Childhood Bereavement Network and National Bereavement Alliance response to the Mental Health and Wellbeing Plan discussion paper

Summary

Grief is a normal reaction to the death of someone close, and not in itself a mental health condition. However, it does have profound impacts on people's wellbeing and can include overwhelming feelings and responses both in the immediate aftermath and for many months to come, often lasting much longer than bereaved people and those around them expect. It also increases the risk of mental health difficulties such as anxiety, depression, PTSD and the newly emerging diagnosis of Prolonged Grief Disorder. The COVID-19 pandemic has increased the complexities of grief and exacerbating pre-existing difficulties in accessing support from family, friends, communities and services.

Supporting bereaved people is everyone's responsibility. We all play a part personally as family members, friends, neighbours and colleagues. For many people, this will be enough. But others – particularly when the death is shocking or living circumstances are difficult – will need the support of trained bereavement supporters or professionals to find a way through their loss.

The tiered approach to bereavement support maps on to the approach taken in the *Mental Health and Wellbeing Discussion Paper*, and we welcome the opportunity to comment on it.

This response provides introductory information about bereavement and mental health, before commenting on each chapter of the *Discussion Paper*.

The National Bereavement Alliance (NBA) is a group of national, regional and local organisations with a shared vision that all people have awareness of and access to support and services through their bereavement experience. The Childhood Bereavement Network (CBN) is the national hub for those working with bereaved children and young people across the UK.

For more detail on this response or our wider work, please contact Alison Penny, NBA Coordinator and CBN Director.

Introduction – mental health and bereavement

Numbers and needs

Each year in England, around 500,000 people die, leaving bereaved families and friends to deal with the aftermath of loss. Many of those bereaved people are already depleted by the strain of caring for someone at the end of their life.

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[1], alongside increases in the population and a dramatic rise in the proportion of elderly people[2]. This will have implications for the profile of bereaved people.

The Childhood Bereavement Network estimates that 23,000 parents die each year leaving around 40,000 newly bereaved children under 18. Many others have been bereaved of a sibling, grandparent or someone else close.

Most people find that their inner resources, combined with support from family and friends and communities, are enough to help them manage their distress and the life changes and adjustments triggered by loss.

NICE guidance and the public health model of bereavement suggest that in pre-pandemic times around 30% of closely bereaved people needed organised opportunities to reflect on their grief and get support, and a further 10% of people struggle intensively with complex or prolonged grief, needing specialist grief or mental health interventions[3].

The impact of the pandemic

The pandemic has left a legacy of loss faced by families, friends, and communities[4]. Those from ethnic minorities, particularly people from certain Black and South Asian backgrounds, had and continue to have a higher risk of mortality from COVID-19 compared to White British people[5]. Those bereaved by other deaths since March 2020 have also been impacted by the social restrictions necessary to control the virus. Families and friends have been bereaved in sudden and shocking ways; many have been unable to be with their loved ones as they died, and to gather to support one another in their grief. These losses have been felt particularly heavily by those from disadvantaged and deprived communities.

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[1] Office of National Statistics (2022) *National Population Projections: 2022-based Statistical Bulletin*. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2020basedinterim#births-deaths-and-migration (accessed 7 July 2022)

[2] Calanzani et al (2013) Current and future needs for hospice care. London: Hospice UK. Accessed 7 July 2022 https://www.basw.co.uk/system/files/resources/basw_103716-5_0.pdf

[3] Summarised in https://nationalbereavementalliance.org.uk/wp-content/uploads/2017/07/A-Guide-to-Commissioning-Bereavement-Services-in-England-WEB.pdf

[4] https://coronavirus.data.gov.uk/details/deaths Accessed 22 September 2021

[5] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/updatingethniccontrastsindeathsinvolvingthecoronaviruscovid19englandandwales/24january2020to31march2021 Accessed 22 September 2021

Experiences at the end of life during COVID-19 and in bereavement have led to higher levels of distress and difficulty, with over half of surveyed bereaved people showing high or severe levels of vulnerability in their grief. Yet only a quarter of these vulnerable bereaved people were accessing formal services or mental health support[6]. Research shows that

- 81% of survey respondents who were bereaved since March 2020 had limited contact with family and friends in their bereavement
- 67% experienced social isolation or loneliness.
- Among those bereaved by COVID-19, 85% were unable to say goodbye to their loved one as they would have liked[7].
- Health and care workers on the frontline have been impacted by death on an unprecedented scale[8].

