A pathway to ensure high quality bereavement care after pregnancy loss or the death of a baby

national bereavement care pathway
for pregnancy and baby loss

Sudden Unexpected Death in Infancy (SUDI) up to 12 months

Full Guidance Document

Led by

sands

In partnership with:

Antenatal Results & Choices
Bliss for babies born premature or sick
iHV Institute of Health Visiting Excellence in Practice
the lullaby trust
Miscarriage Association The knowledge to help
Neonatal Nurses Association
UCL EGA Institute for Women's Health
Royal College of Midwives
RCGP Royal College of General Practitioners
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
NHS England
The Ectopic Pregnancy Trust

nbcpathway.org.uk

NBCP for use in England from September 2025

About the NBCP

The National Bereavement Care Pathway, led by a multi-agency Core Group of baby loss charities and professional bodies, has been developed in order to improve bereavement care, and reduce the variability in bereavement care, for families suffering the loss of a baby through miscarriage, ectopic pregnancy and molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months.

The programme provides a dedicated, evidence-based and independently evaluated care pathway with guidance for professionals delivering bereavement care to parents and families. Whilst the programme encompasses all four nations of the UK, this document relates to England only. Information on the Scotland pathway can be found at nbcpscotland.org.uk, and for information on the emerging Wales and Northern Ireland Pathway projects email bereavementcare@sands.org.uk.

This guidance, developed for healthcare professionals working with bereaved families, relates to one of the five pathways. The Core Group gratefully acknowledges the support and contribution of the Department of Health and Social Care (DHSC) and Teddy's Wish to the early development of the NBCP in England. **For further information, please see nbcpathway.org.uk.**

> "Parents don't need protecting; they need the chance to be parents, provide their child with dignity and create memories."
>
> **Bereaved parent**

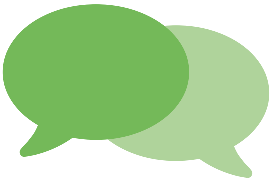
Note to the reader

This is the full version of the pathways guidance produced for the National Bereavement Care Pathway (NBCP). This document contains detailed guidance to support the care of bereaved families. The quick reference guide for this pathway is also available at nbcpathway.org.uk and contains templates and tools for you to adapt and use in the local setting. Please consult the terminology page before reading this document in full.

Key messages

There are 9 bereavement care standards (overleaf), and all of these are underpinned by three important themes since the beginning of the NBCP programme.

1. Good communication is key to delivering good bereavement care



"For me the simple things make a huge difference. Being listened to. Eye contact and someone sitting beside me – communicating they have time for me." Bereaved parent

"Why didn't anyone check in with me afterwards? I had been on their records and yet [there was] no call the week after to see how I was doing. [There was] no information of what to expect or where to get help." Bereaved parent

2. Continuity of care and consistency in approach is vital

"I would have loved to have birthed the baby at home as I had had previous homebirths – but this option was not given, **and I was not aware this was a choice I had."**

Bereaved parent

"I found it really distressing to have to explain over and over again to different members of staff that my baby had died."

Bereaved parent

3. Parent-led family involvement must be supported

"I would have liked to have had been offered a couple of sessions with a midwife with my husband where we could share our story and debrief."

Bereaved parent

"I wish someone had given us more time to talk about the benefits of seeing the baby and spending time with him. Of inviting the other kids to come and meet him." Bereaved parent

Bereavement care standard

These nine standards for bereavement care underpin the NBCP guidance. A Trust that meets these standards is considered to be providing good bereavement care.

Trusts should audit their service provision against these standards to identify gaps in the care they provide, and develop plans for improvement. A self-assessment tool is available for all Trusts in England to conduct this audit, see nbcpathway.org.uk.

Implementation of these standards via the pathway will help Trusts to meet the elements of the Care Quality Commission's assessment framework for maternity.

Parent-focused standards

1. All bereaved parents and families are provided with **personalised care**.
2. All bereaved parents and families have the opportunity to use an appropriate, available and accessible **bereavement room**.
3. All bereaved parents and families are offered opportunities to **make memories**.

Communication and learning standards

4. All bereaved parents and families are informed about and, where needed, referred for **emotional support** and for specialist **mental health support**.
5. A **system** is in place to clearly **signal** to all health care professionals and staff that a parent has experienced a bereavement.
6. Bereaved parents and families are confident that **learning** from their baby's death will take place and are fully informed throughout.

Staffing standards

7. Bereaved parents and families receive their care from an **appropriately staffed** team.
8. All staff involved in the care of bereaved parents and families receive the **training and resources** they need to provide high-quality bereavement care.
9. Healthcare staff are effectively **supported** to care for bereaved parents and families.

