NHS
Lincolnshire
Integrated Care Board

When a Child Dies

An NHS Lincolnshire Framework for General Practice

Published August 2025

Foreword

While GPs and their practices are well-versed in dealing with bereavement, it is felt that a slightly different approach is required when a child dies. This guidance is for General Practitioners and their teams and is intended to support practices and empower professionals in managing these thankfully rare, but challenging situations.

"This event entirely changes lives… you're always grieving – you learn to get through each day"

We would encourage practices to review this guidance and discuss with staff. Practices may wish to develop their own 'in-house' protocols based on this document. We would further encourage you to consider whether it would be appropriate for you to identify someone within your practice to be a lead for child death. This individual could promote awareness of this document, facilitate education and training for staff and identify local support agencies for families.

This document was produced by Dr Jonathan Griffiths and Dr Bryony Kendall (NHS Cheshire and Merseyside) in collaboration with The Alder Centre and Claire House Children's Hospice with input from bereaved parents and general practice staff. We acknowledge and appreciate all the families and professionals whose lived and learned experiences have contributed to this document.

We are grateful to NHS Cheshire and Merseyside for allowing us to produce a Lincolnshire version of this document.

Dr Julian Saggiorato and Dr Mujeeb Pervez

NHS Lincolnshire ICB

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Background

This guidance has been informed by conversations with bereaved parents who have a voice that should be heard, and stories that are important for us to hear.

Underpinning many of the described challenges is the assertion that people do not want to talk about child death. It is a deeply upsetting subject for many, yet as health care professionals we do need to accept the reality that children do, sometimes, die. We need to provide solace and support to parents, families and communities in an appropriate way through their grief during the acute bereavement and on through the rest of their lives.

"I lived through the trauma of him living, the trauma of him dying, and the trauma of living without him"

The NHS-funded National Child Mortality Database (NCMD) was launched on 1 April 2019 and collates data collected by Child Death Overview Panels (CDOPs) in England, from reviews of all children who die at any time after birth and before their 18th birthday. Their most recent data release reports that there were 3,577 child deaths (age 0-17 years) during the year ending 31st March 2024[1].

Deaths of infants (babies under 1 year of age) accounted for 61% of all child deaths. Neonatal deaths (babies under 28 days of age) accounted for 42% of all child deaths.

While the overall estimated rate of child death remains low, it is worth noting where risks are higher. The child death rate was highest for those of black or black British ethnicity, although over a 5-year period, the rate was highest for those of an Asian Pakistani ethnicity. The child death rate for children resident in the most deprived neighbourhoods of England was more than twice that of children resident in the least deprived neighbourhoods.

***"Don't put a time limit on grief…
you'll never 'be over it'"***

Child deaths are a stark and sensitive indicator of the social determinants of health, and the link between higher indices of multiple deprivation and child death is a feature in reviews of deaths in Lincolnshire. Within Lincolnshire we have

[1] Child death data release 2024 | National Child Mortality Database: https://www.ncmd.info/publications/child-death-review-data-release-2024/

an increasingly ethnically diverse population and significant pockets of deprivation.

One of the co-authors of this guidance is a bereaved parent himself. He has shared his personal story, and you can read about some of the challenges he feels bereaved parents face in his blog[2].

You can also watch a short video here where a bereaved parent talks about her experience.

[2] The challenges of being a Bereaved Parent – Dr Jon Griffiths: https://drjongriffiths.wordpress.com/2024/07/12/the-challenges-of-being-a-bereaved-parent/

Practical guidance – a checklist

- Deduct the child from the NHS spine as soon as possible to ensure that no inappropriate contact is made.
- Inform the Child Health Information Service (CHIS) to ensure no immunisation invitations are sent out. (Contact us - SCW Child Health Information Service (CHIS))
- Inform the regular/named GP as soon as possible (if away then inform duty doctor).
- Notify whole practice using usual processes highlighting that this is the death of a child.
- Consider who to notify:
    - Midwife, Health Visitor, Children and Young People Nurse.
    - Paediatric consultant (if under specialist care and the consultant unaware of the death). This provides an opportunity for a conversation between professional colleagues.
    - Nominated Community Pharmacy who may have been supplying medications (and who may be about to deliver more).
- If this is an expected death in the community, then undertake Medical Certificate of Cause of Death process including contacting the Medical Examiner as per usual practice.
- **If you are involved in the sudden and unexpected death of a child in the community then follow your local SUDIC protocol**. The SUDIC team can be contacted on 01476 464693. In a vast majority of such cases, the police or ambulance services would have already contacted the SUDIC team
- If the regular GP is different to the named GP consider making the regular GP the named GP.
- Ensure entire household has the same named GP unless parents request otherwise.
- Regular/named GP or other more appropriate person to contact parent(s):
    - An initial text or letter may be appropriate to alert the parents to expect contact.

