

Childhood Bereavement Network response to the Palliative Care Funding Review

About this response

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.

This response has been informed by discussions with professionals working with bereaved children and their families at CBN regional seminars in London, Leicester, Leeds, Birmingham, Liverpool and Waterlooville, and findings from consultations with children, young people and families. It also represents discussions at a preliminary meeting with members of the Review Team on 24 February 2011 at NCB. Attendees included representatives from Cruse Bereavement Care, the Child Bereavement Charity, the Candle Project at St Christopher's Hospice, Changeworks West Sussex, Wakefield Hospice STARS project, St Kentigern Hospice, Spurgeon's Beyond the Horizon, Saying Goodbye.

If a patient dies in unexpected circumstances, the NHS would not automatically fund bereavement support. Would it therefore be appropriate to include this as a statutory responsibility in palliative care, and what is the evidence to support this?

1. We challenge the assumption that the NHS would not automatically fund bereavement support if a patient dies in unexpected circumstances. Cruse Bereavement Care and the Bereavement Services Association estimate that 80% of hospitals in England now have a bereavement service and more than 90% give information about services in the communityⁱ.
2. Following inquiries at Bristol Royal Infirmary and Royal Liverpool Children's Hospital, the then Chief Medical Officer, Sir Liam Donaldson recommended that *'all NHS Trusts should provide support and advice to families at the time of bereavement'*ⁱⁱ. The Chief Executive of the NHS reminded Trusts of this important area of work during 2004ⁱⁱⁱ and this work is framed by the 2005 DH guidance *When a patient dies: advice on providing bereavement services in the NHS*. This document focused particularly on deaths in hospital – it is currently under revision and will have a greater focus on deaths in the community.
3. Cruse Bereavement Care and the Bereavement Services Association have identified a gap between hospital based and community-based bereavement services, and are currently funded by the Department of Health to run a *Gold Standard Project* to help bridge this to provide a more seamless service to families.

Should bereavement, psychological and psychiatric care (for the patient and family) be wholly or partly a statutory responsibility and/or wholly or partly provided by society?

4. There is a difference between being responsible for care, commissioning/funding care, and providing care. At present, responsibility is unclear, and as a result, the proportions of the state/society mix of funding and of provision vary greatly from area to area.
5. At present, the lion's share of bereavement support for children and young people is provided by their families, communities and wider society. While they should continue to respond to the immediate needs of bereaved children and young people, we need **greater** and **more consistent** state funding to lever in and underpin this support. Services delivered early and flexibly to bereaved children and young people form part of a preventative, public health approach to bereavement, which builds on their strengths and helps them to develop a resilient mindset^{iv}, bringing enduring benefits for the way they deal with future difficulties. By improving outcomes for bereaved children and young people, these services are delivering significant cost savings to society both in the immediate and long term.
6. We would like to see a stronger statutory responsibility for coordinating the provision of bereavement support for children and young people. This would include
 - a. gathering information about the numbers of children affected by the death (or expected death) of someone close. This could be collected by the GP or registrar.
 - b. disseminating information about how children grieve and what services are available
 - c. providing an easy to access consultative process for to determine who and what could help a particular family
 - d. funding for support for parents, 1:1 and peer groups for children and young people, commissioned on a population basis from a range of providers
 - e. a funding premium for support for children and young people who have additional needs affecting their bereavement (eg learning disabilities, offending behaviour, a parent with a significant mental health difficulties)
 - f. training for the children's workforce to demonstrate how they might help someone who has been bereaved, and where to find extra support.
7. There are some benefits to a funding mix for childhood bereavement services – fundraising from the community can raise the profile of a service, increasing referrals as well as other forms of support such as volunteering. It can also allow a service to be more flexible in the way it delivers its services. However, this additional funding for services **must** be underpinned by a planned, sustained financial contribution from the state to meet its identified responsibilities outlined in the policy framework (see below, paras 29-31).

