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



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

Bereavement Care Pathway

Led by Sands



In partnership with:































About the NBCP

The National Bereavement Care Pathway has been developed to improve bereavement care and reduce variability in provision for families after miscarriage, ectopic pregnancy, molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months.

This document has been prepared to assist all healthcare professionals and staff who are involved in the care of parents of a baby who has died neonatally. Other documents are available that describe the pathway for the other childbearing losses (see www.nbcpathway.org.uk).

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.

More detail is given at www.nbcpathway.org.uk

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

(Quote by bereaved parent, 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 Inspection 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.

The NBCP during the COVID-19 pandemic

The NBCP Core Group are aware of the restrictions the pandemic has had on good bereavement care practice. As the terminology page (overleaf) acknowledges, these are guidance notes rather than clinical necessities. As such, some best practice will not always be possible, for example providing face-to-face meetings, enabling partners to appointments, etc.

However, wherever practicably possible, healthcare professionals should aim to put the needs of the mother and partner as the highest level of priority.

Terminology

The NBCP (National Bereavement Care Pathway) Editorial Panel acknowledges the current debates, discussions and difficulties around terminology and language facing healthcare professionals and have attempted to unify language across the pathways to ensure a consistent approach.

The Panel also recognises that as healthcare professionals it may be easier to verbalise the correct terminology with your knowledge of the person in front of you, rather than the panel trying to cover all bases in written documents.

As such, we offer the following as overarching guidance:

- The terms 'healthcare professionals' and 'staff' are used throughout to denote all of those working with bereaved parents
- ➤ Per recent NICE guidance on induction of labour (https://www.nice.org.uk/guidance/ng207), we use the terms 'woman' and 'women', based on the evidence used in its development. The recommendations will also apply to people who do not identify as women but are pregnant or have given birth.
- Similarly, the term 'baby' (or 'babies' in the case of multiple pregnancies) is used throughout, from the early stages of pregnancy through to the neonatal period. Many people will conceptualise their baby and develop strong attachments to them from the moment they discover that they are, or were, pregnant. However, others will be more comfortable with medical terminology such as 'fetus' and may not find the term 'baby' to be appropriate in their situation. Again, while we have used the term baby, it is important to recognise that the wishes and viewpoints of those experiencing the loss should always be the most important factor when communicating with them.
- The term 'parents' is used to refer to expectant and bereaved mothers, fathers, and partners. Many people will consider themselves parents from the time they discover they are, or were, pregnant while others will not. Therefore, it should be acknowledged that not all who have experienced a childbearing loss would consider themselves to be, or have been, a parent. It is also important for those who do identify themselves as parents to have this recognised.
- 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, and as such, the guidance should be adjusted accordingly for example discussions with the birthing partner or accompanying friend/family member.
- 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 and families experiencing a childbearing loss.

As is set out in the pathway guidelines, healthcare professionals should use the terminology preferred by those experiencing the loss when communicating with them.

Finally, because this is a pathway focused on improving outcomes for 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'.

Recommendations: when a baby or infant dies suddenly and unexpectedly

A. First steps

General guidance

- Keep an open mind about how families react. There is no right or wrong reaction to sudden death and grief, and anger is a common expression of emotion.
- Be aware that families often blame themselves, no matter what the circumstances - they will often already be aware of their specific risk factors.
- Offer care and support to the whole family, including step and extended families.
- Keep the family informed and give realistic time scales and honest information, however difficult this is.
- There are known risk factors for sudden infant death syndrome (SIDS), but these are not causes of death - take care to avoid suggesting guilt when discussing these.
- Use phrases such as 'would you like to tell me what happened' rather than 'why didn't you?' Say you are sorry and acknowledge the distress.
- 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 'the body', 'suspicious death' and 'crime scene'.
- Refer families to specialist counselling and bereavement support 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.

General guidance continued

- Be aware that the death may trigger difficult issues for families, including housing, employment, financial problems and mental health issues; offer practical support.
- Know the family's circumstances and the stage of the investigation before you make any contact.
- Do not assume multi-agency communication is happening (although it is an essential part of the process) or that everyone, including you, has the most up-to-date information.
- Listen effectively it is a very important skill that families will often remember.