- We would recommend offering a face-to-face consultation, which may need to be a home visit depending on circumstances, but initial phone contact may be appropriate.
- Be aware that this consultation may be lengthy and be emotionally draining. Consider timing appropriately to allow you the time and emotional space you may need.
- Be alert to language needs and the possibility that translation services may be required.
- Consider asking in this initial consultation if a fit note is required. You may wish to ask about all household members and speaking to them at the time if needed, providing notes as indicated.
- **Please see the next section for more details on supporting the bereaved family.**

➢ Add a Significant and Active code to the parents' record; we recommend the SNOMED code 'Child of patient deceased'.

- Consider adding an 'alert' to the parents' record. Be aware this is not auditable, will not transfer with the EMIS or SystmOne record if the patient moves practice, and will remain there indefinitely if not reviewed.

"I hoped the receptionist knew [because] they make you retell your story; don't make it hard to make an appointment"

➢ After discussion with parent(s) you may need to record bereavement codes on additional family members such as siblings, grandparents, others.

➢ When requested, engage with the Child Death Review (CDR) process (Child death review guidance and support (ncmd.info).

➢ Where a neonatal death has occurred, ensure that the mother still receives an invitation for a 6-week post-natal check. **This should be at a time separate to your usual 'baby clinic'.**

➢ Consider a review meeting within the practice, especially if GPs have been involved in care for the child.

➢ Remember the father/partner/non-birthing parent. This may cause an issue if they are not registered with you, and/or the parents are estranged. You may need to ask about other significant carers.

➢ If you become aware that a child has died abroad and especially in cases where the child has been buried in the country where they have died, ensure that

notifications have been made to your local CDOP and other relevant agencies. This is unusual so do contact for support and signposting.

- Lincolnshire CDOP: LincolnshireCDOP@lincolnshire.gov.uk 01522 553702

Supporting bereaved parents

We would suggest that the nature of support required will be determined by the initial contact with the parent(s) and tailored to their needs. That said, we include some thoughts here regarding the potential actions that may be appropriate as well as highlighting some things to consider in your approach. The circumstances surrounding the death will be highly relevant and will help you determine the need. Bereavement following a child who has died following a long life-limiting illness will require different support to where a child has died suddenly and unexpectedly, either by illness or trauma.

"Say 'I don't know how you're feeling, but I want to help'… say 'I can't make it any better, but I can listen'"

"It's the importance of bearing witness even in our baby steps of grief"

Where death has occurred or been confirmed in a hospital or hospice setting, parents will likely already have spoken to a health care professional (often many) and received advice, support and onward signposting. Remember that as a GP you will also see patients who have been bereaved some time ago or indeed see older patients whose adult child has died. In these situations, you may be the first health care professional dealing with their bereavement.

The following suggestions are intended to be considered as part of long-term support for the family. The pointers are not all appropriate for an initial conversation, and we would encourage flexibility and retaining an open invitation for parents to contact for support.

- **An early face-to-face conversation** with the bereaved parent(s).
    - This may need to be a home visit as attending a health care setting may be too upsetting for the parent(s).
    - This enables both parents to receive support.
    - This will primarily be a listening exercise for you where you can understand what support is in place and what additional help may be required.
    - Explore who is at home, and what extended family/friend support is available.
    - Explore who else may need support – estranged parent/siblings/grandparents.

- Explore what (if any) signposting to helplines/counselling/support services has occurred. Ascertain if there is support being received from a specialist palliative care service or hospice.
- Ensure parents have received the 'What to do if a child or baby dies' information which can be found here: What to do after someone dies: What to do if a child or baby dies - GOV.UK. We would recommend you read this yourself before you speak to the parents.
- Be alert to language needs and the possibility that translation services may be required.
- **Parents we listened to appreciated contact from their GP when this had occurred and were disappointed when it had not.**

"I was taken aback in a good way… it took bravery and gave me something good in a dark time"

➢ **Signposting**

- A list of organisations that may be appropriate to signpost to is available in appendix A, please do review this.
- Familiarise yourself with services local to you.
- Local children's hospices welcome enquiries from GPs wanting to engage and find out more.
- Be aware that children's hospices may not be able to provide bereavement support unless the child was previously known to them either before death or if the family used the hospice's dedicated cold rooms immediately after the death. They may be able to provide helpful signposting to other available services.
- Generic mental health services/talking therapies may not be able to provide the specialised support required.
- Local faith-based support is likely to be available if appropriate for the family.
- **Parents we spoke to often struggled to find appropriate support.**

"Help grieving parents navigate through… no one gives you control, so as a GP, give it back"

- Is a **fit note** required?
    - This is an opportunity to ask about others, most notably the father/partner/non- birthing parent, but also other family members who may not otherwise present to you.
    - During your initial contact you may wish to provide notes to all relevant family members, asking to speak to them if needed.
    - Parents whose children required time on the neonatal unit may be eligible for time off under the new Neonatal Care Leave Act.