Bereavement and its impact on children and young people

8. Bereavement brings change and challenge into the life of a young person, and can be devastating. Around 1 in 29 children and young people have experienced the death of a parent or sibling^v, and many others have been bereaved of someone else close. While some bereavements are experienced as a normal part of growing up, others can be highly disruptive to a child's life^{vi}.
9. We know that bereavement increases the risk of poor outcomes for children and young people – particularly those already in disadvantaged circumstances - and that these outcomes can be costly: to individuals, families and society. Children and young people who have been bereaved of a parent or sibling have more somatic symptoms, accidents^{vii}, and serious illnesses requiring hospitalisation than their peers^{viii}, and consult the GP more often^{ix}. They are 55% more likely to have a diagnosable mental health disorder^x. They are 60% more likely to have been excluded from school^{xi}, and may underachieve at GCSE^{xii}. Girls are more likely than their peers to use drugs and have an early pregnancy^{xiii}. Persistent young offenders are at least four times as likely as the general population to have been bereaved of a parent^{xiv}. Young people bereaved of a parent through suicide are themselves more likely to die by suicide or to be hospitalised for psychiatric difficulties^{xv}.
10. Some young people identify that not getting help at the right time has meant their difficulties escalate. One young woman who had spent time in a psychiatric unit wrote to CBN member Jigsaw4u:

I was 10 when my mum died... After she died I was so upset. All I wanted was someone to talk to but instead they punished me by sending me away. I was in care – why would no one talk with me ... why didn't anyone understand? In the end I suppressed my feelings, because I hadn't been told how to deal with my feelings. They still came through though, but in wrong ways. I would be rude to people, have fights and get into trouble all the time. I was angry and misunderstood. I got bullied so I bullied other people. I never got help because I was in the unit.
11. Bereavement at any age takes adjustment to a new life, but for children and young people, the journey of grief takes place alongside their journey into adulthood. As they get older and develop new understandings of the relationship they have lost, they often revisit their grief and experience and express it in new ways, frequently at times of further loss or change^{xvi}.

Bereaved children's needs

12. William Worden's comparative study of parentally bereaved children and their peers 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.

13. These needs are met primarily by their friends and family, and Worden found that the capacity of the surviving parent to care for a bereaved child was the most critical factor in determining a positive outcome for the child. Family factors associated with children doing better included continued routines, the surviving parent being physically and emotionally available and perceiving the child's needs and behaviour in a similar way to how the child perceived them, consistent discipline and active coping strategies^{xvii}.
14. When a death is expected, parents can struggle to have open, supportive conversations with their children. Dealing with the complexities of palliative care and managing changes to family routines can mean there is 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^{xviii}.
15. 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 mean they may not have the opportunity to develop healthy coping strategies, and studies have shown that their anxiety is greater when communication is poor. Even families with previously good patterns of communication can show poor communication around a parent's diagnosis or impending death^{xix}. 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.
16. Following a death, while parents and carers are grieving themselves, it can be a great strain to support their children. 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.

The wider context of support – what needs to be in place

17. While recognising that the lion's share of bereavement care for children and young people is provided by their friends, family 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 support are shown in figure 1 below.

To underpin this support, the local authority and primary care trust 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.

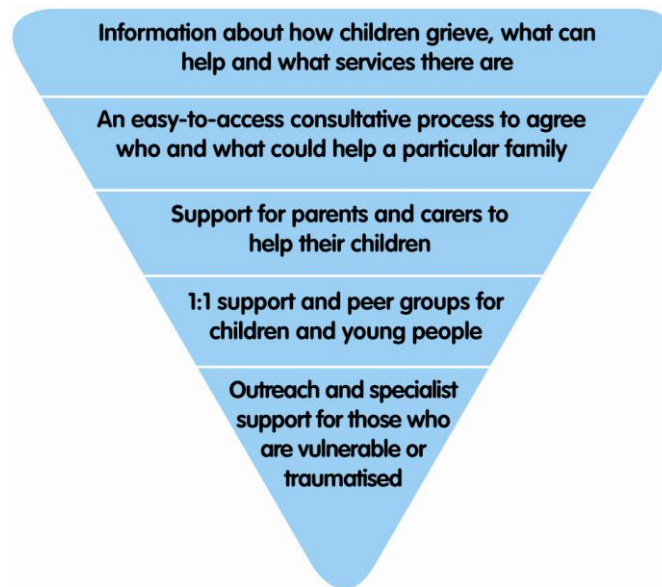


Figure 1: what good provision for bereaved children looks like

To play their part, each school should have sensitive and flexible people and systems who provide support and information to children and staff when someone is dying or has died, and opportunities for children and young people to learn about death and bereavement as part of life.