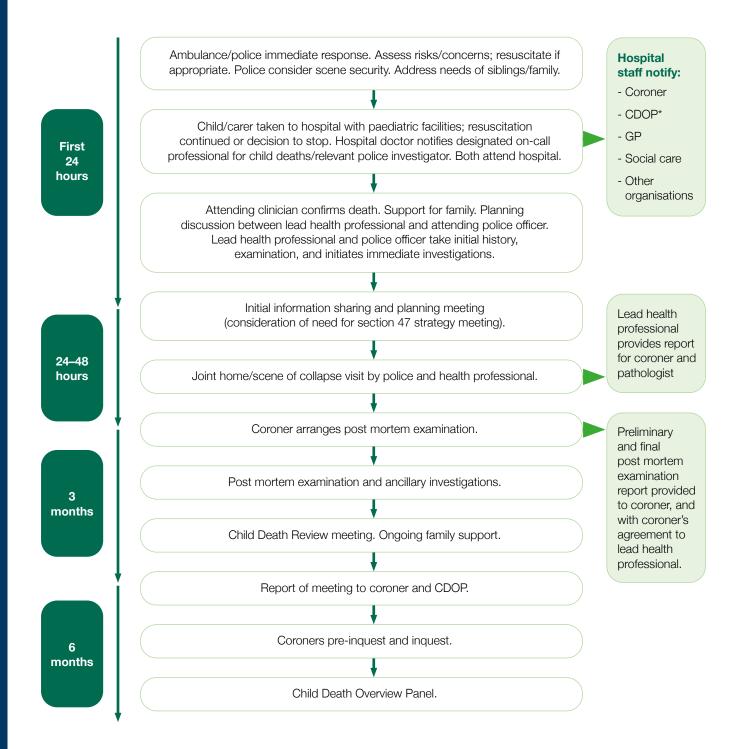
When talking with families

- Introduce yourself, your name, your role and what you are going to do.
- Find out the baby's and parents' names and use them.
- Do not be overly apologetic.
- Try to avoid using euphemisms.
- 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.



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



In this flow-chart, 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.

^{*}Child Death Overview Panel

A. First steps continued

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.
- Be aware that this is an extremely distressing experience for families, who will often not be expecting the police.
- Where a resuscitation is ongoing, it is good practice to allow the parents to watch if they want to.
- The family should be supported to attend the hospital, either travelling with their baby in the ambulance, or separately. Consider the needs of other children or family members.
- Attending police may be able to assist with these arrangements.
- At the hospital, allocate a lead healthcare professional to the family and keep them fully informed in an appropriate and private space.
- Give families as much opportunity to be with their baby at this stage as possible, taking into account that the coroner now has control of the investigation.
- Early interviews must carefully balance the needs of the investigation with the shock, trauma and grief of families. Work jointly, wherever possible, to save the family from needing to repeat the same information to different professionals.

- Offer families a key contact and tell them what will happen next, before they leave the hospital.
- Consider asking, if the mother was breastfeeding, if she would like further information or support regarding this.
- Support the family with practical arrangements, such as how they will get home or to somewhere else they would prefer to stay.
- It can be good to sensitively ask if there were any imminent appointments for the baby in the next week to address e.g. GP, health visitor or vaccination these services should be notified directly if possible to prevent any contact in relation to the appointment.
- Give the family contact details of support organisations and bereavement services before they leave hospital (see Useful contacts).
- Before the family leaves the hospital, tell them that their baby will be transferred to the mortuary before being transferred to the centre where the post mortem examination will take place, and provide the contact details of a key health professional (a template contact card is available from www.nbcpathway.org. uk).



B. After the death

Mementoes

- Once the baby has been examined and all necessary samples taken, with the coroner's permission, the family should be offered:
 - Time to be with their baby and hold them if possible
 - Hand and footprints

- A lock of hair
- The opportunity to take photographs
- Offer choices around mementoes without assuming what the family would like or may be appropriate based on personal characteristics, such as ethnic or religious background.

Coroners and post mortem examination

- Sensitively explain to the family that they may not be able to register the death or arrange the funeral for some time as the death will be referred to the coroner.
- Explain that the coroner will order a post mortem investigation, and that the family will not be able to choose whether this takes place. This may be very difficult for some families, and this should be acknowledged.
- The baby's body will often have to travel, sometimes long distances, to a specialist centre for the post mortem examination.
- This can be very upsetting for families.
- Keep them 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 whether they want to have a funeral before all the samples have been returned. Take care to ensure the family receives timely, sensitive responses to any questions and are supported with any decisions they need to make.