The NBCP bereavement care standards are cited extensively in national reviews, policy and clinical guidance. A full list of citations is available on the website.

A self-assessment form is available to help you assess the quality of care in your Trust against the nine bereavement care standards. Your bereavement lead should have one of these, otherwise contact us via bereavementcare@sands.org.uk.

Terminology

The NBCP editorial panel acknowledges that language matters, and that it is complex and continually changing.

We encourage all staff to follow the principle of asking the person they care for how they would like to be referred to and to mirror the language used by families when speaking to them about their experiences.

The guidance below outlines important points on language use throughout the pathways:

- The terms ‘healthcare professionals’ and ‘staff’ are used throughout to denote all of those professionals working with bereaved parents.
- Throughout the pathways we use the additive language ‘women and birthing people’ to include individuals who do not identify as women.
- The term ‘baby’ (or ‘babies’ in the case of multiple pregnancies) is used throughout the pathways to refer to the first trimester of a pregnancy through to the neonatal period. In earlier losses many people will prefer to conceptualise their baby and will develop strong attachments to them from the moment they discover that they are, or were, pregnant. However, some people will be more comfortable with terminology such as ‘fetus’ or ‘pregnancy’ and will not find the term ‘baby’ to be appropriate in their situation. While we have used the term ‘baby’ throughout the guidance, it is important to recognise that not everyone who experiences a perinatal bereavement will want to refer to their loss using this language. The language preferences of those people experiencing a loss should always be mirrored when communicating with them.
- The term ‘parents’ is used to refer to expectant and bereaved people and partners. Many people will consider themselves parents from the time they discover they are, or were, pregnant. However, not everyone who experiences pregnancy loss or the death of a baby will want to be referred to as a parent. Therefore, when using this guidance staff should be sensitive to the individual preferences of those they are caring for.
- We recognise that who a ‘family’ is may involve different structures and diverse experiences. Where ‘family’ or ‘families’ are referred to in this document, we advise healthcare professionals to consider that there is not one type of bereaved family but to ensure that the individual is given opportunity to explain who they consider their family or support structure to be.
- The term ‘partner’ is used to refer to whoever is there as a close support to the person being cared for. Not everyone will have a partner and/or may not have them with them in the clinical setting, while others may be with a friend or family member, or may have more than one partner. As such, ask rather than assume who is in the room and what their relationship to the woman or birthing person is.
- We have used the phrase ‘Trusts’ because the rapid changes in the way that health services are structured and managed across the country make it impossible to use a phrase that covers all the bodies involved. In the devolved nations the term ‘Board’ is used. However, the pathway will also be applicable to independent healthcare establishments and to all other bodies that may be set up in the future to organise and provide care for women, birthing people and families experiencing a childbearing loss.

Finally, because this is a pathway focused on improving outcomes for women, birthing people and families, by its very nature it is quite directive and as such in a number of sections we have also used the term ‘should’ (for example ‘staff should be trained’). Essentially this is shorthand for ‘good practice suggests that’.

Sudden Unexpected Death in Infancy (SUDI) up to 12 months

The sudden and unexpected death of an apparently healthy baby triggers an established, multi-agency response that can last twelve months, or even longer, and involve many professionals.

Professionals working in this area should be aware of the statutory guidance in Working together to safeguard children, the Child death review: statutory and operational guidance and Sudden unexpected death in infancy and childhood: multi agency guidelines for care and investigation, more commonly known as the 'Kennedy Guidelines.' All three are referred to in these guidelines. Each local area should have a protocol that implements the guidance and explains who to contact when a baby dies suddenly and unexpectedly.

Family care and support is an ongoing process from the moment the baby dies. The death will impact on the family for the rest of their lives. There is no easy check-list for how to support families, but this guidance details the ways that families can be offered support at different stages, and gives some key principles when supporting families who have experienced an unexpected infant death.