The social, psychological and economic impact of interventions

18. Childhood bereavement services aim to help children and young people find healthier ways of coping, which can support them to avoid the difficulties outlined above. A controlled evaluation of an intervention found that timely support could improve bereaved children’s mental health, and that these impacts grew over time, as well as improved parental coping and warmth^{xx}. Children, young people and their parents report that services make them feel less isolated, help them to make sense of what has happened, reduce their anxiety, improve communication within the family, improve confidence and parenting, and relieve them through exploring and expressing feelings^{xxi}.
19. Increasing investment in services which intervene early in children’s lives when problems emerge is recognized to be an important way of making cost savings in the future^{xxii}. It is always difficult to calculate the cost savings of programmes which are essentially preventing the emergence of more serious difficulties and their associated individual and societal costs.
20. In the case of childhood bereavement services, these difficulties are compounded by the diversity of service delivery models across the field – including differences in the ratio of paid staff to trained volunteers; differences in family sizes; differences in the needs of individuals between and within families. Some families will manage well following a series of reassuring telephone calls, others will need more intense face to face support. Some will access the service once, while others will make use of the ‘extended warranty’^{xxiii} and come back to the service for more help at times of future change. For

these reasons we have found it difficult to develop a unit cost for an intervention with a bereaved child and are instead developing a 'cost avoidance' calculator.

21. We can estimate that an intervention with a bereaved child costing £1000 would save in the short to medium term
 - a. at least £1320 if it improved the child's attendance at school over four months avoiding the need for intervention from a Education Welfare Officer^{xxiv}
 - b. at least £2,735 if it avoided the need for the child's involvement with a Tier 2-3 CAMHS (Child and Adolescent Mental Health Team)^{xxv}
 - c. at least £5,000 if it avoided the child being permanently excluded from school for a period of 4 months^{xxvi}.
22. Looking further ahead to include the total lifetime costs to an individual and society (including health, education, lost earnings, crime and social services), New Philanthropy Capital estimates^{xxvii}
 - a. Persistent truancy costs to be £44, 468 (thus a bereavement intervention costing £1,000 and returning a child to full attendance would represent a saving of £43,468)
 - b. Permanent exclusion in 2005 to cost £63, 851 (thus a bereavement intervention costing £1000 and avoiding this exclusion would represent a saving of £62,851).

Current provision and the impact of public sector cuts

23. The majority of services also offer training and support to local children's professionals such as teachers, GPs, and early years staff, helping them to respond to the day to day needs of bereaved children, young people and their families. It is vital that this focus on broadening support for bereaved children and young people is not lost through a new funding mechanism.
24. Currently, around between 65 and 70 per cent of local authority areas have an 'open access' available to any bereaved child in the area, however the death occurred. Other services may be available to certain children, such as care from a hospice where the child's parent or other relative has died. 85% of these child bereavement services are based in the voluntary and community sector^{xxviii}. These services are deeply rooted in communities, developed according to local needs and helping children's existing networks of family, school and community to support children over time as their response to their loss changes and develops, and as they encounter further losses in the future. Services receive referrals from schools, CAMHS, GPs and other professionals, who value their provision, although often do not fund it.
25. These services are currently funded through a variety of sources (see table 1) and often

Table 1: Sources of childhood bereavement service funding from p426 of Rolls L and Payne S (2003) 'Childhood bereavement services: a survey' Palliative Medicine vol 17 pp423-432

Source of funding	% of services in receipt of funding	n
Donations/legacies	82	75
Fundraising	79	72
Grants	46	42
Income generation (training)	32	29
Revenue	13	12
Sponsorship	11	10

struggle to keep their services afloat. They may not be able to cope without extra resources if their profile rises and demand increases.

26. Moreover, because the vast majority - 87%^{xxix} - are reliant to some degree on volunteers, they are an important and long-serving example of the Big Society at work. Volunteers support services with fundraising, governance, publicity, administration, and direct grief support with children and young people. Many of these volunteers are highly qualified professionals and contribute a wide range of knowledge and experience to the sector. Volunteers' enthusiasm for their role and knowledge of their local community can increase awareness of and support for a service, which can result in referrals and funding. Sharing their wide life experience and expertise can generate exciting ideas for service development and re-energize paid staff in their own direct work. Their involvement reinforces that grief is a natural response and not an illness^{xxx}. However, it is important to remember that while using volunteers does save money, it is not without costs. These include recruitment, selection, training, induction and supervision, insurance, travel and other expenses. Paid staff may not be able to deliver all the training necessary and their time invested in supporting volunteers – often a significant amount particularly in the early stages of volunteering – takes them away from other work.

