

Supporting families following the death of an infant or child (aged 1 to 4 years)

“How can it be that a parent outlives a child?”

(Bereaved parent – courtesy of Child Bereavement UK)

In 2018 for England and Wales, the death rates for children 1-4 years was 13 per 100,000 population of the same age:

- **Illness and congenital abnormality accounts for a large proportion of deaths in this age group**
- **A very small number of young children die suddenly and unexpectedly - referred to as sudden and unexpected death in childhood or Sudden Unexplained Death in Childhood (SUDIC)**
- **Accidents remain the leading cause of death for boys aged 1-4 years. In 2018, 48 children aged between 1 and 15 died in road traffic accidents.**

(ONS, 2018)

The agony of losing a child of any age is unparalleled. There is no age or point in time that makes it any easier. The death of a child goes against the natural order we expect life to follow. The longing for the child and the feeling of emptiness can last a lifetime.

Some parents describe feeling complete disbelief, mixed with flashes of reality too awful to think about. Feeling numb, empty, enraged, anxious or exhausted. These feelings mixed with guilt, feeling that they were responsible for their safety and should have been able to prevent whatever happened are often hard to endure; thoughts are replayed over and over again whilst the parent tries to make some sense of what has happened. Some parents also feel guilty because they have survived their child (Child Bereavement UK, 2020).

This Good Practice Points (GPP) resource is part of a series of GPPs on loss and bereavement. This GPP will consider the support families can benefit from when they lose an infant or child and the processes and issues pertinent for families experiencing such loss.

More information on page 2

For additional resources see www.ihv.org.uk

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Processes following the death of an infant or child when cause of death is uncertain

Coroner / infant / child death investigations

A doctor must report the death of a baby or child to the coroner if the cause of a death is uncertain. The parents must be informed and the reasons for reporting the death explained. This can be difficult for parents and they should be offered support (NHS England, 2018).

The coroner may decide that a post-mortem examination should be conducted to establish the cause of death and this may delay the burial, cremation or funeral. Performing a post-mortem examination on an infant is complex and can take several months for all tests to be completed. It may be that the family are asked to make difficult decisions as to whether they wish to have a funeral before all the samples have been returned.

The Coroner may decide to hold an inquest at the end of their investigation. The family is under no obligation to attend the inquest if they do not wish to. The Coroner's Court Support Service is a registered charity who can offer volunteers to support families on the day: please visit <https://bit.ly/39vlekD>

The Child Death Review

All child deaths are reviewed by specialist Child Death Review Panels. The Panels look into every unexpected child death to try and prevent future deaths and improve support to families. This process works alongside all the other elements of the investigation into a baby's death.

Parents are not usually involved in the process but should be informed that it is taking place and how they can input into it should they wish.

Information for families on the process - When a Child Dies: A Guide for Parents and Carers is available on the NHS website: <https://bit.ly/3moyCL4>

Statutory support

Parents are entitled to statutory parental bereavement pay if their child dies under the age of 18 or is stillborn after 24 weeks' pregnancy: <https://bit.ly/37zLpEr>

The Children's Funeral Fund for England which is not means-tested can help pay for funerals. If the family has other funeral expenses, they may be able to apply for additional funds to cover them: <https://bit.ly/33lvToD>

Subsequent pregnancies

It is not possible to predict how individual parents will feel during subsequent pregnancies. One of the most important things that parents can be offered is sensitive support to help them deal with any feelings and worries. Some parents may worry that they will be unable to love the new baby or that they will be disloyal to the baby or child who died by loving the new baby.

Parents who experienced the sudden and unexpected death of their baby or child may not feel reassured by the birth of a healthy baby. Anxiety may continue for some time after the baby is born. Structured support is essential for these parents.

The Care of Next Infant (CONI) programme is run by The Lullaby Trust in partnership with the NHS and is offered across the country where commissioned:

- Provides specialist health visiting support for families, who have had a baby die unexpectedly, with future pregnancies and in the first 6 months following birth.
- Availability, eligibility and details available via the link: <https://bit.ly/33voLLV>. Note: some core elements of support are facilitated by Lullaby Trust if not commissioned locally.

Care of siblings

Parents worry about what to tell siblings – a clear, honest approach is usually best. Even very young children usually sense when something is wrong. If they are not told what it is, they may be frightened and may think that something terrible is about to happen to them or to the people close to them. Fear and anxiety about their parents may affect their behaviour.

