

# Written evidence submitted by the Childhood Bereavement Network to the Health Committee enquiry into Palliative and End of Life Care

## Executive summary

- This submission focuses on the including the availability and quality of bereavement services to children and young people
- We recommend that definitions of end of life care include care into bereavement, for those bereaved suddenly as well as when the death was expected.
- We urge the better collection of data on the number of children bereaved each year, but estimate that around 33,000 children are bereaved of a parent in England each year.
- Bereavement brings significant risks to children's physical and mental health, education, behaviour and self-esteem.
- Parents and carers face significant challenges in caring for bereaved children, which we believe will be worsened by current proposals to reform bereavement benefits. We recommend consideration of our cost-neutral proposals to alter these proposals.
- All schools should have proactive, flexible pastoral support systems in place.
- All bereaved children should be able to access organised support. Pressures are growing on services, largely voluntary sector, which provide this support.
- We recommend that urgent attention is paid to the availability and funding of specialist support, including through inclusion of pre- and post-bereavement support as part of the currency for palliative care funding.

## Introduction

1. The Childhood Bereavement Network is the national hub for those working with children and young people before or after the death of someone important in their lives. We underpin our 250+ members' work with essential representation and support, advocating for bereaved children's needs and helping professionals access the information and support they need to develop high quality services.
2. This response has been prepared by Alison Penny, Coordinator of the Childhood Bereavement Network and Project Coordinator of the National Bereavement Alliance [apenny@ncb.org.uk](mailto:apenny@ncb.org.uk) | 020 7843 6054 | 07894 390 736

## Definitions

3. The inquiry will be looking at the definitions of palliative and end of life care. We would argue that end of life care is that provided to any dying person and their carers and relatives, whether or not their death was expected, and whether or not they had received prior palliative care. We appreciated this specific inclusion in the government's *End of Life Care Strategy* (2008) which

included 'support for carers, both during a person's illness and after their death'. The End of Life Care Pathway offered by the strategy was intended to cover sudden and violent deaths as well as expected ones. **We recommend that any strategy for end of life care should encompass sudden deaths (and bereavements) as well as anticipated ones.**

## Numbers

4. No national data is collected each year on the number of children and young people bereaved of a parent, and this seriously hampers service development and planning. **We urge better data collection on the number of children affected.** In the absence of such data, we rely on studies involving representative samples, and on combinations of mortality and census data.
5. From these sources, we estimate that around 19,100 parents die in England each year, leaving around 33,000 dependent children. Around 90 under-18 year olds are bereaved of a parent every day of every week<sup>i</sup>.
6. Around 3.5% of school age children (aged 5-16) have been bereaved of a parent or sibling<sup>ii</sup>. By the age of 16, around 1 in 20 young people (4.7%) will have experienced the death of a parent<sup>iii</sup>. Many more children will be affected by the death of someone else close: a grandparent, friend or teacher.

## The impact of bereavement on children and young people

7. Bereavement brings change and challenge into the life of a child young person, and can be devastating<sup>iv</sup>.
8. **Physical health:** The death of a parent increases children's risk of somatic symptoms, serious illness, accidents and mortality, with bereaved children being 50% more likely to die before middle age than those not bereaved. They are more likely to show poor or risky health behaviours, with higher rates of substance and alcohol use and early pregnancy.
9. **Emotional and mental health:** Around 1/3 of bereaved children reach clinical levels of behavioural or emotional difficulty during the two years following a parent's death. On average, they have lower emotional well-being and are more likely to have a mental disorder, including depressive symptoms, new-onset depression and anxiety. They have an increase risk of psychosis, and are 70% more likely to have attempted suicide. Those whose parent died by suicide are themselves three times as likely themselves to die by suicide.
10. **Education and employment:** children bereaved of a parent report significantly lower concentration and score an average of half a grade lower at GCSE than their non-bereaved peers. Girls bereaved of a sibling scored almost a full grade lower than their matched controls. After controlling for other factors, the death of a parent by the age of 16 is associated with women failing to gain any sort of qualification, and with men and women being unemployed at the age of 30.
11. **Criminal and disruptive behaviour:** the death of a parent by the age of 26 increases young people's risk of conviction for violent offences. Children bereaved of a parent are

overrepresented among those under supervision by Youth Offending Teams, persistent young offenders, and those convicted of grave crimes.

12. **Self-confidence and life satisfaction:** children bereaved of a parent feel less able to effect change in their lives, and have significantly lower self-esteem than their non-bereaved peers. They report lower life satisfaction. Conversely, some children and young people report how they have grown and developed through their experiences.