27. In our recent round of CBN regional meetings, services have been describing some of the impacts of public service cuts on their organizations. These include in-year budget reductions in contracts and grants; late agreement of budgets making it difficult to retain staff; increasing referral rates as other services (such as behavioural support in school, CAMHS services) are cut and look to 'export' their caseloads; increasing complexity of cases.

What are the current levers for funding bereavement care and bringing about improvements in the quality of service provision, and how well are they working?

28. Support for bereaved children meets government priorities set out in key documents across end of life care and children and young people's mental health. While the current levers provide a comprehensive and convincing justification, they are not applied consistently or strongly.

29. End of Life Care

- a. The Department of Health's End of Life Care Strategy (2008)^{xxxii} states that bereavement care and support needs to be readily available and offered to all carers, family members and friends. *'This is particularly important for children facing and then coping with the death of someone important in their lives'* (Sec 5.17, p112).

It states that all health, social care and other emergency organizations providing care at the end of life and into bereavement should provide information on *'comprehensive and culturally appropriate bereavement services'*. This should include *'support for sudden death and also the needs of children and the challenges of parenting them'* (Sec 5.25, p114).

- b. The Department of Health's *When a patient dies: advice on developing bereavement services in the NHS* (2005)^{xxxiii} recommends that children's needs for information, privacy to spend time with the family or with the body, and specialist bereavement support services should be addressed.
- c. The National Institute for Clinical Excellence's *Improving supportive and palliative care for adults with cancer* (2004) recommends a three-component model of bereavement support, including specialist interventions for children and young people (sec 12.30).
- d. The *Liverpool Care Pathway* now includes links to information for children and young people facing the death of someone important in their lives^{xxxiii}.

30. Children and young people's mental health

- a. *No health without mental health: a cross-Government mental health outcomes strategy for people of all ages* (2011) intends a wholesale shift to put mental health outcomes alongside physical health indicators in assessments of the quality of the NHS. This strategy is accompanied by a four year plan for the talking therapies programme, which includes a focus on children and young people. There is broad consensus about the policy framework for children's mental health services.
- b. Many of the aspirations of the *National Service Framework for Children, Young People and Maternity Services: the mental health and psychological well-being of children and young people* (2004 – London: DH) and its underpinning principles remain relevant. This sets out a vision of a comprehensive CAMHS.
- c. *Children and Young People in Mind* (2008)^{xxxiv}, the report of the Independent Review of CAMHS, listed the groups of children and young people included in their use of the term 'vulnerable' – this included children and young people who have been bereaved. *'These are groups that service managers, providers and commissioners need to ensure they consider and plan for'* (Annex E p116)
- d. *Targeted Mental Health in Schools – Using the evidence to inform your approach: a practical guide for head teachers and commissioners* (2008)^{xxxv}

summarises existing knowledge about effective interventions to help make decisions about how to plan and commission work. Section three covers the evidence on targeted interventions for children in five sets of circumstances that pose a risk to mental health. Childhood bereavement is covered in some depth:

- e. *Standard 2 of the National Service Framework for Children, Young People and Maternity Services : Supporting Parents* sets out that local health, education and social care agencies should provide information to parents on services to support them and their children through disrupted relationships and bereavement (sec 4.2, p71). It also says that PCTs, local authorities and the voluntary sector, working in partnership with providers, need to ensure that local planning addresses the needs of parents who are experiencing problems as a result of disrupted relationships and bereavement (sec 6.5, p76)
- f. *Standard 8: Disabled Children and Young People and those with Complex Health Needs*^{xxxvi} sets out that paediatric palliative care services should provide high quality, sensitive support that takes account of the physical, emotional and practical needs of the child or young person's family, including their siblings (sec 5.15, p33). Following the death of a child, whether sudden or anticipated, families should receive ongoing support to cope with their loss (sec 5.18, p35)
- g. *Promoting social and emotional well-being in primary education (2008)*^{xxxvii} sets out the National Institute for Clinical Excellence's formal guidance. It includes recommendations that staff in schools should be trained to identify and assess early signs of anxiety and emotional distress, including among children who are at higher risk including those who have been bereaved. They should be able to discuss options with the child and their parents, make appropriate referrals and provide an appropriate range of interventions.

31. We anticipate that important additional future levers will include the NHS and Public Health Service Outcomes Framework, the NICE Quality Standard for End of Life Care, and revisions of the DH guidance *When a patient dies*, and the *UK Bereavement Care Standards*.