Children and young people have also been significantly affected by the pandemic, with a recent study estimating that 10,300 have been bereaved of a primary caregiver directly as a result of COVID-19[9][10] and many others restricted in their grief for those dying of other causes[11].

The costs of grief

Bereavement is associated with risks to health and wellbeing, increasing the risk of mortality, physical health problems, physical disability, use of medication and hospitalisation[12]. Widow(er)s and children bereaved of a parent are more likely to visit their GP[13][14].

In Scotland in 2011, the annual cost of hospital stays for people bereaved of a spouse was estimated at £20 million[15] – the National Bereavement Alliance estimates that across England in 2019-2020 (before the pandemic) this would equate to annual costs between £180m and £260m.

Grief experienced by employees who have lost a loved one costs the UK economy £23bn a year and costs HM Treasury nearly £8bn a year, through reduced tax revenues and increased

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[6] Harrop, E, Goss, S, Farnell, D, Longo, M, Byrne, A, Barawi, K, Torrens-Burton, A, Nelson, A, Seddon, K, Machin, L, Sutton, E, Roulston, A, Finucane, A, Penny, A, Smith, KV, Sivell, S & Selman, LE 2021, 'Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic', Palliative Medicine.

[7] Harrop E et al (2020) ibid

[8] Yasmine Olabi, Sophie Campbell, Beth Greenhill & Andrew Morgan (2022) NHS frontline staff experiences of an in-house psychological support service during the COVID-19 pandemic, Psychology, Health & Medicine, 27:1, 131-138, DOI: 10.1080/13548506.2021.1954674

[9] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)01253-8/fulltext

[10] https://imperialcollegelondon.github.io/orphanhood_calculator/#/country/United%20Kingdom

[11] Marshall S et al (2020) Children, dying parents and Covid-19 *British Journal of Child Health*, 1, 4, 161

[12] 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

[13] Stroebe et al (2007) ibid

[14] 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

[15] Stephen AI, Macduff C, Petrie DJ, Tseng FM, Schut H, Skår S, Corden A, Birrell J, Wang S, Newsom C, Wilson S. The economic cost of bereavement in Scotland. Death Stud. 2015 Jan-Jun;39(1-5):151-7. doi: 10.1080/07481187.2014.920435. Epub 2015 Jan 28. PMID: 25255790.

use of NHS and social care resources, according to economic research commissioned by Sue Ryder[16].

The Childhood Bereavement Network's *Grief Matters for Children* campaign summarises evidence which shows that bereaved children are at increased risk of depressive symptoms and anxiety, physical health symptoms, accidents and serious illnesses, risky health behaviours and early mortality. They have lower average GCSE scores and are less likely to be employed at age 30. They are over-represented in the criminal justice system. These risks will be primarily met by the current NHS and social care services, which are already under severe strain[17].

How can we all promote positive mental wellbeing?

A basic level of knowledge about grief can help us to respond compassionately and supportively, looking after ourselves when we are bereaved, and caring for our grieving family members, friends and neighbours.

Studies of public attitudes towards dying, death and bereavement show that death continues to be difficult to discuss socially[18]. This creates a barrier and decreases the availability of social support.

Because of our complex attitudes to our own mortality and that of those we love, it is unlikely that death will ever be a topic that is completely comfortable for all of us, all of the time. Therefore it is important that we capitalise on key moments and provide scripts to help people be good friends to those who are grieving, as exemplified by the Dying Matters campaign.

Case study: The simple messages promoted during National Grief Awareness Week included very clear actions that people can take to reach out to someone.

We recommend **public health approaches** to help educate people about grief is like, what helps, and when and how to seek extra help. This approach includes death cafes, arts projects, memorial activities, as well as more traditional public communications approaches.

We also recommend the **inclusion of coping with bereavement in the school curriculum**. This would support the next generation to manage their own bereavements and support their peers, both in childhood and into adulthood. There are opportunities within the Health Education and Relationships and Sex Education curricula (and other areas) for the teaching of these topics, but these will be missed unless the Department for Education gives a clear direction, given the anxieties that many teachers have about tackling these topics. We believe that grief education should be part of a wider, whole school approach.