Definitions

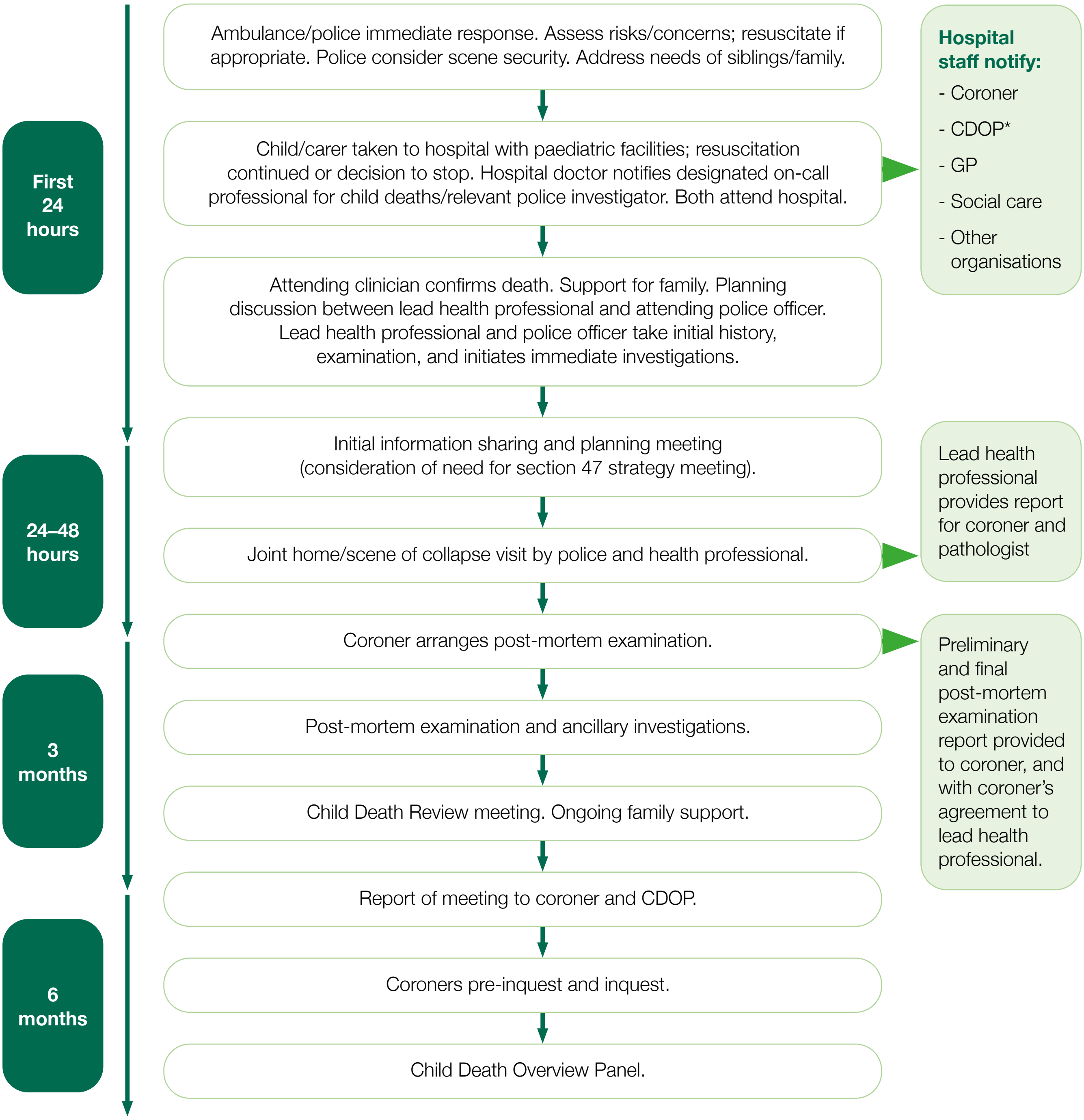
References are made in this document to the terms SUDI (sudden unexpected death in infancy) and SIDS (sudden infant death syndrome). The definitions of these are taken from the Kennedy Guidelines:

SUDI – this 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 in which no pre-existing medical cause of death is apparent. This is a descriptive term used at the time the baby dies, and will include those deaths for which a cause is ultimately found as well as those that remain unexplained following investigation.

SIDS – this refers to the sudden and unexpected death of a baby under 12 months of age which remains unexplained after a thorough investigation.

Joint Agency Response

The multi-agency response referred to above is known as a Joint Agency Response (JAR) in the guidance documents. The criteria for when a JAR should happen is laid out in the Child death review: statutory and operational guidance (Chapter 3.3) The diagram below shows the steps involved



First 24 hours

Ambulance/police immediate response. Assess risks/concerns; resuscitate if appropriate. Police consider scene security. Address needs of siblings/family.

Child/carer taken to hospital with paediatric facilities; resuscitation continued or decision to stop. Hospital doctor notifies designated on-call professional for child deaths/relevant police investigator. Both attend hospital.

Hospital staff notify:

- Coroner
- CDOP*
- GP
- Social care
- Other organisations

Attending clinician confirms death. Support for family. Planning discussion between lead health professional and attending police officer. Lead health professional and police officer take initial history, examination, and initiates immediate investigations.

24–48 hours

Initial information sharing and planning meeting (consideration of need for section 47 strategy meeting).

Joint home/scene of collapse visit by police and health professional.

Lead health professional provides report for coroner and pathologist

3 months

Coroner arranges post-mortem examination.

Preliminary and final post-mortem examination report provided to coroner, and with coroner’s agreement to lead health professional.