## **What do children and young people need around a death? What challenges does this pose for their carers?**

13. Following his longitudinal study of children and young people bereaved of a parent, William Worden<sup>v</sup> identified ten needs which most children will share. These are adequate information; having their fears and anxieties addressed; being reassured that they are not to blame; careful listening to their fears, fantasies and questions; validation of their feelings; help with overwhelming feelings; being involved and included; continued routine activities; modeled grief behaviours; and having opportunities to remember.
14. In the first instance, these needs are met by their friends and family. The capacity of the surviving parent to care for a bereaved child is a critical factor in how the child manages to live with the death.

### ***Challenges before a death***

15. When a death is expected, parents can struggle to have open, supportive conversations with their children. There may be little time to talk about what is happening and reassure children about the changes they are facing. The uncertainties of a journey through illness can leave parents struggling to give children clear and consistent information<sup>vi</sup>.
16. There are emotional barriers to talking, too. Sometimes parents are worried about breaking down in front of their child or don't want to upset them with difficult news. Yet shielding children from conversations about an impending death means they may not have the opportunity to develop healthy coping strategies, and studies have shown that their anxiety is greater when communication is poor<sup>vii</sup>. Silences or taboos leave children alone with their fears, and being excluded from conversations can diminish their trust in the adults who want to support them.

### ***Challenges after a death***

17. Following a death – whether expected or sudden - while parents and carers are grieving themselves, it can be a great strain to support their children. Surviving spouses living alone with dependent children report more distress than those without children<sup>viii</sup>. They have a range of additional demands, including responding to their children's emerging needs over time. Many report that the second and subsequent years following a death are even harder than the first, as the reality of their new circumstances sinks in. Studies indicate a 'late effect' of bereavement with some children showing new and greater difficulties two or three years after the death of parent<sup>ix, x</sup>, despite a relatively mild initial reaction. Regardless of the age at which they were

bereaved, children often revisit or re-experience their grief as they mature cognitively and emotionally<sup>xi</sup> and face additional changes such as starting school, bringing new parenting challenges for their surviving mother or father.

18. Stability is key. Children and young people need as much continuity as possible following the death of a parent. Stressful changes and disruptions which accompany or follow a death (such as moving house or school, changed household routines and childcare arrangements) are associated with worse mental health<sup>xii</sup>, and the longer these changes persist, the greater the effect<sup>xiii</sup>. Studies suggest that a drop in income and the changes in lifestyle this brings are more predictive of mental health difficulties than the level of income per se<sup>xiv</sup>.
19. Widowed parents have to make a new role for themselves as a single parent – a role which they have not chosen. Childcare and access to flexible working can be a significant barrier to returning to work – both for those who had been working prior to their bereavement, and for those who had previously been stay-at-home primary carers.
20. The bereavement care which parents and carers can provide to children and young people is closely bound up with the welfare benefits system supporting widowed parents. We have serious concerns about the impact of forthcoming changes to bereavement benefits. Currently paid until the youngest child leaves full-time education, the new benefit will be paid for just one year. Using DWP figures, we estimate this will make 75% families worse off (88% of those in work, 57% of those out of work).
21. **We have developed cost-neutral proposals which would allow for widowed families to receive payments – and the breathing space they bring – for three years rather than one. We urge the Government to consider these proposals.**

## Support in school

22. Other adults in children's lives such as teachers and other children's workers often report feeling unsure and uneasy when faced with children before and after a death in the family: worried about making the situation worse or of becoming overwhelmed themselves.
23. We recommend that all schools should have:
  - A lead person with responsibility for ensuring that pastoral support is proactive and flexible
  - Checking with individual bereaved children, young people and families how they would like to be supported
  - A system for managing a system for managing and communicating important information about a bereavement, including across transitions from one class or school to another
  - Bereavement being included in relevant plans and policies
  - Staff training and support to increase their awareness and confidence in providing day-to-day support to a bereaved child

- Staff training and support in delivering lessons on loss, change and bereavement as part of the PSHE curriculum
- Swift and easy referral to a range of provision including local child bereavement service, national helplines and websites
- Partnerships with childhood bereavement services. For a directory, see [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

## What about organised, specialist support?

24. While recognising that the vast majority of bereavement care for children and young people is provided by their friends, family, school and immediate community, **we believe that all bereaved children and their families should have access to organised support if they choose to use it.** The components of such local support are

- Information about how children grieve, what can help and what services there are
- An easy to access consultative process to agree who and what could help a particular family
- Support for parents and carers to help their children
- 1:1 support and peer groups for children and young people
- Outreach and specialist support for those who are vulnerable or traumatized.

