

Supporting families following the death of a baby

The death of a baby is one of the most traumatic and distressing experiences and will inevitably bring about immense pain and grief. Health visitors are an important source of ongoing care and skilled support for bereaved parents in the weeks, months and years following this most tragic and traumatic of experiences.

Supporting families at this time of immense pain can create feelings of inadequacy and anxiety even in the most experienced professionals. None of us are immune to grief and loss and it is important that we recognise this work as emotionally demanding.

- There may be times in your life when you feel that you are not able emotionally to work with this level of distress, either because of your own emotional wellbeing or because the work triggers difficult emotions for you.
- It is important to be aware of our own emotional states and to develop the capacity to think about and manage the impact and effect that work has on us.
- It is also important to have adequate support within work and to have to access supervision sessions.

This Good Practice Points (GPP) resource is part of a series of GPPs on loss and bereavement. This GPP will consider Stillbirth, Neonatal Loss and Sudden Unexplained Death of an Infant (SUDI). See also iHV GPP “Supporting families after the death of an Infant or Child (1-4 years)” for more information on grief.

Stillbirth & Neonatal Death

“As you grieve and live life in a new normal, it is the little things that people say to you that you remember. A positive interaction can be replayed and brings comfort”

(Words of a bereaved parent - Courtesy of Sands)

“The intensity of the pain was overwhelming and frightening. My arms ached to hold her again so much that I considered digging up her grave to be with her”

(Words of a bereaved parent - anonymous)

“I found an Instagram group for people that had lost babies, to find this group that can say what’s in your head when you can’t get the words out, makes you feel less alone”

(Words of a bereaved parent - Courtesy of Sands)

Stillbirth

Stillbirth is when a baby dies before birth after 24 weeks of pregnancy (a loss before 24 weeks gestation is known as a miscarriage). The cause of stillbirth is not always identified and is often the result of various contributory factors. In the UK, the stillbirth rate is 4 per 1000 live births (ONS, 2018).

Neonatal death

Neonatal death is the death of a baby up to 28 days after birth. Most neonatal deaths are linked to prematurity, however there are other possible causes including genetic disorders, infections and birth complications. In the UK, the neonatal death rate is 2.8 per 1,000 live births which equates to 1 in 357 (ONS, 2018).

More information on page 2

For additional resources see www.ihv.org.uk

The information in this GPP version was created on 07/12/2020.

Whilst we have taken every care to ensure the content of iHV resources are accurate and peer-reviewed at time of publication, evidence may change over time and advice needs to be tailored to individual circumstances. The inclusion of references, content or website links from external organisations does not imply any endorsement of the organisation, or their materials, by the iHV. The iHV does not warrant or guarantee the accuracy or completeness of the information in this resource and cannot accept liability for its use. Therefore, please always exercise your own judgement. For further information, please contact us: info@ihv.org.uk

Supporting families following the death of a baby

Every family who experiences stillbirth or neonatal death is unique and their experience depends on a variety of factors, such as the circumstances of the loss, cultural beliefs and individual personality.

Parents may have been involved in decisions about withdrawing life-sustaining treatment or made difficult decisions around termination; others may have had an uncomplicated pregnancy and birth.

While in hospital most families will spend hours/days making cherished memories with their baby, either before the baby dies or after death. These memories include family visiting, photos, videos, taking baby home, and making handprints/footprints.

Overwhelming feelings of shock and isolation are common among parents on discharge, as going home to face the world without their baby can be frightening and painful. Compassionate and sensitive support is essential to minimise any additional emotional and psychological distress.

Alongside emotional pain, there are various practical elements that are needed. These include: arranging a funeral; being part of a medical review of their care; awaiting post-mortem results; and attending follow up appointments with medical professionals.

Almost all parents report negative psychological symptoms after a stillbirth or neonatal death. In the Listening to Parents (2014) study, most frequently reported were negative psychological symptoms, including high rates of depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic, and phobias. Many parents reported persistent feelings of remorse or guilt for not being able to save their baby (NPEU, 2014).

The trauma and loss that surrounds the death of a baby can result in complex grief that parents will inevitably need support to navigate.

Sudden Unexpected Death in Infancy up until 12 months

Sudden Unexpected Death of an Infant (SUDI) encompasses all cases in which the death of a baby would not have been reasonably expected in the 24 hours prior to their death and no pre-existing medical cause of death is apparent. It is the term used at the time the baby dies and will include those deaths for which a cause is later found and those that remain unexplained following investigation (ONS, 2019).

Sudden Infant Death Syndrome (SIDS) refers to the sudden and unexpected death of a baby under 12 months of age which remains unexplained after a thorough investigation.

Current unexplained infant death rate in the UK for live births is 1 per 3,845 with almost 88% during the first 6 months of life (ONS, 2019).