Post-mortem examination and ancillary investigations.

Child Death Review meeting. Ongoing family support.

6 months

Report of meeting to coroner and CDOP.

Coroners pre-inquest and inquest.

Child Death Overview Panel.

*The term CDOP refers to Child Death Overview Panel. This is a multi-agency panel is used to represent the group established by CDR Partners that is responsible for ensuring the child death review process (including the JAR) is carried out. They are also responsible for conducting the final review of each child death.

Communication

All communication with parents experiencing a pregnancy loss or the death of a baby must be empathic, sensitive, non-judgemental and parent-led.

Staff should have a conversation with parents as early as possible, to find out about their background and individual needs. This can help staff identify health inequalities and practical barriers and tailor communication to the needs of each individual family, should they experience pregnancy loss or the death of a baby. These conversations should be recorded in the woman or birthing person's medical notes (with their consent).

Use warm, open body language by sitting near parents at a similar height (not above them), facing them, making eye contact and using touch if appropriate (see differentiations below for parent(s) with specific communication needs including neurodiversity). Be mindful of your tone and background noise if communicating over the telephone. Be honest with parents while being as sensitive as possible. It is okay to show emotion, but the parents should not feel they need to look after your feelings. Professionals should aim to be empathic, avoiding being too "cold and calculated" whilst still maintaining professional clinical boundaries. In INSIGHT (Siassakos et al, BJOG 2017) parents asked for 'friendly contact'.

Parents may be shocked and/or very distressed, and may find it difficult to understand information or think clearly. Staff should speak clearly, use simple language and parents should be encouraged to ask questions. Staff should also provide information in writing (or other formats) where possible. Be aware that cultural norms or personal circumstances may affect a parent's readiness to ask questions, request clarification or express their wishes.

It should be noted that women and birthing people with a multiple pregnancy are 4.9 times more likely to experience neonatal death than those with a singleton pregnancy (MBRRACE 2022) and are much more likely to be born early, so practitioners should bear this in mind when communicating with parents of multiples (further sections of this pathway go into more detail).

Supporting parents when communication barriers are present

Staff should never assume that they can anticipate the needs of any individual with a sensory impairment, learning difficulties or who is experiencing a language barrier without first asking them. Parents may have a hospital or communication passport with them to indicate their communication preferences. Staff should have a conversation with parents about their needs and preferences as early as possible, and these should be recorded in the woman or birthing person's notes (with their consent).

Staff should be patient and sensitive to individual needs. Where an interpreter is required, staff should have easy access to trained and experienced interpreters (ideally face-to-face) when supporting parents.

NHS England have created a resource pack for maternity service providers on supporting interpretation. The Office for Health Improvement and Disparities have also created guidance on language interpreting and translation.

Sands and Tommy's Joint Policy Unit have produced a report on the provision of interpreting services in maternity and neonatal care with recommendations for practice.

Communication

Communicating if there is no formal interpreter

- Using family and friends to interpret is strongly discouraged.
- Parents may not want the informal interpreter to know everything about them and may not feel able to discuss things fully or truthfully.
- An informal interpreter who is a family member or friend may themselves be deeply affected by the situation and their ability to interpret may also be affected if they become distressed.
- It is never acceptable to use a child or a young person under the age of 16 years to interpret for parents who are experiencing the death of a baby unless immediate emergency care is required and no other options are available. This can put the child in an extremely difficult situation and can cause serious emotional trauma.
- Some parents may be accustomed to their children interpreting for them. They may have a cultural expectation that their children will interpret for them. However, staff should inform parents that it is the hospital or clinic's policy to not allow children to interpret in order to avoid distress or confusion and to adhere to safeguarding procedures.

Communicating with parents who are deaf or who have a hearing impairment

In addition to offering a sign language interpreter, staff who are communicating with parents who are deaf or have a hearing impairment should ensure that:

- A quiet place is available for discussions.
- They avoid shouting, speaking slowly or exaggerating speech or facial expressions.
- They use clear, simple language and provide clear, simple written information.

Communicating with parents who are blind or who have a visual impairment

Staff should introduce parents who are blind or visually impaired to everyone involved in any discussion and let them know where everyone is located.

Communicating with parents who have a learning disability and/or neurodiversity

It is important to remember that parents with a learning disability and/or neurodiversity often have a hospital or communication passport with them, which indicates their communication preferences. For many neurodiverse parents, eye contact and touch can feel difficult, so the typical communication approaches outlined above may need to be adjusted. Please try and check this out however, as every parent is individual.

Support to the family

The sudden and unexpected death of an apparently healthy baby is a deeply distressing time for families.