- The coroner should ensure that families are offered the choice about what happens to tissues taken for the purpose of the post mortem examination, once this has taken place.
- Ensure that you are aware of relevant statutory death review processes (e.g. Child Death Overview Panel [CDOP] and Learning Disabilities Mortality Review LeDeR; www.bristol.ac.uk/sps/leder) and that these link with your Trust's internal processes (e.g. morbidity and mortality [M&M] meeting, serious incident [SI] review and serious case review [SCR]) and inform the family as appropriate.

B. After the death continued

Registration of death and funeral

- Explain to the family that:
 - The baby's death will not be able to be registered formally until the coronial process has been completed, which can take up to 6 months or sometimes even longer
 - An interim death certificate will be given to allow a funeral to take place once the initial post mortem examination has been completed
 - The funeral can only take place once a death certificate has been issued, or an interim certificate of the cause of death is issued by the coroner
- Encourage families to consider the different options for a funeral while they are waiting for the death or interim certificate - funeral directors should be used to this process and support families until a date is confirmed.

Follow up meetings/appointments

- When arranging updates for the family. either about their baby's death or the support and care they have received:
 - 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 to meet families face to face; 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
 - Offer information about local and national bereavement support services

Care and support for families in the community

- Provide details of support services, locally and nationally, at every available contact; there can often be long periods where there is no information, and families can find these quiet times the most difficult to get through.
- Encourage families to seek support from their GP or health visitor if they are particularly struggling with issues such as sleep, or re-living the time when their baby died.
- Remember the GP and health visitor are there for lots of issues. This may include additional needs for the whole family. There is a notifications process that will take place to ensure the GP and other health professionals are aware of the death, after which standard notifications will be stopped (for example, vaccinations).
- Ask the father or 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.

Emotional support

- Staff should flag with families:
 - Chaplaincies that should have contacts with religious and spiritual advisers of all local faiths and spiritual organisations.
 - A contact to provide ongoing emotional support via the care provider (e.g., a bereavement lead or community midwife (up to 28 days after birth) or health visitor thereafter).
 - Counselling services available via the care provider.
 - Access to counselling and further support via secondary care (e.g., GPs and health visitors).
- National and local support organisations (see Useful contacts).

C. Further investigations into the death

Inquest

- If the coroner decides to hold an inquest at the end of their investigation, explain this fully to the family, with good notice and support given before the day of the inquest.
- Warn the family that inquests are open to the public and journalists can therefore attend.
- Let the family know that they are under no obligation to attend the inquest.
 The coroner's Court Support Service is a registered charity who can offer volunteers to support families on the day.

D. Financial considerations

- Parents are entitled to statutory parental bereavement pay if their child dies under the age of 18 or is stillborn after 24 weeks' pregnancy - https://www.gov.uk/ parental-bereavement-pay-leave
- The Children's Funeral Fund for England which is not means tested can help pay for funerals. If the family has other funeral expenses, they may be able to apply for additional funds to cover them -

www.gov.uk/child-funeral-costs

E. Subsequent pregnancy

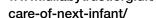
The Child Death Review

Inform the family that the specialist Child Death Review process is taking place. Although the family would not usually be involved in the process, they should be kept informed and invited to offer feedback if they wish. An NHS England booklet describing the Child Death Review process for families, entitled: 'When a Child Dies: A Guide for Parents and Carers', is available at www.england.nhs.uk/publication/learningfrom-deaths-information-forfamilies/

Care of Next Infant (CONI)

The CONI scheme 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/professionals/



F. Staff care

Staff care

- Recognise your own support needs.
- Identify your own training needs.
- Communicate these needs with management and colleagues; other staff may have similar needs.
- Ensure you are aware of the support structures and systems in place within your Trust.
- Be aware of the stresses and challenges faced by your colleagues. Where appropriate flag support systems with them.