ⁱ Cruse Bereavement Care/Bereavement Services Association (2011) *Gold Standard Bereavement Care Project information*

ⁱⁱ Department for Health, Department for Education and Employment, Home Office (2001) *The removal, retention and use of human organs and tissue from post-mortem examination. Advice from the Chief Medical Officer*

ⁱⁱⁱ Department of Health (2004) *Chief Executive's Bulletin 4 April 2004*

^{iv} Stokes J (2007) Resilience and bereaved children: helping a child to develop a resilient mind-set following the death of a parent. In Monroe B and Oliviere D (eds) *Resilience in Palliative Care – Achievement in Adversity* Oxford: OUP

^v Fauth, B; Thompson M; Penny A (2009) *Associations between childhood bereavement and children's background, experiences and outcomes: Secondary analysis of the Mental health of children and young people in Great Britain 2004 data* London: NCB

^{vi} Ribbens McCarthy, with Jessop, J (2005) *Young People, Bereavement and Loss: Disruptive transitions?* London: NCB

^{vii} Worden, WJ (1996) *Children and grief: when a parent dies*. New York: Guilford Press

^{viii} Fauth, B; Thompson M; Penny A (2009) *ibid*

^{ix} 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

^x Fauth, B; Thompson M; Penny A (2009) *ibid*

^{xi} Fauth, B; Thompson M; Penny A (2009) *ibid*

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- ^{xii} Abdelnoor A and Hollins S (2004) The effect of childhood bereavement on secondary school performance *Educ. Psych. in Practice* 20(1) 43-54
- ^{xiii} Sweeting, H West, P, and Richards, M (1998) 'Teenage family life, lifestyles and life chances: associations with family structure, conflict with parents and joint family activity', *International Journal of Law, Policy and the Family*, 12.
- ^{xiv} Vaswani, N (2008) *Persistent Offender Profile: Focus on bereavement*. Criminal Justice Social Work Development Centre for Scotland Briefing Paper 13. www.cjsw.ac.uk
- ^{xv} Wilcox et al (2010) Psychiatric morbidity, violent crime and suicide among children and young people exposed to parental death. *Journal of the American Academy of Child and Adolescent Psychiatry* 49, 5
- ^{xvi} Christ, G H (2000) *Healing Children's Grief* New York: OUP
- ^{xvii} Worden, J W (1996) *Children and Grief: when a parent dies* New York: Guildford
- ^{xviii} 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.
- ^{xix} 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
- ^{xx} Sandler, I and others (2003) 'The Family Bereavement Program: Efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents', *Journal of Consulting and Clinical Psychology*, 71.
- ^{xxi} Rolls, L., and Payne, S. (2007) Children and young people's experiences of UK childhood bereavement services, *Mortality* 12, 3, 281-303
- ^{xxii} Allen, G (2011) *Financing Early Intervention: Interim Paper*
- ^{xxiii} Monroe B and Kraus F (Eds) *Brief Interventions with Bereaved Children* Oxford: OUP
- ^{xxiv} National CAMHS Support Service (2010) *The costs of TaMHS Interventions and potential avoidance of associated costs of treating escalated mental health problems or providing social care – emerging information from the South West Region*
- ^{xxv} National CAMHS Support Service (2010) *ibid*
- ^{xxvi} National CAMHS Support Service (2010) *ibid*
- ^{xxvii} <http://philanthropycapital.org/download/default.aspx?id=352> p12
- ^{xxviii} Rolls, L and Payne S (2003) Childhood bereavement services: a survey *Palliative Medicine* 17, 423-432
- ^{xxix} Rolls, L and Payne S (2003) Childhood bereavement services: a survey *Palliative Medicine* 17, 423-432
- ^{xxx} Nicol-Harper R (2009) Working with volunteers to provide grief support to children. In Monroe B and Kraus F (Eds) *Brief Interventions with Bereaved Children* Oxford: OUP
- ^{xxxi} http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
- ^{xxxii} http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4122191
- ^{xxxiii} <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/documentation-lcp.htm#Supporting%20Children>
- ^{xxxiv} <http://www.dcsf.gov.uk/CAMHSreview/>
- ^{xxxv} <http://publications.everychildmatters.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductID=DCSF-00784-2008&>
- ^{xxxvi} http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090556.pdf
- ^{xxxvii} National Institute of Clinical Excellence <http://www.nice.org.uk/Guidance/PH12>