[16] For more information, see https://www.sueryder.org/news/sue-ryder-calls-for-statutory-paid-bereavement-leave

[17] https://childhoodbereavementnetwork.org.uk/sites/default/files/uploads/files/grief-matters-for-children-2017.pdf

[18] See Cotton, Barney, 'YouGov Survey reveals startling attitudes towards death in UK', *Business Leader*, 11 December 2018, Co-op Funeral Care, 'Making peace with death: National attitudes to death, dying and bereavement', 17 August 2018, Castell S, Barrett S, Hollings P, 'The Departure Lounge: Public attitudes to death and dying', *Academy of Medical Sciences & Ipsos MORI*, 4 February 2020, Sue Ryder, 'A Better Grief', 2019.

How can we all prevent the onset of mental health conditions?

As described above, grief is not a mental health condition itself, but it increases the risk of developing anxiety, depression, PTSD and Prolonged Grief Disorder.

Support from schools and employers

Whatever their stage in the life course, we know that while some people get excellent support in the settings where they learn and work, others struggle to get the help they need.

In schools, many children and young people struggle to find the help they need, and may face loneliness and even bullying as a result of their bereavement. **We recommend a whole school approach**, including clear processes for managing a death in the school community, and training for school staff. This isn't about giving them another job or training them as counsellors, it is about equipping them with the knowledge and confidence to have a supportive conversation and know how and when to refer on. Other adults dealing with bereaved children and young people (e.g. youth workers, health visitors) should also receive training in bereavement awareness. **We also recommend that Mental Health Awareness Teams work in partnership with their local child bereavement services, as well as offering interventions where such services are not available.**

Case study: The Childhood Bereavement Network's *Growing in Grief Awareness* programme is a free toolkit to help schools, colleges and early years settings audit their support for bereaved pupils and staff and curriculum development, and develop an action plan to address gaps. It links to local and national training offers from bereavement services, as well as online resources and materials.

In workplaces, support is variable and inconsistent. Recent guidance from ACAS[19], CIPD[20] and Business in the Community[21] [insert references] sets out principles and examples of good practice, but we need these to be adopted by employers in all sizes and types of organisation.

There is huge variation in the amount of time people can take off following a close family bereavement. This is often at managerial discretion and people often have to take sick leave. Recent legislation has provided two weeks' statutory leave and pay for parents bereaved of a child under 18 – this should be extended to other significant bereavements to avoid the costs outlined above.

Case study: Good Life, Good Death, Good Grief have developed a toolkit for bereavement friendly workplaces in Scotland. This includes prompts to improve practice, such as developing a bereavement policy, and training managers, incentivised by a charter mark which can be achieved in ways that are flexible for organisations of different sizes and types.

[19] https://www.acas.org.uk/acas-publishes-new-bereavement-advice

[20] https://www.cipd.co.uk/knowledge/culture/well-being/bereavement-support#gref

[21] https://www.bitc.org.uk/blog/mental-health-loss-and-bereavement/

Tackling loneliness

Recent research for DCMS has demonstrated the consistent link between bereavement and loneliness across the life course, with participants identifying how bereavement in childhood could lead to difficulties later in life, and how older people may be faced with multiple losses of close friends and family[22]. Strategies to tackle loneliness at different ages should acknowledge and address the relationship between bereavement and feeling lonely.

We recommend that **volunteers and staff in general community groups (for all ages) should have a basic awareness of the impact of bereavement** and how to have a supportive conversation, so that they are able to make sure that bereaved people feel acknowledged and included. This includes faith groups, which are present in most communities in the provision of bereavement support and have an important role to play in the continuity of support beyond the rituals around a death.

Further, **we recommend the development of community based groups that are specifically for those who have been bereaved**, building on successful examples of bereavement help points and cafes

Reducing additional stresses

The emotional impact of bereavement can be made more complicated and difficult when people are in practical and financial turmoil and crisis. Having to deal with significant administrative tasks while grieving, adjusting to a reduced household income, and dealing with the practical challenges of family life such as juggling work and childcare pose different challenges at different stages of the life course.

We recommend improvements to the practical tasks that people have to do following a bereavement, and to the safety net provided by state benefits to those who have been bereaved. Examples of current campaigns in this area include

- extending Bereavement Support Payment entitlement to cohabiting parents with children
- developing a nationwide cross-industry Bereavement Standard
- allowing people to choose whether to register a death online or in person.

