidance and the public health model of bereavement to elaborate a three component model of support:
 - **Universal:** information about bereavement and sources of support
 - **Targeted or indicated for those seeking support or at risk:** social support, self-help groups, faith groups, befriending and community groups and trained bereavement support workers
 - **Specialist interventions for those with complex needs or prolonged/complicated grief:** specialist bereavement counsellors and practitioners, and specialist mental health/psychological support for those with mental health difficulties predating or triggered by their bereavement.
19. It is notable that currently, less than half of people in the annual VOICES survey of bereaved people who wanted to talk to someone from health, social care or a bereavement service about their feelings about the death get to do so^{xiv}. There is also evidence that those who need services the most may be reluctant to ask for help (Prigerson et al, 2001).
20. Limited catchment areas, long journey times, waiting lists and limited provision all preclude access to support. Even where services are available, people may not know about them, or may feel stigmatised by seeking support.
21. Staff in community- and hospice-based bereavement services are reporting increasing levels of complexity and comorbidity among the bereaved people they are supporting, and also increasing barriers to referring in to specialist mental health services. Better partnerships between specialist bereavement provision and child and adult mental health teams – including reciprocal training, consultation and supervision - could help to bridge this gap.

ⁱ <http://www.ncpc.org.uk/sites/default/files/LifeAfterDeath.pdf>

ⁱⁱ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationsummarytablesenglandandwalesdeathsbyingleyearofagetables>

ⁱⁱⁱ <https://www.sueryder.org/sites/default/files/2019-03/a-better-grief-report-sue-ryder.pdf>

^{iv} <http://www.childhoodbereavementnetwork.org.uk/research/key-statistics.aspx>

^v Stroebe, M.S., Schut, H., and Stroebe, W (2007) Health outcomes of bereavement. *Lancet*, 370, 1960-73.

<http://www.comsegovia.com/paliativos/pdf/Health%20outcomes%20of%20bereavement.pdf>

^{vi} Stroebe et al (2007) *ibid*

^{vii} Lloyd-Williams, M and Wilkinson, C and Lloyd-Williams, F (1998) Do bereaved children consult the primary health care team more frequently? *European Journal of Cancer Care* 7, 120-124

^{viii} Childhood Bereavement Network (2009) *Grief Matters for Children: A Call to Action* London: National Children's Bureau

^{ix} Prigerson, H et al (2008) A case for inclusion of prolonged grief disorder in DSM-V. In Stroebe M et al (eds) *Handbook of Bereavement Research and Practice* Washington DC: American Psychological Association

^x Birrell et al (2013) Socio-Economic Costs of Bereavement in Scotland: Main Study Report.

^{xi} Stroebe, M.S., Schut, H., and Stroebe, W (2007) Health outcomes of bereavement. *Lancet*, 370, 1960-73.

<http://www.comsegovia.com/paliativos/pdf/Health%20outcomes%20of%20bereavement.pdf>

^{xii} ComRes interviewed 4,038 GB adults online between 15th and 21st November 2013

^{xiii} <http://www.acas.org.uk/bereavement>

^{xiv} <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people-voices-.html#tab=Support-for-relatives--friends-or-carers-at-the-end-of-life>