"Terminology is really important… what you write impacts other things such as insurance, so talk to the parents about what you are going to say"

- **Returning to work**
    - Encourage parents to engage with the Occupational Health via their employer.
    - You may wish to help them consider the support that may be required when they return to work. Does the nature of their work raise specific challenges?
    - Bereaved parents who are healthcare workers may have to undergo annual CPR training including resuscitation of children – how will they cope with this?
    - Many job roles require mandatory safeguarding training (often now via eLearning). Safeguarding issues can be triggering for bereaved parents, and they may need to think about this on return to work.
    - Child Bereavement UK have this excellent resource for employers: How you can help someone return to work after their baby or child has died? Guidance for employers | Child Bereavement UK
    - **Non birthing partners tend to return to work sooner or may not have had any significant time off work. This can be driven by financial pressures.**
      Consider being proactive and enquiring about work and whether time off is required.

"There's a vacuum as a dad that you won't have any contact with the GP, and you cope until you don't… I didn't feel seen"

- **Language**
    - We have provided a glossary of sorts in Appendix B. This includes medical and legal terminology as well as some commonly used lay words/phrases you may need to be aware of.
    - Please think carefully about your choice of words.
    - Try not to use medical terminology that may not be understood. For bereaved parents who are health care professionals, check which language they wish to use.
    - **In our engagement with bereaved parents, language and communication were key important themes – remember every word counts.**

"Non-verbal communication needs to be congruent; it will be hard – lean in and learn from it"

- **Ask if it is appropriate to use the child's name**
    - This links to language and continuity. Ask about the name of the child and don't be afraid to use it if the family are happy with this.
    - Be aware of cultural differences as in some cultures it is more respectful not to use the name of a deceased person. This practice is observed by peoples in many parts of the world, including the indigenous peoples of northern Australia, Siberia, Southern India, the Sahara, Sub Saharan Africa, and the Americas.

- **Continuity**
    - "If continuity was a drug… then it would be top of what we write on our prescriptions every single day"[3].
    - Bereaved parents value continuity. They do not want to have to continually re-tell their story. They benefit from a consistent approach from someone who knows them.
    - Please consider how you will achieve this in your practice bearing in mind which clinician the parent(s) may prefer to see.

[3] Continuity of Care 'Achievable, Improves Services, Admissions, Mortality': https://www.medscape.co.uk/viewarticle/continuity-care-achievable-improves-services-admissions-2021a10021jh

- **Bereaved parents who spoke to us valued speaking to the same GP to a much greater extent that you might expect.**

➢ **Access**

- This is where appropriately used alerts on the record can help reception and triaging staff to facilitate smooth access and continuity.
- Consider how you can provide easier access to appointments to the regular GP for bereaved parents.

"An e-consult is even more impersonal… the capacity to make an appointment, get dressed, [and] function has gone"

➢ **Listening**

- Your main role through all of this may be to bear witness to the pain, loss and grief experienced.
- You cannot 'fix this', but you can be there for them and listen to their story.
- Be present.
- This quote from Nicholas Wolterstorff may help you to frame things:

  "*Don't say it's not really so bad. Because it is. Death is awful, demonic. If you think your task as comforter is to tell me that really, all things considered, it's not so bad, you do not sit with me in my grief but place yourself off in the distance away from me. Over there, you are of no help. What I need to hear from you is that you recognise how painful it is. I need to hear from you that you are with me in my desperation. To comfort me, you have to come close. Come sit beside me on my mourning bench.*"[4]

"I can't imagine means I don't want to imagine"

"Being well-intentioned is not enough – be honest if you've not encountered this before"

"Make contacts more than transactional"

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[4] Wolterstorff, N (1987). Lament for a Son. Grand Rapids: Wm. B. Eerdmans

- **Awareness**

    - Be aware that the parent(s) may be part of multiple processes and receiving information from many different sources, especially if there is involvement of the coroner.
    - Note that for sudden and unexpected deaths there may be police and safeguarding involvement.