The guidelines for professionals on how to investigate such deaths take into account the need to balance a sensitive approach to parents with the need to find an explanation for why a baby has died. Professionals working in this area should be aware that the vast majority of sudden infant deaths are of natural causes and many will never have an explanation for the death of their baby even after a full investigation. Allow families sufficient time to ask questions, some of which will be very difficult for them to ask. Keep in regular contact so families don't have to chase for information.

If the baby that died was a twin, triplet or higher order multiple, the health professional will need to be aware that the family will be grieving for the baby that has died but will also need to continue caring for their twin or triplet/s. This could bring many challenges. Please refer to Twins Trust who will be able to support the family with their bereavement and offer the family support.

Some guidelines that may be useful when supporting families through this tragedy:

- There is no right or wrong reaction to sudden death and grief, and anger is a common expression of emotion.
- Parents will often blame themselves, no matter what the circumstances, feeling that a key parental duty was to keep their baby alive – they will often already be aware of their specific risk factors.
- The whole family needs to be cared for and support offered, including step and extended families.
- Families want to be kept informed and given realistic time scales and honest information, however difficult this is.
- There are known risk factors for SIDS, but these are not causes of death, and care should be taken to avoid any suggestions of blame when discussing these. It is important to use phrases such as 'would you like to tell me what happened' rather than 'why didn't you?".
- Understand that the presence of police, even when not in uniform, will have an impact on the family and the wider community, and avoid using terms such as 'suspicious death' and 'crime scene'.
- There is specialist counselling and bereavement support available, and professionals should feel empowered to refer families for this at any time.
- The process following the sudden death of a baby is often so traumatic that families may not seek support for several weeks or months, once the contact from healthcare professionals has become less frequent.
- The sudden death of a baby can trigger a number of difficult circumstances for families which professionals should be aware of, and offer practical support with, including housing, employment, financial problems (for example withdrawal of benefits) and mental health issues.
- Make sure you are aware of 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 that this has already taken place and everyone, including yourself, has the most up-to-date information.
- Families will remember how professionals made them feel during this difficult time so it is important they feel heard and respected, make sure you give every conversation extra time, showing you are listening to them even if it is information which has already been shared.
- Staff should ensure the cultural and religious needs of the parents and family are supported wherever possible and that, where appropriate, parents are offered religious or spiritual care. Staff should offer to contact the family's spiritual/religious support or hospital chaplaincy/spiritual service.

When visiting families, these key points may also be helpful:

- Introduce yourself, your name, your role and what you are going to do.
- Find out the baby's and parents' names beforehand and use them.
- Say you are sorry and acknowledge their distress.
- Do not be overly apologetic.
- Try to avoid using terminology families may not understand.
- Give information plainly and invite questions as you go along.
- Don't assume someone else has given any information to families.
- Establish and confirm what happens next.

The immediate response

Most babies that die suddenly and unexpectedly are found by their families who will call an ambulance. The initial 999 call will request an ambulance and also notify police, who will also attend. Resuscitation is almost always attempted, and families will be encouraged to be a part of this before the ambulance arrives. The baby will then be transferred to an emergency department.

The Kennedy Guidelines give detailed information on the initial assessment and management of sudden deaths in infancy and childhood.

This is an extremely distressing experience for families, who will often not be expecting the police to also attend. Only one parent is usually able to travel in the ambulance, and there may be other children or family members who need to be considered. Any questions that need to be posed at this time should be done so as quickly as possible to allow parents to travel to the hospital with their baby.

Where a resuscitation is ongoing it is good practice to allow the parents to watch if they wish to.

The family should be allocated a lead health professional once at the hospital, and kept fully informed in an appropriate and private space. This lead health professional should then tell the family that their baby has died, using clear language, and explaining what happens next. Families should be given as much opportunity to be with their baby at this stage as is possible, taking into account that the coroner will be contacted and will ask for a post-mortem to be carried out as part of the process for discovering why the baby died.

Early interviews, including taking a history of the baby with parents by any professional, need to take into account the careful balance between the needs of the investigation and the shock, trauma, and grief of families. Joint working wherever possible will save the family from needing to repeat the same information to different professionals. Practical support including how they will get home and ensuring there are family and friends to help is useful. Some families do not wish to return to their home if this is where their baby died, and may need support arranging where to go. Contact details of support organisations and bereavement services should be given before they leave the hospital. The Lullaby Trust offers support to families and professionals affected by a sudden infant death, and professionals can either give details to the family or make a referral directly with a family's permission.

Ensure that if the woman or birthing person was breastfeeding, they are given information on suppression of milk supply. Medication can be prescribed where appropriate. The family should be allocated a key worker; a single, named point of contact to whom they can turn for information on the child death review process, and who can signpost them to sources of support.