- Look after yourself by:
 - Getting enough sleep
 - Eating healthily
 - Exercising
 - Employing relaxation techniques
 - Booking annual leave
 - Watching your favourite film or television programme
 - Spending time in green space outdoors
 - Spending time with a friend or on a hobby

Not all of these contacts will be appropriate for all pathways

National contacts:

Action on Pre-Eclampsia (APEC)

Helps and supports women and their families who are affected by or worried about pre-eclampsia and aims to raise public and professional awareness of pre-eclampsia.

www.action-on-pre-eclampsia.org.uk

Antenatal Results and Choices (ARC)

Offers non-directive individualised information and support for parents making decisions around antenatal testing, including when a baby has a significant anomaly.

www.arc-uk.org

Baby Mailing Preference Service (MPS) online

Free site where parents can register online to stop or help reduce baby-related mailings.

www.mpsonline.org.uk/bmpsr

Bereavement Advice Centre

Offers information and advice for people with practical concerns after the death of someone close to them.

www.bereavementadvice.org

Bliss

Offers support for families of premature or sick babies, including bereaved families.

www.bliss.org.uk

British Pregnancy Advisory Service (BPAS)

Offers advice and treatment for termination of pregnancy in the UK.

www.bpas.org

Child Benefit Office

Parents can contact the Child Benefit Office at HM Revenues and Customs for information about eligibility, claiming and stopping Child Benefit.

www.gov.uk/government/organisations/ hmrevenue-customs/contact/child-benefit

Child Bereavement UK (CBUK)

Provides support for families when a baby or child has died or is dying and offers support for children faced with bereavement. Offers training for professionals.

www.childbereavementuk.org

The Compassionate Friends

An organisation of bereaved parents, siblings and grandparents that offer support to others after the death of a child or children.

www.tcf.org.uk

Contact

Provides support, information and advice for families with disabled children.

www.contact.org.uk

Cruse Bereavement Care

Offers support to bereaved people and training for professionals.

www.cruse.org.uk

Each Baby Counts

The Royal College of Obstetricians and Gynaecologists' programme to reduce the number of babies who die or are severely disabled as a result of incidents occurring during term labour in the UK.

www.rcog.org.uk/eachbabycounts

Ectopic Pregnancy Trust

Provides support and information for people who have had or been affected by an ectopic pregnancy, including health professionals.

www.ectopic.org.uk

Federation of British Cremation Authorities (FBCA)

Professional organisation of burial and cremation authorities in the UK.

www.fbca.org.uk

Funeral Payments - NI Direct

Financial help that is available for individuals on low-incomes in Northern Ireland who need help to pay for a funeral that they are arranging.

www.nidirect.gov.uk/articles/funeral-expensespayments

Funeral Payments - UK Government

Financial help that is available for individuals on low-incomes in England, Wales and Scotland who need help to pay for a funeral that they are arranging.

www.gov.uk/funeral-payments

Gifts of Remembrance

Provides photography training for hospital staff and volunteers who support parents after a stillbirth or neonatal death.

www.giftsofremembrance.co.uk

Human Fertilisation and Embryology Authority

Independent regulator overseeing the use of gametes and embryos in fertility treatment and research that provides information for parents about the fertility process and fertility clinic.

www.hfea.gov.uk

Human Tissue Authority (HTA)

Regulator for human tissue and organs and organisations that remove, store and use tissue.

www.hta.gov.uk

Infertility Network UK

Provides support for people dealing with infertility and/or who are facing involuntary childlessness.

www.infertilitynetworkuk.com

Institute of Cemetery and Crematorium Management (ICCM)

Professional organisation of burial and cremation authorities in the UK that promotes the improvement of cemeteries, crematoria and public services.

www.iccm-uk.com

International Stillbirth Alliance (ISA)

International alliance of organisations and individuals working to prevent stillbirth and improve bereavement care worldwide.

www.stillbirthalliance.org

Jobcentre Plus - Bereavement Services Helpline

Provides information about benefits claims.

Telephone: 0345 608 8601

www.gov.uk/contact-jobcentre-plus

Lullaby Trust

Offers support and advice for parents whose baby dies suddenly and advice on safer sleep.

www.lullabytrust.org.uk

Miscarriage Association

Offers support and information for individuals affected by pregnancy loss and for health care professionals.

www.miscarriageassociation.org.uk

MSI Reproductive choices

Independent provider of sexual and reproductive health services in the UK.

www.msichoices.org.uk

Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK)

Provides surveillance of maternal, perinatal and infant deaths in the UK.

www.npeu.ox.ac.uk/mbrrace-uk

Also provides an online reporting system for healthcare units to report maternal, perinatal and infant deaths.