The sudden and unexpected death of an apparently healthy baby triggers an established, multi-agency response that can last six months. Detailed guidance is provided in Sudden unexpected death in infancy and childhood: multi-agency guidelines for care and investigation (Kennedy, 2016) and many areas have local guidelines for SUDI investigations.

Parents will often blame themselves and will often already be aware of their specific risk factors, but these are not causes of death, and care should be taken to avoid any suggestions of guilt or judgement when discussing these.

It is helpful to know as much as you can about the family's circumstances and the stage the investigation is at before you make any contact. Multi-agency communication is an essential part of the process, but do not assume you have the most up-to-date information.

Good Practice Points – What can HVs do?

“My lovely health visiting team kindly posted a card through my door to say they were thinking of me and they all attended Freddie’s funeral. Although I didn’t speak to them personally in those first few weeks, knowing that they were thinking of me and paying their respects to Freddie was so incredibly important to me”

(Charlotte Jolliffe – 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.
- 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.

More information on page 3

www.ihv.org.uk

Institute of Health Visiting c/o Royal Society for Public Health, John Snow House, 59 Mansell St, London E1 8AN.

Email: info@ihv.org.uk Phone: 020 7265 7352 Registered Charity: 1149745

Follow us on Facebook [facebook.com/iHealthVisiting](https://www.facebook.com/iHealthVisiting) Twitter @iHealthVisiting or LinkedIn

© Institute of Health Visiting 2020

Supporting families following the death of a baby

Say their name

- When working with bereaved families, use the name of the baby who has died often. Those who are bereaved appreciate hearing the name of their loved one and it importantly signals recognition of the presence of the baby as part of the family.
- Most families will have photos of their baby if they were stillborn or died neonatally. Ask the parents if they have any photos that they wish to share with you of their loved one and use the name of the baby.
- Some bereaved parents will use terms such as “passed away”, “born sleeping”, “could not be revived” or “angel baby”; others will prefer terms such as “death” and “died”. All are normal – follow the parents’ lead when it comes to language.

Whole family approach

- Friends and relatives often treat parents differently after the death of a child. Fathers are often asked “how is your wife?”, and people may forget to say, “how are you?” Fathers, same sex co-parents and partners are often overlooked. Always ensure that you also focus on their experiences and feelings of fathers and partners which may differ (Obst et al, 2020).
- Specific advice for supporting children whose baby brother or sister has died can be found at:
 - Sands: <https://bit.ly/3loi6JD>; or
 - Lullaby Trust: <https://bit.ly/3oisrZH>

Support postnatal issues (including mental health)

- Some women may choose to donate their milk to a breast milk bank, others may wish to take medication to suppress milk. United Kingdom Association for Milk Banking can provide information if there is not a local milk bank: <https://bit.ly/3fXWbrz>
- Remember that bereaved parents have an increased risk of developing mental illness. Follow your local PMH care pathway to undertake a high-quality needs assessment and seek appropriate specialist therapies suited to the bereaved parents:

- Parents who have lost a child due to SIDS may be at particular risk of PTSD and should be monitored. Consider active monitoring for people with subthreshold symptoms of PTSD within 1 month of a traumatic event. Arrange follow-up contact to take place within 1 month (NICE, 116 – 1.6.4) (NICE, 2018).
- The risk of traumatic/complicated grief may also be higher (Goldstein, 2018).

- Parents of multiples may have a surviving infant(s) at home or still in the neonatal unit. In these instances, some parents may find that they are not ready to access support, particularly if they are putting their feelings on hold while focusing on the surviving baby or babies. When they are ready, there is a bereavement support group specifically for multiple births:

<https://bit.ly/33uWa9G>

Practitioner wellbeing when offering support

- The death of a baby is associated with so much pain, it is easy for professionals to feel overwhelmed or inadequate. There is no solution or fix for grief, and demonstrating our humanity and listening to a family’s pain is the greatest support we can offer them.
- It may be okay to share your own experience of loss if you sense it would benefit the parents. However, this should always be done with the greatest caution so that the parents do not feel burdened by your experiences or that they need to look after your feelings.

NEVER try to find a silver lining for grief or make any “at least” statements.

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

More information on page 4

www.ihv.org.uk

Institute of Health Visiting c/o Royal Society for Public Health, John Snow House, 59 Mansell St, London E1 8AN.