- **Lactation after loss**

    - Please note that cabergoline is green on formulary to suppress lactation in women who have suffered loss of the baby.

- **Try not to over-medicalise**

    - Grief is not the same as depression or anxiety.
    - We should be cautious about labelling grief as abnormal and avoid jumping to diagnoses without good cause.
    - There are models of grief that may be useful:
        - Kübler-Ross[5]
        - 'Growing around Grief' (Tonkin 1966)[6]
        - 'The Whirlpool of Grief' (Wilson)[7]
        - 'The dual process model of grief' (Strobe and Schut 1995)[8]
    - Parents reported to us that they were offered antidepressants when they really did not feel they were required.
    - Think very carefully about prescribing sedatives, even for challenging situations like funerals. Funeral rituals are important, you may wish to explore whether an individual would wish to be sedated for such a key event.

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[5] Understanding the five stages of grief: https://www.cruse.org.uk/understanding-grief/effects-of-grief/five-stages-of-grief/
[6] Growing around Grief: Dr. Tonkin's Model of Grief | Sue Ryder: https://www.sueryder.org/grief-support/about-bereavement-and-grief/growing-around-grief/
[7] Whirlpool of Grief (reimagined using animation): https://www.youtube.com/watch?v=VpNViACSKw4
[8] Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. Death Stud. 1999 Apr-May;23(3):197-224. https://pubmed.ncbi.nlm.nih.gov/10848151/

- Please be alert to the fact that some cultures do not recognise or have a language around mental distress and may express it in terms of physical/somatic symptoms.
- **Parents we spoke to did not wish to be labelled as depressed or prescribed antidepressants for their bereavement and grief.**

"Don't just reach for medication… validate the feeling – you're not going mad, this is a normal reaction to an abnormal event"

➢ **Preparing for future pregnancy**

- Bereaved parents may want a conversation about this.
- The circumstances surrounding their child's death will determine the nature of this conversation and specialist input may be required, especially where genetic causes were, or were thought possible to have been a cause.
- Future pregnancies may bring mixed feelings including anxiety, guilt and fear as well as joy and healing.
- Be aware of the emotional impact that future pregnancies may cause in parents and look to support.
- The term 'Rainbow Baby' is increasingly used to describe a baby born to a family who have previously suffered baby loss, and this term may be used during subsequent pregnancy.
- For the next baby, discuss CONI scheme (care of next infant) with the parents

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"We couldn't face going back to the hospital where she was born"

"Our thresholds have changed – we know how easy it is to die"

➢ **The challenges of Sudden and Unexpected Death in Childhood (SUDIC)**

- "This encompasses all cases in which there is death (or collapse leading to death) of a child, which would not have been reasonably expected to

occur 24 hours previously and in whom no pre-existing medical cause of death is apparent”[9].

- Be aware that all cases of SUDIC will trigger a safeguarding review, this does not necessarily mean there are safeguarding concerns.
- There may well be police involvement which can be very upsetting for parents.
- There is currently a national lack of paediatric pathologists, so post-mortem can be delayed for many months.
- Certain genetic testing can take additional time for results.
- A Coroner’s inquest will want any post-mortem findings, so expect significant delays.
- Be prepared to support the family through a prolonged period of waiting for ‘answers’.
- The local SUDIC team will always invite GP of the child to their meetings (usually initial meeting followed by the final child death review meeting). Make sure that a representative from the GP surgery (ideally the GP of the deceased child) attends. GPs will also be asked to complete ‘Child death reporting forms’ within a few days after the death of the child, before the initial SUDIC meeting.

[9] Sudden unexpected death in infancy and childhood – multi-agency guidelines for care and investigation: https://childprotection.rcpch.ac.uk/resources/sudden-unexpected-death-in-infancy-and-childhood-multi-agency-guidelines-for-care-and-investigation/

Supporting each other

The death of a child is a traumatic event, and members of the practice team could find this challenging. We suggest that the surgery proactively addresses this.

The first step is to acknowledge that this may be an issue. People work professionally and will likely compartmentalise their feelings from their work. You may not be aware that anyone is struggling unless you ask.

- **Check in with each other.**
    - Specifically check on:
        - The individual who took the call.
        - The GP dealing with the family.
        - The GP who may have verified the death.
        - Anyone who personally knew the child and/or the family (remember that GPs and their staff frequently live and work in the community).
        - Wider team members such as pharmacists (who may have been communicating with the family for many years).
- Are there members of your team who are bereaved parents?
    - Be aware that this event could be very triggering for them.
    - Note that in general, any bereaved parents in your team may need support with annual mandatory training including Basic Life Support and Safeguarding.
    - Be aware of this resource for employers from Child Bereavement UK: How you can help someone return to work after their baby or child has died? Guidance for employers | Child Bereavement UK.
- Staff members who are struggling may benefit from signposting to support services (see appendix A).