- Winston's Wish - offers support and information to families with grieving children: <https://bit.ly/35szRU4>
- Sands - offers advice for supporting children whose baby brother or sister has died: <https://bit.ly/3loi6JD>
- Lullaby Trust offers befriending/ sibling support service – further information at: <https://bit.ly/3lmzRsY>

More information on page 3

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Good Practice Points – What can HVs do?

“I always tell parents to treat themselves with the level of understanding and care that they would give to a toddler. Coping with big and overwhelming emotions and learning new coping mechanisms. I tell people to go back to basics.”

(Charlotte Joliffe – mother of Freddie who died at 13 months of age)

Reach out and offer support

- On receiving information about a death, contact the family and offer face-to-face contact:
 - When you are contacting the family by telephone, ensure that background noise and interruptions are avoided.
 - Remember families may choose to decline HV contact. Seek their permission to check in at specific intervals by phone and provide information with your contact details.
 - There can be an issue regarding electronic records being closed when a baby dies. Contacts can be recorded in mother’s/family records with service level agreements agreed to maintain contact if there are no other children in the family.
- When visiting, sensitively and jointly agree the time available for the contact. This creates a safe environment where parents know what they can expect, and it avoids the interaction ending abruptly.
- Always follow a parent-centred approach – seeking to identify with the family what will help most in that moment, and identify an agreed pattern of support going forward.
- Bear in mind that parents may feel shocked and may find it difficult to understand information or think clearly:
 - Speak clearly and use simple language.
 - Be aware that family beliefs, cultural norms or personal circumstances may affect parents’ ability to grieve and it may be appropriate to explore this with parents.

Talk about grief

- Reassure parents and families that there is no right or wrong way to grieve for their baby or child – remember to always use the child’s name.

- Many parents say that their child is always on their mind, that they experience aching arms, and hear their child’s voice or cry. Some people have a strong need to continue with routine childcare tasks. Encourage parents to take each moment as it comes, not thinking too far ahead and giving themselves credit for getting through each day.
- Grieving people can sometimes fear they are becoming mentally ill:
 - They may feel confused or find it difficult to make decisions or concentrate for any length of time.
 - Even if they can sleep, they may still feel exhausted.
 - Some can experience wide-ranging emotions within the space of hours.
- Some partners may cope in different ways and this should be acknowledged. Adjustment to bereavement involves a flexible oscillation between two types of coping strategies: loss-oriented and restoration-oriented (Stroebe & Schut, 1999).
- Parents may describe the feeling that they want to go to bed and not wake up. This is often different from suicidal ideation where parents have a plan and want to act on the plan. It is normal to want to escape the extreme pain without being at immediate risk of suicide at that time, but these thoughts and expressions should always be properly assessed.

Encourage self-care

Top tips for self-care from another bereaved parent:

- Eat well and stay hydrated
- Good sleep hygiene
- Self-compassion – “I’m doing the best I can do” - lower your expectations of yourself
- Try to get out in nature and get physical exercise – see further advice The Lola Project: <https://bit.ly/2L8oMPP>
- Listen to your body – if you need to cry, cry, if you need to sleep, sleep.
- Let others know what you need
- Write your thoughts and feeling down if it helps
- Spend time with people that nurture you
- Do things that you enjoy doing, even if it’s only for a short time

More information on page 4

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Recognise and support physical and mental health issues

- Trauma can be so extreme following the death of a child that parents may experience physical symptoms and illness related to the grief. This can include the mother's periods stopping, eczema, skin complaints and hair loss etc.
- It can be helpful to explain the symptoms of depression, anxiety and post-traumatic stress disorder (PTSD). There may be a need for further assessment and formal treatment. Active monitoring for PTSD is recommended by NICE (2018). There is an increased risk of suicide following loss, and any suicidal ideation should prompt immediate assessment.
- Feelings of guilt and blame are normal. Listening, acknowledging and validating how difficult those feelings must be and showing understanding without agreeing can be helpful. Parents often go over and over in their minds, everything they did or did not do. They may blame themselves or each other, or feel angry with the doctor, health visitor or anyone who had seen the child recently.
- Feelings of anger are normal. Parents sometimes find helpful outlets for anger, such as crying and shouting in an outdoor open space, or exercise like walking/running/jogging.
- Feelings of doubt and fear are normal. Some people start to doubt or question their religious beliefs. It is not unusual to feel anxious or to fear something happening to other family members.
- Partners and family members may feel it is their job to discourage looking back and to encourage facing the future. They may not ask for or refuse support. Conversely, fathers, same sex co-parents and partners are often overlooked – support should be offered to both parents where practical.
- Sensitive enquiry about the parent relationship and acknowledgement that couples may find their relationship becoming strained can be helpful. Discussion should be encouraged so feelings and needs are shared. There are many ways to express grief and these vary from person to person and can change over time. It is important they understand what the other needs to cope and grieve.

