Supporting families after the unexpected death of a child

**Greater access to multidisciplinary bereavement services is essential**

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Globally, more than 6.2 million children die before the age of 19 each year, with many of these deaths occurring suddenly or unexpectedly.1 Sudden unexpected death in infancy and childhood (SUDIC) refers to deaths not expected within 24 hours, encompassing causes such as unintentional injury, suicides, homicides, sudden cardiac death, and deaths from unexplained medical conditions. In higher income countries, where advances in neonatal care and vaccination programmes have reduced child mortality, sudden unexplained death now constitutes one third of all child deaths.2 Such events are deeply traumatic for families and may result in severe and enduring psychological distress across generations.3 Support is often inadequate, even in countries with established children’s services and bereavement care.

Bereaved families are highly vulnerable and often unable to advocate for themselves.4 The associated trauma profoundly affects family physical and mental health and can trigger post-traumatic stress disorder, acute anxiety, and depression.5 Parents who experience the unexpected death of a child are at greater risk of severe psychological distress than other bereaved parents including suicidal ideation, particularly early in bereavement.6

Investigations into the cause of death often involve liaising with police, coroners, and medical examiners, which can exacerbate distress. This may be compounded by the wait for a postmortem examination and to learn why the child died, and by interactions with legal systems and multiple professionals.4 7 8 In the UK, Jack’s law extended statutory parental bereavement leave to two weeks.9 However, evidence based, trauma informed approaches to support families in the immediate and longer term are urgently required. Many families find themselves isolated and without bereavement support,4 8 compounding their vulnerability and distress.10

SUDIC also causes stress and trauma to people working with bereaved families. Most professionals receive no specific training in providing appropriate care11 and lack formal support from their employers, leaving them open to longer term adverse effects of traumatic exposure.12 Staff need training, peer support, and psychosocial interventions, such as debriefing and stress management, to protect their mental health and support them in delivering compassionate care. Some training initiatives exist,13 but these are inconsistent across regions.

Inequity in care

Families experiencing sudden bereavement require a highly skilled and sensitive response from professionals with expertise in end-of-life care and child death,14 but in practice this response is varied. In Sweden, national guidelines mandate immediate psychological and logistical support for families, ensuring that bereavement care begins immediately after a child’s death.15 In England, the joint agency response framework mandates multiagency collaboration for SUDIC. Statutory guidance on child death reviews outlines the importance and role of a key worker as a single point of contact for the bereaved family,16 and some regions offer specialised SUDIC professionals as key workers who can provide emotional support alongside the review process. In Wales, the charity 2Wish offers community based bereavement care to all families affected by SUDIC and coordinates with police, emergency services, and health providers to offer immediate support that extends well into bereavement. These models demonstrate the potential for consistent and compassionate responses to SUDIC, but availability and quality vary substantially across regions.13

In Australia, several states have implemented paediatric palliative care networks that integrate bereavement support for SUDIC into their standard response.17 England’s palliative care framework acknowledges the need for palliative care for unexpected deaths,14 and several children’s hospices in England have responded by offering a dedicated SUDIC service, working alongside the joint agency response,4 8 that includes access to a cold bedroom (a facility that enables families to spend time with their deceased child in a private, supportive environment)18 and bereavement counselling. However, while families value these services, psychological benefits remain anecdotal. Robust evaluation, including input from families, is needed to measure the effectiveness of these interventions using clear, trauma informed metrics that consider both the immediate and longer term needs of bereaved families.

Guidance on palliative and end-of-life care for children, such as from the World Health Organization, National Institute for Health and Care Excellence, and the European Association for Palliative Care highlight palliative care teams’ focus and expertise in holistic family support, sibling care, and bereavement services.19-21 But the historical focus of these services on life limiting conditions means their workforce is not routinely deployed to families affected by a sudden unexpected death.

Integrated care for families should include coordination between emergency services, child death review professionals, and bereavement care. It should ensure culturally sensitive individualised care for the entire family that extends beyond the period of death investigation. Key components include home visits, trauma informed counselling, sibling support, practical support with legal, financial, and funeral processes, and opportunities for the family to spend time with their child’s body.4-6 18 Specialist key workers should coordinate families’ immediate and ongoing care.

Evaluative research will determine the optimal ways to support families, with fair access to care. Palliative care services are well positioned to lead, but effective care after a sudden unexpected death of a child will require an integrated, cross disciplinary response.

Competing interests: We have read and understood BMJ policy on declaration of interests and declare that IF is director of Living and Dying Well (non-financial) and vice president of Hospice UK and Marie Curie.

Provenance and peer review: Commissioned, based on an idea from the author; externally peer reviewed.

This editorial builds on the pioneering contributions and dedicated efforts of the following people and organisations: Joanna Garstang, Nikki Speed, Emily Cooper, Emma Kneebone, Sarah Hodkinson, Stacey John, SUDC UK, 2Wish, Shooting Star Children’s Hospice, and Forget Me Not Children’s Hospice. David Wright contributed to finalisation of the manuscript.

