


Sudden Unexplained Death in Childhood

 This Good Practice Point aligns to the NMC 2022 Standards of Proficiency for SCPHN Health Visitors, in particular Sphere of Influence D, D.HV16. See page 4 for more details.

Sudden Unexplained Death in Childhood (SUDC) is one of the less recognised medical tragedies of our time¹. Families often receive limited support but, with clear, compassionate communication, health visitors can have a positive impact on how the family copes²⁻⁵.

SUDC is the sudden and unexpected death of a child between 1 and 18 years of age, which remains unexplained after a thorough investigation is conducted. This must include examination of the death scene, a post-mortem, and a review of the child and family's medical history⁶.

Data available for England reveals unexpected child deaths account for 30% of the child deaths and, surprisingly, nearly two-thirds of these have no clear explanation immediately after the death⁷. For all these deaths, there is a 'Joint Agency Investigation' led by the Child Death Review team. The investigation will include a post-mortem, and police may be present on the team as the coroner's representative. Most families will find an explanation for the child death during this process, but 16% of families will not⁷ – equating to 40 children across the UK nations every year who are affected by Sudden Unexplained Death in Childhood^{8,9}. Up to two seemingly healthy children die every fortnight, often going to sleep and never waking up⁹. SUDC is most prevalent in toddlers (aged 1-2 years) and children in their late teens. In the 1-4-year age group, it is the 4th leading category of child death⁶⁻⁹.

Can SUDC be prevented?

There are currently no known modifiable factors for SUDC. Through research, it is hoped that risk factors and underlying causes of SUDC will be detected leading to its prevention^{1,2,7,9}.

How is SUDC different to Sudden Infant Death Syndrome (SIDS)?

Although SUDC and SIDS are both terms used for an unexplained death, there are three important differences:

1. SIDS affects babies under 12 months, SUDC affects children aged between 1 and 18 years of age.
2. The incidence is different. Approximately 200 infants are affected by SIDS every year and 40 children affected by SUDC⁸.
3. Research into SIDS and awareness campaigns have resulted in important 'safer sleep' guidance for babies, leading to an 80% reduction in SIDS cases¹¹. Research into SUDC remains limited and there is currently no evidence on how to mitigate the risk of unexplained death in children aged between 1-18 years². There is no evidence that the modifiable factors and safer sleep messages for SIDS are relevant for SUDC^{7,9}.

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For additional resources see www.ihv.org.uk

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The key worker role and SUDC

The SUDC of a child is intensely traumatic for parents. Families have reported that they felt abandoned upon returning home from hospital and most families do not understand the process that happens after a child dies²⁻⁵.

The statutory child death guidelines state that every family should be assigned a 'key worker'. The key worker is a member of the Child Death Review team, and may be a doctor, nurse or health visitor - to help support and inform the family, and to act as a single point of contact and facilitate effective communication between the family and other professionals involved. The compassionate, informed, and proactive care and connection to services provided by the role is crucial²⁻⁵.

Support for families following the sudden death of a child

Going in to wake your child and finding them deceased, or suddenly witnessing or learning of their unexpected death, is a traumatic experience and can lead to complicated grief and sometimes post-traumatic stress disorder (PTSD)^{2,3}. Early information, support and connection with others who truly understand can be helpful²⁻⁵. Please see the additional resources section for recommended resources. For local counselling support, please check details of local charities and check whether your local children's hospice accepts referrals for support following sudden death.

Searching for answers – medical referral

If the post-mortem concludes that the death is unexplained, the family should be referred by a GP for cardiac screening and also discuss whether other medical referrals are appropriate. The family should also be referred for SUDC genetic analysis (test R441 in the National Genomics Test Directory) by their paediatrician or GP^{7,9,10}.

Siblings and pregnancy

Just like grief, anxiety following loss is individual and no two people will feel the same. Pregnancy after loss can be incredibly hard on emotional health and can lead to increased anxiety with a subsequent child born following child loss. Some parents can also become extremely anxious about the wellbeing of any older children. Some families find that monitors for siblings are helpful for reassurance². These monitors cannot prevent unexpected deaths; the main value is that the parents can know their child is alive without having to keep checking on them.

Bereavement midwives and the Care of Next Infant (CONI) scheme (where commissioned) can provide helpful advice and enriched care for families affected by sudden unexpected death in infancy and childhood^{2,5,7,9}. The CONI scheme (usually for 6 months following birth) includes additional postnatal appointments, paediatric checks, apnoea monitors and important 'safer sleep advice' (which applies to babies up to 1-year old) for subsequent babies.