Finding support – signposting and proactive offers

Many people describe the difficulties they have faced in finding bereavement support for themselves and their children. Prior to the pandemic, between 20 and 30% of bereaved adults were not getting the support that they would like from organised services - beyond their

[22] https://www.gov.uk/government/publications/mental-health-and-loneliness-the-relationship-across-life-stages/mental-health-and-loneliness-the-relationship-across-life-stages (Accessed 28 June 2022)

family and friends[23] [24]. We know there are major barriers to people accessing bereavement support. There is evidence that those in greatest need may be more reluctant to seek help[25].

There are both gaps in service provision, and also gaps in knowledge about what services are available. clearly gaps in the support available and how to access them. Signposting may be provided e.g. by hospital bereavement officers or by palliative care staff, but people bereaved in the community often receive no information.

Given the difficulties that people describe in accessing the support they want, **we recommend consistent, high quality information about bereavement support to be available at all 'touchpoints'** such as from funeral directors, registrars, faith groups, coroners, GP surgeries, and the wider community such as libraries and supermarkets. This would also help the general public to connect family and friends to sources of support.

Case study: AtALoss.org, the national signposting website for bereavement services, are developing a national standard for bereavement signposting, covering aspects such as accessibility, reliability and a range of services and choice.

Social prescribers have an important role to play here and **we recommend that all prescribers and community connectors have training in bereavement awareness as well as knowledge of local and national provision.**

We also recommend research to test the feasibility and effectiveness of proactive approaches to offering bereavement support, for example a routine bereavement call from the GP.

National leadership for commissioning bereavement services

There is huge variation in the provision of formal organised bereavement support services across England for children and adults. Services have developed in an ad hoc way, leading to inequities in provision. There have been sector-led attempts to improve consistency (such as the National Bereavement Alliance's *Guide to Commissioning Bereavement Services in England*, and Cruse and the Bereavement Services Association's *Bereavement Care Service Standards*). However, leadership from DHSC and NHS England is needed so that the expectations on commissioners are clear, to drive consistency and quality improvement and address inequities in provision. This should be supported by leadership and coordination of bereavement services in each ICB.

[23] Around 20% of people who register a death say that they would have liked to talk to someone about their feelings about the illness or death, but they did not get this chance. 13.3% did get to speak to someone, and 66.3% had not wanted to (Office for National Statistics (2015) National Survey of Bereaved People (VOICES) 2015)

[24] Sue Ryder found that only 9% of the adults they polled about their experiences of bereavement in the last 5 years had received any support aside from that provided by family or friends. 31% of those who did not receive any formal support said that it would have been helpful (i.e. 28% of those who had been bereaved). Sue Ryder (2019 *A better grief*).

[25] Lichtenthal WG, Nilsson M, Kissane DW, BreitbartW, Kacel E, et al. (2011) Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. Psychiatr Serv. 62: 1225–1229. doi: 10.1176/appi.ps.62.10.1225

Funding to increase capacity in the voluntary sector

The ad hoc development of services and reliance on fundraising rather than a national coordinated approach to service provision have contributed to people people unable to access support. Coronavirus has exacerbated existing inequalities. Services are now faced with greater numbers of bereaved people, grieving more difficult deaths. Coronavirus has made community fundraising more difficult and many services report reduced and precarious income.

In September 2020, 41% of voluntary sector bereavement service managers were already reporting an increase in the number of people seeking their help, with 90% expecting demand to increase further. 80% of voluntary sector bereavement services are having to meet this increased demand from a frozen or reduced income[26].

These pressures are having an alarming impact on the availability of support. 56% of those bereaved during the pandemic who had sought help from bereavement services faced difficulty in accessing support, including limited availability and long waiting lists[27]. Emergency grants, which have been welcome in the short term, are not sufficient to meet the ongoing and future needs of bereaved people. 40% of voluntary sector bereavement service managers will consider closing or further reduce or restrict their services if they do not secure further funding[28].

Despite the case for funding bereavement support being made in submissions to the Comprehensive Spending Review in 2020 and 2021, these crucial services were overlooked. We urge the Government to look again at how this critical provision can be supported for bereaved children, young people and adults, stabilising these services and helping to address the postcode lottery in provision. We recommend

- A specific and intentional approach to funding the bereavement sector, stabilising the voluntary sector response to bereaved people, and enabling the sector to respond to the growing need we have identified
- Investment in research and quality improvement to ensure that the bereavement sector is able to offer the right support to the right people at the right time.