Email: info@ihv.org.uk Phone: 020 7265 7352 Registered Charity: 1149745

Follow us on Facebook [facebook.com/iHealthVisiting](https://www.facebook.com/iHealthVisiting) Twitter @iHealthVisiting or LinkedIn

© Institute of Health Visiting 2020

Supporting families following the death of a baby

More information for HVs:

- Two e-learning modules for Bereavement Care after Pregnancy Loss or Baby Death are available on the e-LfH platform at: <https://bit.ly/3gcsFNF>
- The National Bereavement Care Pathway (NBCP) provides specific materials for HCPs involved in the care of parents of babies who were stillborn, parents of babies who died neonatally and those who died following SUDI at: <https://bit.ly/36cs9gE>
- Sands provides support and information for anyone affected by the death of a baby, before or after birth. They also offer support, training and practical guidance for health care staff including health visitors at: <https://bit.ly/2VsdGa0>
- Lullaby Trust provides support and information for families, friends and professionals at: <https://bit.ly/33voLLV>
- Listening to Parents study (2014) provides a wealth of insights around stillbirth and neonatal death for HV practice at: <https://bit.ly/3g1ZhK2>
- Out of Sight, Out of Mind (2019) report for Baby Loss Awareness Week highlights how parents who have lost a baby are currently falling through the gaps between policy and funding, and are often overlooked altogether at: <https://bit.ly/3glkyif>
- The Good Grief Trust has developed a range of videos for professionals at: <https://bit.ly/39vWtoD>
- Brene Brown's Video on Empathy is helpful and can be accessed on YouTube at: <https://bit.ly/2AcaYyv>

Resources – support for parents and professionals:

- Review specific support listed at The Good Grief Trust: <https://bit.ly/38Bhb61>
- Specific national charities for stillbirth, neonatal and SUDI deaths:
 - Sands: <https://bit.ly/3fy0nYz>
 - BLISS: <https://bit.ly/3fW4Hr4>
 - The Lullaby Trust: <https://bit.ly/33voLLV>
 - Tommy's: <https://bit.ly/3mwORWv>
 - The Lola Project: <https://bit.ly/3mtk3FX>
- Charities providing online information and regionally-based support for parents:
 - Freddie's Wish (Warwickshire): <https://bit.ly/3fUvDre>
 - A Child of Mine (Staffordshire): <https://bit.ly/3qliA6Y>
 - Abigail's Footsteps (Kent): <https://bit.ly/3qkjv7K>
 - Lily Mae Foundation – (Birmingham, Midlands & NI): <https://bit.ly/2VpbYqg>
 - Elsie's Moon (Wirral): <https://bit.ly/33xxzRN>
 - Love, Jasmine (Liverpool & Wirral): <https://bit.ly/36snc3B>
 - Zephyrs (Nottingham): <https://bit.ly/3mtPslY>
 - Charlies Angel Centre (Leeds): <https://bit.ly/3fUpXy5>
 - Abbie's Fund (Leeds): <https://bit.ly/33AzOnb>
- National bereavement support:
 - StrongMen (for men following bereavement): <https://bit.ly/3g89S7L>
 - Grief Chat UK: <https://bit.ly/2KOWGZA>
 - CRUSE: <https://bit.ly/2JplvtL>
 - Child Bereavement UK: <https://bit.ly/39xAhKQ>
 - Let's Talk About Loss: <https://bit.ly/37mLL16>

References

- Goldstein, R.D. (2018) in Duncan J.R. & Byard R.W. (eds) SIDS Sudden Infant and Early Childhood Death: The Past, the Present and the Future. <https://bit.ly/3jNtY8p>
- Kennedy (2016) Sudden unexpected death in infancy and childhood: multi agency guidelines for care and investigation. <https://bit.ly/31xtBsd>
- NICE (2018) Post-traumatic Stress Disorder. <https://bit.ly/33BhWbT>
- NPEU (2014) Listening to parents. <https://bit.ly/3g1ZhK2>
- Obst, K.L., Due, C., Oxlad, M. (2020) Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. BMC Pregnancy Childbirth, 11. <https://bit.ly/2AerkXz>
- ONS (2018) Birth rates in England & Wales. <https://bit.ly/2YIG6zl>
- ONS (2019) Unexplained deaths in infancy, England and Wales: 2017. <https://bit.ly/3g6qDPI>

Acknowledgements:

This GPP was written by Charlotte Jolliffe – Bereaved parent and founder of Freddie's Wish, Clare Worgan – Sands, Jenny Ward – Lullaby Trust and the CONI team with Rachel Stephen, Philippa Bishop & Sasha Barber as HV advisors on behalf of iHV.

www.ihv.org.uk

Institute of Health Visiting c/o Royal Society for Public Health, John Snow House, 59 Mansell St, London E1 8AN.

Email: info@ihv.org.uk Phone: 020 7265 7352 Registered Charity: 1149745

Follow us on Facebook [facebook.com/iHealthVisiting](https://www.facebook.com/iHealthVisiting) Twitter @iHealthVisiting or LinkedIn

© Institute of Health Visiting 2020