Good Practice Points for Health Visitors

Preparing to support families who experience SUDC

- Go to: SUDC-UK – <https://sudc.org.uk/professionals/> the national charity's website offers a range of professional resources and information. Contact the organisation directly for specific information and support.
- Access iHV's Insights Event - When the worst happens: Sudden Unexplained Death in Childhood (SUDC) - <https://bit.ly/3SvdgN2>
- Locate and review the procedures following SUDC for your local area – these will be included in the Child Death Review Policy.
- Learn from your local policy about the structure of teams that would be convened locally following SUDC (including presence of a SUDC nurse who would be key worker).
- Access local training opportunities on child death and bereavement.
- Reach out to experienced peers/managers to learn from their experience of working with families.

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- Update knowledge of local bereavement and support services for parents and siblings. The database held by The Good Grief Trust is growing - <https://www.thegoodgrieftrust.org/>. Check if your local children's hospice accepts sudden death referrals for counselling.
- Actively seek formal and informal support for self – ask for scheduled managerial support and increased supervision while supporting a family who have experienced SUDC.

Supporting families who experience SUDC

- **Help manage communication** and connect with the key worker. They will be the single point of contact with the family, they will help with their questions, go through the process and keep families informed. It is helpful to identify who the key worker is and understand the key worker's role and how to work alongside them.
- **Be proactive and reach out** to the family. It is not about having all the answers, show up with a willingness to listen and help at this extremely difficult time. Write a condolence card with a planned time to call or visit – it is easier for the family to refuse a visit than it is for them to make the call asking for help in the first place.
- **Show emotion** as this can be helpful to families. Rather than being purely 'transactional' in interactions, families who have shared this say that they recognise this is 'human' and it can be appropriate.
- **Reassure** families who may feel that the child death investigation is invasive or insensitive. It is important to explain that the same process is followed every time a child dies suddenly and reassure parents that everyone is working together to try to help them understand why their child has died.
- **Be honest** when discussing SUDC and explain with compassion that some families do not find an answer, that SUDC exists, and that scientists and doctors do not yet understand why or how it happens.
- **Repeat information** as families may wish to hear the same details several times for clarity. Help parents to understand and be involved in the Child Death Review process. Data collection is so important to learn from and prevent future deaths.
- **Listen** and never underestimate the value of simply employing active listening if the family chooses to talk.
- **Be aware of cultural or religious beliefs** – every family is unique, so ask rather than making assumptions. Beliefs and practices can support families navigating death, but they can also influence how individuals express needs or seek support.
- **Support referrals** – liaise with the key worker regarding referrals. Where agreed, connect families to local or national emotional and bereavement support options, including the national charity SUDC UK. Families benefit from layers of support.
- **Continue to advocate** for the whole family. The parents' grief can be complex due to post-traumatic stress disorder (PTSD) and fear for the survival of any other siblings or pregnancies. Look for and connect the family (via the key worker if still engaged) with appropriate support services for parents and siblings.

Future support to families who experience SUDC

Health visitors are well-positioned to deliver consistent trauma-informed care during future pregnancies, supporting the family to navigate grief coupled with the joy that a new baby brings.

Health visitors can also recognise and support a family's concerns about older siblings, offering information, support, reassurance and referrals as necessary. Provision of compassionate individualised support and care from the antenatal visit until the 2-year review and beyond can reduce demand for other services e.g. GP, A&E.

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www.ihv.org.uk

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Additional resources

- **SUDC UK** – www.sudc.org.uk – there is a wealth of information on the SUDC-UK website including a section for professionals.
- **Lullaby Trust** – www.lullabytrust.org – find out more about the CONI scheme and availability in your area.
- **Child Bereavement UK** – www.childbereavementuk.org – providing support to families and resources for professionals.
- **2 wish** - www.2wish.org.uk/ - providing support to families following sudden death of a child or young person under 25 years across England & Wales and support to professionals.

National Guidance

- **Scotland** – <https://bit.ly/3Tl0cyC>
- **Wales** – <https://bit.ly/4c0kEJs>

Further reading

- Nikki Speed, Joanna Garstang, Editorial Review on Sudden unexplained death in childhood, Paediatrics and Child Health, 2023. <https://bit.ly/4c3YYfQ>
- Sudden and Unexpected Deaths in Infancy and Childhood - NCMD Thematic review, 2022. <https://bit.ly/3wCOKCK>
- SUDIC Joint Agency Guidelines, 2016. <https://bit.ly/42ZWLOh>

 This Good Practice Point aligns to the NMC 2022 Standards of Proficiency for SCPHN Health Visitors, in particular:

Sphere of Influence D:

Population health: enabling, supporting and improving health outcomes of people across the life course:

D.HV16: Provide, evidence-based support to bereaved parents, children and families in the event of a miscarriage, stillbirth or parent death and refer to additional support as appropriate.

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