They can be the 'voice' of the family; they are often a health professional but not always; often the professional who 'knows' the family best. The family should be reminded of the importance of liaising with the key worker.

The healthcare team should ensure that the baby's death is notified to the local Child Health Information System (CHIS), and that the child's GP and health visitor are notified of their death. The Child Death Overview Panel (CDoP) administrator should also be informed of the death. These are all crucially important to ensure other professionals are made aware of the baby's death and do not contact the family for other appointments relating to the baby which could be hugely distressing. It also helps other agencies to think about support for the family.

Ask the partner if they would like their GP to be informed about the loss so it can be added to their notes, and record their consent if they did.

The family should be allocated a key worker; a single, named point of contact to whom they can turn for information on the child death review process, and who can signpost them to sources of support.

Mementoes

Once the baby has been examined and all necessary samples taken, the family should be offered the opportunity to hold their baby. The coroner should be informed and with their permission, it would be expected that the family are offered:

- Time to be with their baby and hold them if possible.
- Hand and footprints.
- A lock of hair.
- To take photographs.

These should be offered sensitively. All of the above are a choice for the family to make, and it is important that professionals do not impose their own feelings. Inform the family that they will also have the opportunity to hold their baby after the post-mortem examination (with the coroner's consent). These mementoes may be important to some families, but not to others, for many different reasons.

Before leaving hospital

Before the family leave hospital, they should be told that their baby will be transferred to the mortuary before being transferred to the centre where the post-mortem examination will take place and be given the contact details of their key worker. The family should be told if their baby is being transported out of area for the post-mortem and details given.

Early response

Home visit (also known as Scene visit)

As soon as possible after the baby's death, a visit will take place where the baby was found to be unresponsive, if this is where the baby was found to be unresponsive. This should be a joint visit with police and a specialist health professional, and the parents will usually be invited to be there. This visit is a crucial part of the investigation, and helps to gather a great deal of information. This is also a good opportunity to give details of other bereavement support the family may wish to access.

The coroner

Where a baby's death was sudden and unexpected, the death will be reported to the coroner. This means the family may not be able to arrange the funeral or register the death for some time, and families should be made aware of this.

The coroner officially has custody of the baby's body from the point at which they are informed of the death, and will then make decisions about what investigations take place, where and when. Although in most situations families will be able to see their baby after death, the coroner ultimately has control over allowing this to happen. Do not discuss post-mortem examination details with the family until the coroner has decided what should happen.

Post-mortem examination

All sudden and unexpected deaths of babies will have a post-mortem examination, which should be undertaken by a specialist paediatric pathologist. This often means the baby will have to travel, sometimes long distances, to a specialist centre. This is clearly upsetting for families, and they should be kept up to date with where their baby has been moved to and when the post-mortem examination is going to take place. Performing a post-mortem examination on an infant is complex and it 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 tissue samples have been returned.

The coroner should ensure families are offered the choice about what happens to these tissues once the post-mortem examination has taken place. It will normally be possible for the family to visit their baby following the post-mortem examination at the mortuary and details of how to arrange these visits should be given.

Whole Genome Sequencing (WGS)

WGS is now available through the NHS in England for babies and children who have died suddenly and unexpectedly where the death is unexplained following full investigation including a post-mortem examination. It might tell families about known cardiac, neurological and metabolic genes that are associated with sudden death. This test is R441.1 for unexplained death in infancy and childhood (SIDS and SUDC). The test is available following the baby or child's post-mortem if the death is recorded as unexplained. Please advise families ask their Paediatrician or clinical geneticist for more information.

Registration of death

The baby's death will not be able to be registered formally until the coronial process has been completed, which can take several months. However, an interim death certificate will be given to allow a funeral to take place once the initial post-mortem examination has been completed.

The Ministry of Justice leaflet Guide to Coroner's Services details this process in full.

- Appendix 6 of the Kennedy Guidelines details the post-mortem examination protocol for sudden unexpected deaths in infancy that are non-suspicious.

Funeral

The funeral can only take place once a death certificate has been issued. After the post-mortem examination has taken place, the coroner will issue an Interim Certificate of the Cause of Death to allow this to take place. Whilst this may take a few weeks, families are able to plan their baby's funeral in the meantime, and should be encouraged to consider the different options for doing this. The arrangements can be made in advance of the baby's body being released by the Coroner, and funeral directors should be used to this process and support families until a date is confirmed.

Families on low incomes may be eligible for help with the costs of the funeral.

Statutory Bereavement Pay

Further information on the Children's Funeral Fund for England is available.