With funding stabilising the sector and strengthening support across the framework[29], we would hope to see a dismantling of the postcode lottery in service availability and the provision of culturally appropriate services, leading to

    - Improved well-being and decreased loneliness and social isolation

[26] Covid-19: the response of voluntary sector bereavement services. Available at https://nationalbereavementalliance.org.uk/ourpublications/covid-19-the-response-of-voluntary-sector-bereavement-services/

[27] E. Harrop et all (2021) *Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic*; https://doi.org/10.1101/2021.06.11.21258575

[28] Covid-19: the response of voluntary sector bereavement services. Available at https://nationalbereavementalliance.org.uk/ourpublications/covid-19-the-response-of-voluntary-sector-bereavement-services/

[29] A guide to commissioning bereavement services in England. Available at: https://nationalbereavementalliance.org.uk/ourpublications/a-guide-to-commissioning-bereavement-services-in-england/

- Reduced levels of mental health difficulties including depression, PTSD and prolonged grief disorder
- Increased attendance, performance and productivity at work and in education
- Substantial decreased use of healthcare and medication.

How can we improve the quality and effectiveness of treatment for mental health conditions?

Tailoring support, demonstrating impact and improving quality

The tailoring of support for bereaved people is inconsistent. While some formal services (which may or may not include paid counsellors or psychologists) are using well-established and validated methods for assessing people's needs and deciding with them what support would fit best, others continue to deliver the same model of support to everyone, regardless of their needs.

Better use of validated assessment tools and evaluation tools would not only ensure that the right support gets to the right people, but would also drive quality improvement in the sector as services gain intelligence on what works for particular groups. A coordinated approach across the sector would also help services to understand how they perform against a national average, and help funders make decisions about how best to support services. Further work is also needed on the development and validation of models of assessment and intervention that meet needs across ethnic and other diversities[30].

Better interface between statutory and voluntary sector

Voluntary sector bereavement service managers and practitioners report difficulties in referring bereaved people with diagnosable mental health difficulties to Tier 4 services, and sometimes lack of knowledge and skills within the statutory sector on addressing bereavement. This can result in voluntary sector services receiving unsuitable referrals, with children's or adults' needs exceeding the support that the voluntary sector service can provide; and services left 'holding' people as they wait for statutory support.

More positive examples exist of voluntary sector services working in partnership with statutory services. This depends on both services working to clear boundaries, having a shared understanding with the person or family being supported about what issues will be addressed by which service, and robust data sharing and safeguarding arrangements.

[30] Mayland CR, Powell RA, Clarke GC, Ebenso B, Allsop MJ (2021) Bereavement care for ethnic minority communities: A systematic review of access to, models of, outcomes from, and satisfaction with, service provision. PLoS ONE 16(6): e0252188. https://doi.org/10.1371/journal.pone.0252188

Prolonged Grief Disorder

Prolonged Grief Disorder (PGD) was included in the World Health Organisation's International Classification of Diseases (ICD) 11th Revision in May 2019 and came into effect on 1 January 2022. The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision (DSM-V-TR) includes PGD as a novel disorder[31], which can be diagnosed when acute grief stays acutely distressing and disabling, beyond 12 months following bereavement, and beyond cultural norms and expectations. There is controversy about the basis and value of a new diagnostic category[32]. Nevertheless, we are concerned by the lack of progress in the UK around implementation of the ICD and in particular, the development of treatments for PGD in a UK context.

We recommend that NICE should be commissioned to develop national guidance for specialist bereavement support, including the treatment of PGD, which would necessarily include a full review of the evidence on prevalence, risk factors and effective approaches.

How can we all improve support for people in crisis?

Support after suicide

The NHS Long Term plan included a welcome commitment to providing proactive bereavement support to those affected by suicide. The roll-out of this programme is well underway in local areas, supported by the information and resources provided by the Support after Suicide Partnership (SASP). We would like to see a greater emphasis on the needs of bereaved children and young people within this provision. We support the submission made by SASP.

[31] https://psychiatry.org/news-room/news-releases/apa-releases-diagnostic-and-statistical-manual-of (Accessed 7 July 2022)

[32] https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(22)00150-X/fulltext (Accessed 7 July 2022)