Appendix A – signposting

Please familiarise yourself with these support services/websites which may be appropriate for signposting.

For bereaved parents/families

What to do after someone dies: What to do if a child or baby dies - GOV.UK

- Helpful practical information from the government detailing actions that parents need to/may need to take.

Child Death Helpline – Home

- National free helpline staffed by volunteers who are bereaved parents. Run by the Alder Centre. For anyone affected by the death of a child at any age.

Lincolnshire Centre for Grief and Loss

- Based in Lincoln. Offering individual counselling that responds to the needs of children/ young people and adults in Lincolnshire who are experiencing the unmanageable symptoms of grief and loss following a significant life event.

SUDC UK

- Charity for all those affected by the sudden and unexpected death of a child aged between 1-18 years that remains unexplained.

I need support with a bereavement | Hospice UK

- Website providing wealth of resources around bereavement including further signposting to support services.

Survivors of Bereavement by Suicide – Overcoming the isolation of people bereaved by suicide (uksobs.com)

- Support specifically for where someone has died by suicide.

Amparo

- Offers support for anyone affected by suicide in the Lincolnshire area.

Support for Bereaved Parents and Siblings in the UK (slowgroup.co.uk)

- Support groups (face-to-face in London or Zoom meetings) for bereaved parents and siblings.

Child Bereavement UK

- Support for those grieving the death of a child.

The Compassionate Friends (tcf.org.uk)

- Support for bereaved parents and families.

Sands | Saving babies' lives. Supporting bereaved families.

- Support for all types of baby loss – miscarriage, molar pregnancy, ectopic pregnancy, stillbirth, neonatal death, Termination for Medical Reasons, Sudden Infant Death Syndrome.

Home | The Lullaby Trust

- Support for those who have experienced sudden and unexpected death of a child.

Dad Still Standing | baby loss support for dads

- A podcast and resources specifically for fathers who have experienced child loss.

Sands United | Sands - Saving babies' lives. Supporting bereaved families.

- Bereavement support for dads.

Peeps HIE Charity | HIE Awareness & Support

- Bereavement support for those affected by Hypoxic-Ischaemic Encephalopathy (H.I.E.) also sometimes referred to as birth asphyxia.

The PABL Project

- Trauma based physiotherapy support for postpartum recovery after baby loss.

Sudden Unexpected Death in Childhood

- Resources for families and professionals.

Bliss

- Bereavement support and professional resources relating to babies born prematurely.

Winston's Wish - Bereavement Support for Children

- Bereavement support for children and young adults (up to the age of 25 years).

For professionals

Practitioner Health

- Mental health support for healthcare professionals.

British Association of Perinatal Medicine

- Management of lactation following the death of a baby.

Working Together to Safeguard Children (2023)

- Chapter 6 for statutory guidance on child death reviews.

Sudden Unexpected Death in Childhood

- Resources for families and professionals.

Course: Pregnancy Loss and Child Bereavement | RCGP Learning

- RCGP eLearning on Pregnancy Loss and Child Bereavement.
- Requires log-in to access.

Appendix B – glossary

Baby loss	Death of a baby which could be during pregnancy or shortly after birth
Child death	Death of a child under the age of 18 years
Hypoxic-Ischaemic Encephalopathy (HIE)	Also known as birth asphyxia
Infant death	Death of a child under the age of 1 year
Miscarriage	The loss of a pregnancy before 24 weeks of gestation (note this guidance is not aimed at supporting those who have experienced miscarriage)
Neonatal death	Death of a baby under the age of 28 days
Perinatal event	Between 22 weeks of pregnancy and 7 days of life
Rainbow baby	A child born to a family who have previously experienced baby loss due to miscarriage, stillbirth, ectopic pregnancy, termination for medical reasons or death during infancy
Stillbirth	The death of a baby after 24 weeks gestation, but before birth
Sudden unexpected death in childhood (SUDIC)	As SUDI (below) but for a child (less than 18 years of age)
Sudden unexpected death in infancy (SUDI) – also referred to as **Sudden Infant Death Syndrome (SIDS)**	Sudden and unexpected death of an infant where no cause can be found after detailed post-mortem examination
Termination for Medical Reasons (TFMR) – also referred to as **Termination of Pregnancy for Fetal Anomaly (TOPFA)**	Where a pregnancy is ended for medical reasons by medical intervention