Support access to counselling and further support

- Parent-centred support should be identified in the interim to recognise, manage or prevent PTSD e.g. trauma-focused CBT interventions are recommended by NICE guidelines (NG116) (NICE, 2018).

- It is important to know what the local options and service criteria are for counselling services. Discuss appropriate counselling referrals with GP and care team.
- Parents who have lost a child will usually need ongoing support for some time. Support is available from a range of organisations – do check in with any charity prior to passing support and offer details to the parents.

Be aware of complex, prolonged or incomplete grief

- It can take several years to begin to adjust to life after the death of a child. Complex, prolonged or incomplete grief are terms that are sometimes applied if a grieving person is not able to move through the process of grieving. Prolonged grief disorder and complicated grief are collections of difficulties, which are distinct from, but often found alongside other mental health disorders such as depression, anxiety and post-traumatic stress disorder. Around 10% of bereaved people experience these difficulties, with higher rates found in parents whose child has died and these parents should receive specialist intervention (Boelen et al, 2019).

Practitioner wellbeing when offering support

- It can be emotionally demanding to care for parents after the death of their infant/ child. The reasons for this will be individual and may include managing emotions around the practitioner's own experience(s) of loss. Also, there is significant anxiety around getting it right for traumatised and grieving parents. The emotional load can be heavy, as when we empathise we put ourselves in touch with the other person's pain and feel it. In some circumstances, this can lead to secondary trauma.
- HVs should seek support for themselves and pay attention to their own thoughts and feelings. Seeking out supervision that has a space for them to focus on how the work is affecting them is good practice. Lullaby Trust offers listening support to professionals:

Email: support@lullabytrust.org.uk
Phone: 0808 802 6868

NEVER try to find a silver lining for grief or make "at least" statements.

For a parent, the pain of losing a child has no silver lining and any suggestion of this is particularly intolerable.

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More information for HVs:

- The Good Grief Trust has developed a range of videos for professionals at: <https://bit.ly/39vWtoD>
- Brene Brown's Video on Empathy at: <https://bit.ly/2AcaYyv>
- Lois Tonkin Growing around Grief film at: <https://bit.ly/2X11tKM>

Resources (support for parents and professionals):

- Review specific support listed at The Good Grief Trust: <https://bit.ly/38Bhb61>
- Specific national charities for families following a child death:
 - SUDC provides information and support for parents whose child over the age of 1 year has died following a sudden unexplained death: <https://bit.ly/2JzXMrL>
 - Child Bereavement UK: <https://bit.ly/39xAhKQ>
 - The Compassionate Friends: <https://bit.ly/3qhsy9F>
- National bereavement support:
 - StrongMen (for men following bereavement): <https://bit.ly/3g89S7L>
 - Good Grief Trust: <https://bit.ly/38Bhb61>
 - CRUSE UK: <https://bit.ly/2JplvtL>
 - Grief Chat UK: <https://bit.ly/2KOWGZA>
 - Let's talk about Loss: <https://bit.ly/37mLL16>

- Charities providing online information and regionally-based support for siblings:

- Freddie's Wish (Warwickshire): <https://bit.ly/3fUCyRk>
- Winston's Wish (UK – 3 hubs Gloucestershire, Sussex, London): <https://bit.ly/2Vraf3r>
- Rainbow Trust (9 locations across UK) – supports families of seriously ill children including bereavement support: <https://bit.ly/2HYpii1>
- Halo Children's Foundation (Middlesex): <https://bit.ly/3ocx1Zb>
- Harry's Rainbow (Milton Keynes): <https://bit.ly/36sEVHV>
- Guy's Gift (Coventry and Warwickshire): <https://bit.ly/33A14SL>
- Once Upon A Smile (Manchester): <https://bit.ly/3lrrxln>
- Harvey Hext Trust – memory boxes for siblings: <https://bit.ly/33zDWUz>
- Apart of Me – app for young people losing sibling: <https://bit.ly/36qkxhm>

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