

National Bereavement Alliance and Childhood Bereavement Network response to Developing the NHS Long Term Plan

The issue

1. 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. 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 issues¹
2. 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.
3. The Childhood Bereavement Network estimates that 23,000 parents die each year leaving around 40,000 newly bereaved children under 18². Many others have been bereaved of a sibling, grandparent or someone else close.

Bereavement and health

4. 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 triggered by loss. However, general awareness and understanding of grief is often lacking, which can leave bereaved people feeling lost and misunderstood. Additionally, bereavement is associated with risks to health and wellbeing and can give rise to a wide range of needs.
5. 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 hospitalisation³. Widow(er)s⁴ and children bereaved of a parent⁵ are more likely to visit their GP.
6. 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 death⁶.

¹ Davidson S and Gentry T (2013) End of Life Evidence Review . London: Age UK

² <http://www.childhoodbereavementnetwork.org.uk/research/key-statistics.aspx>

³ 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>

⁴ Stroebe et al (2007) *ibid*

⁵ 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

⁶ 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

7. 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 year⁷. 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 services⁸ and days off work.

Responses to specific questions

1.3 How should the NHS and other bodies build on existing measures to tackle the rising issues of childhood obesity and young people's mental health?

8. Grief is not an illness, but bereavement does increase young people's risk of mental health difficulties and associated poor health outcomes. Compared to their non-bereaved peers, those bereaved of a parent in childhood have an increased risk of early mortality from all causes, suicide attempt, suicide, serious illness or accident, mental disorder, physical symptoms in the clinical range, risky health behaviours including smoking, drinking and not wearing a seatbelt, unemployment at age 30.
9. All children, young people and their families should be able to access high quality bereavement support easily, wherever they live and however their special person has died. This includes
 - a. Information about how children grieve, what can help and what services there are
 - b. An easy-to-access consultative process to agree who and what could help a particular family
 - c. Support for parents and carers to help their children
 - d. 1:1 support and peer groups for children and young people
 - e. Outreach and specialist support for those who are vulnerable and traumatised.
10. The Childhood Bereavement Network estimates that around 65-70 per cent of local authority areas have an 'open access' service available to any bereaved child in the area, however the death occurred. 85% of these child bereavement services are based in the voluntary and community sector, and funded from a range of sources⁹. CBN members report in-year budget reductions in contracts and grants; late agreement of budgets making it difficult to retain staff; increasing referral rates as statutory services including CAMHS are cut and look to 'export' their caseloads; and increasing complexity of cases.
11. *Transforming children and young people's mental health provision: a green paper* sets out plans including those for community-based mental health support teams. We hope that these teams will complement existing child bereavement services, and help to spearhead their development in areas currently lacking provision. We would urge a more ambitious approach to roll-out so that more children can benefit from these reforms.

⁷ Birrell et al (2013) Socio-Economic Costs of Bereavement in Scotland: Main Study Report.

⁸ 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>

⁹ Rolls L and Payne S (2003) 'Childhood bereavement services: a survey' *Palliative Medicine* vol 17 pp423-432

1.5 What is the top prevention activity that should be prioritised for further support over the next five and ten years?

12. 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.
13. However, some bereaved people will need more support than their families and friends can currently provide. 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 disasters and incidents.
14. The National Bereavement Alliance has built on NICE guidance and the public health model of bereavement to elaborate a three component model of support:
 - a. Universal: information about bereavement and sources of support
 - b. 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
 - c. 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.
15. The three components are interdependent. Without the resources of component 1 and the opportunities for component 2 support, component 3 services would be overwhelmed by people unable to find less intense support, and whose difficulties either may not warrant counselling or therapy, or have escalated because of the lack of easily available support. Without component 2/3 services there would be nowhere to signpost people in greater need, overwhelming friends and families' capacities to support and straining health services that may lack the resources to respond.

1.15 How can we ensure that people, along with their carers are offered the opportunity to have conversations about their priorities and wishes about their care as they approach the end of their lives?

16. Even when they have been caring for someone with a terminal illness, some carers report they were unprepared for the death. Feeling unprepared increases the risk of anxiety, depression and problematic grief following the death among carers of adults and children.
17. Having conversations about the dying person's priorities and wishes should be accompanied by opportunities to prepare the carers for the death, which includes being aware of symptoms and prognosis, being emotionally prepared, and doing necessary tasks such as sorting finances and writing wills. Supporting carers' preparedness for the death may have benefits for bereavement

outcomes¹⁰. Examples of effective interventions include the patient's engagement in Advance Care Planning¹¹ and psychoeducational programme for carers¹², but there is a gap in studies on interventions to support the emotional dimension of preparedness (Nielsen et al 2016).

2.7 What gaps in [mental health] service provision currently exist and how do you think we can fill them?

18. 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 (Shear, 2015; Prigerson et al 2009). 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 feel remorse for their own past behaviour.
19. As described above, mental health services are only part of the picture of health provision for bereavement care. However, it is notable that currently, less than half of people who wanted to talk to someone from health, social care or a bereavement service about their feelings about the death get to do soⁱ. There is also evidence that those who need services the most maybe reluctant to ask for help (Prigerson et al, 2001).
20. 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 adult mental health teams – including reciprocal training, consultation and supervision - could help to bridge this gap.

ⁱ <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>

¹⁰ Caserta, M., Utz, R., Lund, D., Supiano, K., & Donaldson, G. (2017). Cancer Caregivers' Preparedness for Loss and Bereavement Outcomes: Do Preloss Caregiver Attributes Matter?. *OMEGA-Journal of Death and Dying*, 0030222817729610

¹¹ Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of palliative medicine*, 18(2), 127-133.

¹² Hudson, P., Trauer, T., Kelly, B., O'connor, M., Thomas, K., Summers, M., ... & White, V. (2013). Reducing the psychological distress of family caregivers of home-based palliative care patients: short-term effects from a randomised controlled trial. *Psycho-Oncology*, 22(9), 1987-1993