
A pathway to improve bereavement care for parents in England after pregnancy or baby loss



national bereavement
c a r e p a t h w a y
for pregnancy and baby loss

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

Full Guidance Document

Our National Bereavement Care Pathway core partners



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 project provides a dedicated, evidence-based care pathway with guidance for professionals delivering bereavement care to parents and families. As its name infers, it is a national project, although at this stage its scope is limited to England and not the devolved nations.

This booklet, developed for healthcare professionals working with bereaved families, relates to one of the five pathways which have been piloted in 32 sites and independently evaluated, the report for which can be found on the website below.

For further information, please see www.nbcpathway.org.uk

“Parents don’t need protecting; they need the chance to be parents, provide their child dignity and create memories.”

(Quote by bereaved parent, 2017)

Key messages

In our consultation with parents three clear messages came through:

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.”
(M.E., 2017)

“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.” (N.B., 2017)

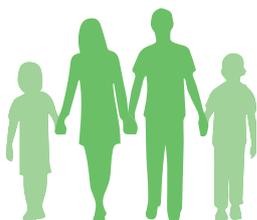
2. Continuity of care and consistency in approach is vital



“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.**”
(M.E., 2017)

“I found it really distressing to have to explain over and over again to different members of staff that my baby had died.”
Mother (Sands Guidelines, 2016)

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.”
(M.E., 2017)

“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.” (M.E., 2017)

Bereavement care standards

A Trust that meets these standards is considered to be providing good bereavement care. Trusts should audit provision against these standards and improve the bereavement care they offer where gaps are identified.

Implementation of these standards via the pathway will help the Trust to meet the elements of the Care Quality Commission's Maternity Assessment Framework that cover these points (www.bit.ly/2zNYZEd).

- A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
- Bereavement care training is provided to all staff who come into contact with bereaved parents, and staff are supported by their Trust to access this training.
- All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
- There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
- Bereavement rooms are available and accessible in all hospitals.
- The preferences of all bereaved families are sought and all bereaved parents are offered informed choices about decisions relating to their care and the care of their babies.
- All bereaved parents are offered opportunities to make memories.
- A system is in place to clearly signal to all healthcare professionals and staff that a parent has experienced a bereavement to enable continuity of care.
- Healthcare staff are provided with, and can access, support and resources to deliver high-quality bereavement care.



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 six 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 and the more detailed guidance in 'Sudden unexpected death in infancy and childhood: multi agency guidelines for care and investigation', more commonly known as the Kennedy Guidelines. Both are referred to in this framework. In addition many areas have local guidelines for investigation Sudden Unexpected Deaths in Infancy (SUDI), and professionals should be aware of these.

Parental 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 tick-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.

Communication

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

Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate. Be mindful of your tone and background noise if communicating over the telephone. Be honest with parents while being as sensitive as possible.

Parents may find it difficult to take in complex information or think clearly. Staff should speak clearly and use simple language and parents should be encouraged to ask questions. Be aware that cultural norms or personal circumstances may affect a parent's readiness to ask questions, request clarification or express their wishes.

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. Staff should ask parents if they need additional support and about their preferences.

Staff should be aware of, 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.

Communicating if there is no 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 teenager 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.
- 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 possible misunderstandings.

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 wearing a mask or covering their mouth.
- 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 told where everyone is located.



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 may have died. Professionals working in this area should be aware, through this and local guidance, 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.

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 timescales 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 guilt when discussing these. So 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 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 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.
- Listening is a very important skill and one which families will often remember.

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 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 unexpected infant deaths 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. Families should be offered a key contact and be told what will happen next before they leave the hospital. Practical support including how they will get home and ensuring there are family and friends to help is often 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 to make a referral directly with a family's permission.

Ensure that if the mother was breastfeeding, she is given information on suppression of milk supply. Medication can be prescribed where appropriate.

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 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.

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 his or her 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 have the opportunity to hold their baby and take photographs 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. The health professional with the family should be able to explain what the resuscitation attempts involved, what investigations were done and what will happen next. 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 have the contact details of a key health professional. The baby should be transported in a sensitive and appropriate manner from the Emergency Department to the mortuary.