Later responses

Other meetings and findings

Later in the investigation updates may be given to the family, either about their baby's death or the support and care they received if this is also being reviewed or questioned. Families have found the following useful:

- Give as much notice of meetings as possible, and give families an indication of what the meeting is about.
- Allow plenty of time for families to ask questions.
- Try and meet families face to face wherever possible. Sending results in the post or via email is strongly discouraged unless the family have asked for this.
- If the meeting is online, ensure in advance there is good connection, appropriate IT, and that the meeting is still private.
- Ensure the family understand the information that is given to them, and have access to professionals who can explain each part.
- Be prepared with information about local and national bereavement support services.
- Remember that the key worker is the link between professionals and the family.

Inquest

The coroner may decide to hold an inquest at the end of their investigation. This should be explained to families fully with good notice and support given before the date of the inquest. Families should also be warned that inquests are open to the public and journalists can therefore attend. The Coroner's Court Support is a registered charity which can offer volunteers to support families on the day. The family are under no obligation to attend the inquest if they do not wish to, unless they have been called to be a witness.

Inform the family that the inquest may be online. Warn families that the overall inquest process can be very lengthy. Families want answers, so prepare the family that there may not be a conclusive cause of death.

Remember the key worker is the link for families and should be kept informed and should input into the process.

The Child Death Review

All child deaths are reviewed by specialist Child Death Overview Panels (CDOPs), and this includes unexpected infant deaths. CDOPs review the death of every child in England who dies before their 18th birthday. The aim of these reviews is to identify learning to 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 should be informed that the child death review process is taking place and be informed how they can input into it should they wish.

The NHS England booklet for families, 'When a child dies: a guide for parents and carers' describes the Child Death Review process.

Care and support for families in the community

Professionals involved in the investigation into a baby's death are important sources of ongoing care and support for many bereaved parents. Some rely on professionals to be the ones who make regular contact and engage in conversations about the baby who died. There can often be long periods where there is no information, and families can find these quiet times the most difficult to get through. Make sure they have been given details of support services, such as The Lullaby Trust, locally and nationally, at every available contact.

Chapter 6 of the Child Death Review Statutory and Operational Guidance (2018) describes the support that should be provided to all bereaved families and carers after the death of a baby. Health visitors work as part of the primary care team with the whole family and can assess needs and access appropriate support. It is important that staff recognise the complex emotional journey that a parent may be experiencing and ask open, non-judgemental questions to ensure they can provide personalised care. Further, encourage families to seek support from their GP if they are particularly struggling with issues such as sleep, or reliving the time when their baby died.

Families will have their own memories and photos of the baby, and may wish to create other memorials in the future. Third sector organisations may be able to provide additional and longer term support and these can be found in the 'useful contacts' section of the quick reference pathways. Some hospitals may also have a Sands Hospital Liaison volunteer (HLV) who will be best placed to provide information on what is available locally.

The processes that follow the death of a child are complex, in particular when multiple investigations are required. Recognising this, all bereaved families should be given a single, named point of contact to whom they can turn for information on the child death review process, and who can signpost them to sources of support. This person is called a "key worker". It is the responsibility of the organisation where the baby was certified dead to identify a key worker for the family. The role can be taken by a range of practitioners regardless of professional background.

Feedback and Review

Parent feedback

The majority of bereaved parents want to give feedback about the bereavement care they received from any organisation after their baby died and feel it is appropriate for them to be sensitively asked about the care they received.

Good feedback mechanisms provide parents with opportunities to inform service improvements and feel listened to. Receiving feedback from parents in a structured and supported way gives room for reflection and learning and also promotes the sharing of best practice. . In addition, it is also paramount that feedback mechanisms are accessible to all bereaved parents, including those who don't speak English or may face other barriers when it comes to providing feedback. Different ways of collecting feedback should be thought of and implemented in collaboration with parents.

When parents have had a good experience of care at this often very difficult time, it can be important for the staff who cared for them to know that the care they provided was beneficial.

It is important that parents understand how valuable their feedback is. Being on the receiving end of care they are in a unique situation to highlight to staff the areas that were helpful and also what can be improved upon. Many parents want to make a positive difference to those coming after them.

Conversely, it is important staff are supported and trained to listen to parents who didn't receive optimal care. This feedback allows for reflection and learning and promotes service improvements. All feedback from parents should be taken as an opportunity to learn and develop the bereavement care service.

Subsequent pregnancies

Ensuring that there is good communication between staff (including across teams and departments) is essential in subsequent pregnancies.

All staff who care for bereaved parents in subsequent pregnancies should be well-informed about parents' history so that they can respond sensitively to any anxieties or concerns that parents may express. One of the first questions most families will ask is 'will this happen again?'. Information should be given to families on the safer sleep advice for reducing the chance of SIDS, and honest discussions should take place with families about this. However, it should also be noted that where a death is certified as 'unascertained' or 'sudden infant death syndrome', we do not know a cause: safer sleep advice, advice on cessation of smoking may reduce the risk of recurrence but cannot eliminate the risk entirely.