www.mbrrace.ox.ac.uk

Money Helper (formerly Money Advice Service)

Provides free and impartial money advice, including information for bereaved parents about benefits and entitlements after the death of their baby.

www.moneyhelper.org.uk

Multiple Births Foundation (MBF)

Provides support and information for multiple birth families (including bereavement support) and information for professionals.

moneyhelper.org.uk

National Association of Funeral Directors

Provides support and guidance for funeral firms and bereaved families using their services.

www.nafd.org.uk

National Association of Memorial Masons (NAMM)

Sets standards for memorial stones and provides information for individuals who are choosing a memorial www.namm.org.uk

National Perinatal Epidemiology Unit (NPEU)

Multidisciplinary research unit at the University of Oxford who provide evidence to improve care for women and their families in the perinatal period and promote the effective use of resources by perinatal health services.

www.npeu.ox.ac.uk

The Natural Death Centre

Offers support, advice and guidance for families and other individuals who are arranging a funeral, including information about environmentally-friendly funerals and woodland burial sites.

www.naturaldeath.org.uk

Now I lay me down to sleep

An American website that puts bereaved parents in touch with professional photographers who will take photographs of their babies at no cost. Site shows examples of photographs of babies of all gestations. Photographers in the UK can also be found through the Find a Photographer page.

www.nowilaymedowntosleep.org

Our Missing Peace

Resources for bereaved families and a helpful repository of information under 'useful links' across the four Home Nations.

www.ourmissingpeace.org

Parental Bereavement Leave

Government scheme enabling parents who lose a baby or child to be entitled to parental leave.

www.gov.uk/government/news/uk-first-parentswholose-a-child-entitled-to-bereavement-leave

Perinatal Institute for Maternal and Child Health

National non-profit organisation that aims to enhance the safety and quality of maternity care and provides resources for healthcare professionals.

www.perinatal.org.uk

Rainbow Trust Children's Charity

Offers support to families in England with life-limiting and life-threatening conditions.

www.rainbowtrust.org.uk

Registry Offices for England and Wales, Scotland, and Northern Ireland

England and Wales: General Register Office www.gov.uk/general-register-office

Scotland: National Records for Scotland www.nrscotland.gov.uk/registration

Northern Ireland: General Register Office Northern Ireland (GRONI)

www.nidirect.gov.uk/gro

Relate

Offers relationship support to help people strengthen their relationships.

www.relate.org.uk

Remember My Baby Remembrance Photography

UK-based charity who have professional photographers who voluntarily provide their photography services to parents whose baby dies before, during or shortly after birth.

www.remembermybaby.org.uk

Sands (Stillbirth & Neonatal Death Charity)

Provides support and information for anyone affected by the death of a baby, before or after birth. National helpline, local parent-led support, literature and online support. Works to improve care when a baby dies and promotes research to reduce the loss of babies' lives

www.sands.org.uk

Samaritans

Offers confidential support that is available 24 hours a day to people who need to talk.

Telephone: 116 123 (UK) or 116 123 (ROI) for free. www.samaritans.org

Twins Trust Bereavement Support Group

Offers support for families who have lost one or more children from a multiple birth during pregnancy, birth or at any time afterwards.

www.twinstrust.org/bereavement

Together for Short Lives

Offers support for families with children who have lifethreatening or life-limiting conditions and professionals and services (including children's hospices).

www.togetherforshortlives.org.uk

United Kingdom Association for Milk Banking (UKAMB)

Supports human milk banking and aims to provide safe and screened donor breastmilk for premature and sick babies.

www.ukamb.org

Winston's Wish

Offers support to bereaved children, their families and professionals.

www.winstonswish.org.uk

Working Families

Helps working parents, carers and their employers balance home and work responsibilities. They also provide information about parents' rights at work and to benefits after they experience miscarriage, stillbirth and neonatal death.

www.workingfamilies.org.uk/articles/ miscarriagestillbirth- and-neonatal-death-yourrights-at-work

Other

Supporting documents

The following supporting documents are available from nbcpathway.org.uk

- Best practice in bereavement
- Contact card
- Creating memories offering choices
- Form for parents who take their baby's body home
- Funeral consent form for parents
- Previous neonatal death form for notes
- Terminology



For more information visit: **nbcpathway.org.uk**

www.sands.org.uk



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