**References**

1. World Health Organization. Child mortality and causes of death. 2024. https://www.who.int/data/gho/data/themes/topics/topic-details/GHO/child-mortality-and-causes-of-death

2. Williams T, Sleep V, Pease A, et al. Sudden and unexpected deaths in infancy and childhood. National Child Mortality Database Programme Thematic Report. 2022. https://www.ncmd.info/publications/sudden-unexpected-death-infant-child/

3. Lichtenthal WG, Corner GW, Sweeney C, Roberts KE. Grieving the traumatic death of a child. In: Black BP, ed. Perinatal and pediatric bereavement in nursing and other health professions. Springer, 2015: 249-69. doi:10.1891/9780826129277.0014

4. Garstang J, Griffiths F, Sidebotham P. Rigour and rapport: a qualitative study of parents’ and professionals’ experiences of joint agency infant death investigation. BMC Pediatr 2017;17:48. PubMed doi:10.1186/s12887-017-0803-2

5. Morris S, Fletcher K, Goldstein R. The grief of parents after the death of a young child. J Clin Psychol Med Settings 2019;26:321-38. PubMed doi:10.1007/s10880-018-9590-7

6. Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. Lancet 2007;370:1960-73. PubMed doi:10.1016/S0140-6736(07)61816-9

7. Batra EK, Quinlan K, Palusci VJ, Needelman H, Collier A; AAP Section on Child Death Review and Prevention; Council on Injury, Violence, and Poison Prevention; Council on Child Abuse and Neglect. Child fatality review. Pediatrics 2024;153:e2023065481. PubMed doi:10.1542/peds.2023-065481

8. Fleming P, Pease A, Ingram J, et al. Quality of investigations into unexpected deaths of infants and young children in England after implementation of national child death review procedures in 2008: a retrospective assessment. Arch Dis Child 2020;105:270-5. PubMed doi:10.1136/archdischild-2019-317420

9. UK Government. Parental bereavement leave regulations 2020. 2020. https://www.legislation.gov.uk/uksi/2020/249/contents/made

10. Finlay I, Dallimore D. Your child is dead. BMJ 1991;302:1524-5. PubMed doi:10.1136/bmj.302.6791.1524

11. Tatterton MJ, Scholes SL, Henderson S, Croucher F, Gibson C. The role and experiences of responders attending the sudden or unexpected death of a child: a systematic review and meta-synthesis. Illn Crises Loss 2022;31:426-44. doi:10.1177/10541373221075300

12. Greenberg N, Brooks S, Dunn R. Latest developments in post-traumatic stress disorder: diagnosis and treatment. Br Med Bull 2015;114:147-55. PubMed doi:10.1093/bmb/ldv014

13. Grither A, Leonard K, Whiteley J, Ahmad F. Development, implementation, and provider perception of standardized critical event debriefing in a pediatric emergency department. Pediatr Emerg Care 2024;40:292-6. PubMed

14. NHS England. Ambitions for palliative and end of life care: a national framework for local action 2021-2026. 2021. https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf.

15. Wennergren G, Nordstrand K, Alm B, et al. Updated Swedish advice on reducing the risk of sudden infant death syndrome. Acta Paediatr 2015;104:444-8. PubMed doi:10.1111/apa.12966

16. Department of Health and Social Care, Department for Education. Child death review: Statutory and operational guidance (England). 2018. https://assets.publishing.service.gov.uk/media/637f759bd3bf7f154876adbd/child-death-review-statutory-and-operational-guidance-england.pdf</unknown>

17. Australian Commission on Safety and Quality in Health Care. National consensus statement: Essential elements for safe and high-quality paediatric end-of-life care. 2016. https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-consensus-statement-essential-elements-safe-and-high-quality-paediatric-end-life-care

18. Hackett J, Beresford B. ‘Cold bedrooms’ and other cooling facilities in UK children’s hospices, how they are used and why they are offered: A mixed methods study. Palliat Med 2021;35:603-10. PubMed doi:10.1177/0269216320984335

19. Tol WA, Barbui C, Bisson J, et al. World Health Organization guidelines for management of acute stress, PTSD, and bereavement: key challenges on the road ahead. PLoS Med 2014;11:e1001769. PubMed doi:10.1371/journal.pmed.1001769

20. National Institute for Health and Care Excellence. End of life care for infants, children and young people with life-limiting conditions: planning and management (NICE guideline NG61). 2016. https://www.nice.org.uk/guidance/ng61

21. Keegan O, Murphy I, Benkel I, Limonero JT, Relf M, Guldin M-B. Using the Delphi technique to achieve consensus on bereavement care in palliative care in Europe: an EAPC white paper. Palliat Med 2021;35:1908-22. PubMed doi:10.1177/02692163211043000