The Care of Next Infant (CONI) programme is run by The Lullaby Trust in partnership with the NHS and local health visiting providers and is offered widely across the country for families who have had a baby die unexpectedly. The programme provides specialist health visiting support for families with future pregnancies and in the first 6 months following birth, but can be extended depending on individual circumstances. Information on where CONI is available, who is offered CONI support and what the CONI scheme entails can be found via The Lullaby Trust.

Emotional support

Ongoing emotional support

Both immediate and long term follow up care and emotional support should be available to all parents who experience a pregnancy loss or the death of a baby.

Good communication between staff and healthcare teams is essential to providing good bereavement care and ensuring appropriate continued emotional support is available.

Policies should be in place to ensure that there are efficient processes for keeping all health and other agencies informed about the death of a baby.

Services should be accessible and inclusive to all parents and systems and standard practices should not discriminate against parents. Services should be flexible so that they can be adapted wherever possible to meet the needs of all parents.

Staff should flag support available to families

- Chaplaincies should have contacts with religious and spiritual advisers of different faiths and spiritual organisations.
- Access to counselling and further support via secondary care (for example, GPs and health visitors).
- Specialist psychological services.
- National and local support organisations, such as The Lullaby Trust and Sands.

The death of a baby will be experienced differently by each parent. There might be recognisable themes, but staff should not make assumptions about how a parent is feeling at any point, or about what they may need in terms of ongoing support.

Parents who experience the death of one of their twins, triplets or higher order multiple pregnancy may find it challenging and need extra support from charities such as Twins Trust who can help provide emotional support as the families continue to look after their surviving children.

Mental health

Policies and practices should be in place to offer bereaved parents ongoing follow up care, further assessment and treatment for mental health problems. Sufficient time must be available in follow up appointments with bereaved parents to enquire about their emotional well-being and offer assessments for mental health difficulties where necessary.

Good communication is crucial between staff and healthcare teams regarding parents who may be at risk of developing, experiencing or who have been diagnosed as having mental health problems after a baby loss.

Where appropriate, and if the woman or birthing person is physically well, staff could encourage physical activity as this can be beneficial for emotional wellbeing.

Staff support

Healthcare staff should be effectively supported to provide high quality bereavement care for bereaved parents and families. When staff are properly supported, working with families experiencing the death of their baby can be special and rewarding. Good training and support for staff improves the quality of bereavement care offered to parents when a baby dies.

Training

All staff involved in the care of bereaved parents and families must receive the training and resources they need to provide high-quality bereavement care. Bereavement care training should be mandatory for all staff who may come into contact with bereaved parents and families, including those in non-clinical roles. Staff should receive training on induction and annual refresher training, and must be able to access this training in working hours. Staff should also have access to up-to-date and relevant bereavement care resources.

Bereavement care training can help staff to develop skills in communicating more sensitively and empathetically with parents and increase their awareness of the needs of bereaved parents.

Training can help staff to feel more confident in the care they provide and help to understand their emotions. Support and training are essential to ensure staff well-being and avoid staff burn out.

Staff wellbeing

To provide parents with high quality, personalised care, workplaces must be supportive environments where staff feel valued. This applies to all members of staff – at all levels and in all disciplines – including all primary care staff who may have long term relationships with the family and who may be working in greater isolation.

There are many reasons why it can be stressful and demanding to care for parents during a pregnancy loss or when a baby dies. These may include staff having their own experience(s) of loss; a feeling of personal and professional failure following a baby death; anxiety caused by wanting to ‘get it right’ knowing this is a difficult time for parents; working in understaffed and unsupportive work environments.

A trauma-informed approach should be taken to providing support for staff. Staff should have access to wellbeing services and specialist psychological support and have opportunities to debrief. It is important to have different support options available for members of staff to use as they need.

Staff wellbeing should be prioritised and monitored as a key part of a safe, effective and high-quality healthcare service. Managers and senior staff have a duty to provide encouragement, support and training for staff, to watch for signs of strain or difficulty in individuals and within teams and to facilitate discussion between colleagues, teams and centres. It is important to note that stigma and concerns about not appearing to be coping with their job may cause some staff to avoid seeking support.

Trusts should also ensure that managers and senior staff have access to appropriate support, both for themselves and so they can support their staff. Where staff are bereaved, this NHS guide to bereavement and cultural practice can be helpful to managers.

For further resources, see the NBCP toolkit on staff wellbeing.

The Sands helpline is available for anyone affected by pregnancy loss or the death of a baby, including healthcare staff.

Notes

Notes

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for pregnancy and baby loss

For more information visit:
nbcpathway.org.uk

sands.org.uk

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