25. Bereavement is a change and may be a crisis, but it is not an illness. It increases the risk of difficulties, but does not make them inevitable. Around one third of bereaved children and young people will reach clinical levels of difficulty. The model of organised support offered by many child bereavement services is perhaps more akin to the psycho-educational model of antenatal services than the medical model of specialist CAMHS services. This support helps any bereaved child adapt to a changed life: it also allows for screening and treatment of those who are struggling more or at increased risk.

**26. To underpin this support, we recommend that the local authority and clinical commissioning group should work with other services to make sure they know how many children and young people have been bereaved that year, and what services they need. They should also ensure that adult who work with children get training and support to understand how they might help someone who has been bereaved, and where to find extra support.**

## How available is this support?

27. Currently, the provision of universal bereavement services for children is inconsistent and vulnerable. 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 sources<sup>xv</sup>.

28. Our 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.
29. **We recommend that urgent attention is paid to the availability and funding of specialist support, including through inclusion of pre- and post-bereavement support as part of the currency for palliative care funding.**

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<sup>i</sup> Rounded to the nearest 100. This combines age-banded mortality statistics (2011) from the Office of National Statistics with 2011 census data on the proportion of adults living with dependent children, and on the average number of dependent children by family type.

<sup>ii</sup> This combines mid-term population estimates (ONS 2013) with data from a nationally representative sample of 7,977 children aged 5–17, which found that 3.5 per cent had been bereaved of a parent at some point in their childhood. Fauth, B, Thompson, M and Penny, A (2009) *Associations Between Childhood Bereavement and Children's Background, Experiences and Outcomes: Secondary Analysis of the 2004 Mental Health of Children and Young People in Great Britain Data*. London: National Children's Bureau.

<sup>iii</sup> This is the percentage of young people in the 1970 British Cohort Study (BCS1970) who had been bereaved of at least one parent by the age of 16. Parsons, S (2011) *Long-term Impact of Childhood Bereavement: Preliminary Analysis of the 1970 British Cohort Study (BCS70)*. London: Child Well-being Research Centre.

<sup>iv</sup> All references in this section taken from Penny and Stubbs (2014) *Childhood Bereavement: what do we know in 2015?* London: National Children's Bureau. Full citations available from Alison Penny.

<sup>v</sup> Worden, WJ (1996) *Children and Grief: When a Parent Dies*. New York: Guilford Press.

<sup>vi</sup> Eg Kennedy, Vida L.; Lloyd-Williams, Mari (2009) Information and communication when a parent has advanced cancer. *Journal of Affective Disorders*. Vol 114(1-3), 149-155.

<sup>vii</sup> Siegal, K; Karus, D; Raveis, V (1996) 'Adjustment of children facing the death of a parent due to cancer' *Journal of the American Academy of Child and Adolescent Psychiatry* 35: 442-450

<sup>viii</sup> Lin, K et al (2004) Resilience in parentally bereaved children and adolescents seeking preventive services *Journal of Clinical Child and Adolescent Psychology*. 33:4, 673-683.

Worden JA (1996) *Children and Grief: When a parent dies* New York: Guilford Press

<sup>ix</sup> Worden JA (1996) *Children and Grief: When a parent dies* New York: Guilford Press

<sup>x</sup> Christ (2010) 'Children bereaved by the death of a parent' In Corr, C and Balk D (eds) *Children's Encounters with Death, Bereavement and Coping* New York: Springer Publishing Company

<sup>xi</sup> Christ (2010) 'Children bereaved by the death of a parent' In Corr, C and Balk D (eds) *Children's Encounters with Death, Bereavement and Coping* New York: Springer Publishing Company

<sup>xii</sup> Haine, R.A., Ayers, T.S., Sandler, I.N. and Wolchik, S.A. (2008). Evidence-based practices for parentally bereaved children and their families. *Professional Psychology: Research and Practice*, 39(2)

<sup>xiii</sup> Worden JA (1996) *Children and Grief: When a parent dies* New York: Guilford Press

<sup>xiv</sup> Lin, K et al (2004) Resilience in parentally bereaved children and adolescents seeking preventive services *Journal of Clinical Child and Adolescent Psychology*. 33:4, 673-683.

<sup>xv</sup> Rolls L and Payne S (2003) 'Childhood bereavement services: a survey' *Palliative Medicine* vol 17 pp423-432