Early response

Home visit

As soon as possible after the baby's death, a visit will take place to the home, if this is where the baby was found to be unresponsive. This should be a joint visit with police and a 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 will not be able to register the death or arrange the funeral 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 examinations with the family until the Coroner has decided what should happen.

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 up to six months or sometimes even longer. 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.

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 can take several months for all tests to be complete. It may be that the family are asked to make difficult decisions as to whether they wish to have a funeral before all the samples have been returned. 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.

When the initial post-mortem examination is completed, families should be given an interim certificate of death and be able to have the funeral. There will still be some tests to be undertaken which make take several months to be completed. It is important that families are given full explanations of these tests, with a realistic timetable, and are kept up to date at every stage; even if this is to report that nothing has been found.

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



Tissue retention

As part of the post-mortem examination the pathologist will take small samples of tissues, which are then put into slides for testing. The Coroner should ensure families are offered the choice about what happens to these tissues once the post-mortem examination has taken place.

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. More information can be found at: www.gov.uk/funeral-payments

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 not recommended.
- 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.

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 Service is a registered charity who 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.

The Child Death Review

All child deaths are reviewed by specialist Child Death Review Panels, and these include unexpected infant deaths. The Panels look into every child death to try and prevent future deaths and improve support to families. This process works alongside all the other elements of the investigation into a baby's death. Parents are not usually involved in the process but should be informed that it is taking place and how they can input into it should they wish.

A NHS England booklet for families, describing the Child Death Review process called *When a Child Dies: A Guide for Parents and Carers* can be downloaded from www.england.nhs.uk/publication/learning-from-deaths-information-for-families.

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. 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. Support and information on these is available from bereavement support organisations.

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 is offered widely across the country. The programme provides specialist health visiting support for families who have had a baby die unexpectedly with future pregnancies and in the first 6 months following birth. Information on where CONI is available, eligibility criteria and what the CONI scheme entails can be found via the Lullaby Trust: www.lullabytrust.org.uk

Staff care

There must be appropriate provision for staff support and training to ensure professionals can provide high quality care to bereaved families. It is also important that staff recognise they have a professional responsibility to access support and training when they feel they need it.

All staff should be supported practically and emotionally so they feel comfortable, confident and competent in this area of care.

Training

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

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.

Good training and support for staff improves the quality of bereavement care offered to parents when a baby dies.

Support

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 reasons will be individual and may include staff having to manage their own emotions following their own experience(s) of loss; a feeling of professional failure following a baby death and anxiety caused by wanting to 'get it right' knowing this is a difficult time for parents.

To provide parents with high quality, individualised care, staff must be well-supported and have time for breaks; an open and supportive work environment; opportunities to share stories and experiences and scheduled multidisciplinary debriefs and reviews. 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. This support for staff should be built into the systems in which they work.

The type and amount of support that staff need can vary depending on the individual and the situation. It is important to have different support options available for members of staff to use as they need.

Stigma and concerns about not appearing to be coping with their job may cause some staff to avoid coordinated professional counselling and this should be offered as a confidential service through the central hospital human resources team.

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.

Managers and senior staff should also make sure they themselves get support so they can support their staff.

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 to parents from different backgrounds 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.

Before leaving the hospital immediately following the baby's death, families should be offered information about the emotional support available to them

Staff should flag with families:

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

Staff should communicate with parents about the difficult emotions they might experience, and reassure them that it is okay and normal to not feel okay. Parents should be reassured that they can be in touch with their healthcare team if they need further support and should be given a contact name and number for this purpose.

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 parents is feeling at any point, or about what they may need in terms of ongoing support.

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 conditions where necessary.

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



For more information visit:
nbcpathway.org.uk

Lead organisation and ©:

Sands (Stillbirth & Neonatal Death Charity)
Victoria Charity Centre
11 Belgrave Road
London, SW1V 1RB

Sands (Stillbirth and Neonatal Death Society)
Company Limited by Guarantee Number: 2212082
Charity Registration Number: 299679
Scottish Charity Registration Number: SC042789