
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

Bereavement Care Pathway

Our National Bereavement Care Pathway core partners



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 families of a baby who has died suddenly and unexpectedly in infancy (up to 12 months). Other documents are available that describe the pathway for the other childbearing losses (see www.nbcpathway.org.uk).

'Healthcare professionals' and 'staff' mean any practitioner who has contact with a bereaved parent. 'Parent' refers to an expectant or bereaved mother, father or partner, and 'baby' is used throughout. Not everyone will want these words to be used, though, and healthcare professionals should use the words preferred by the individual. We refer to 'Trusts', but we hope that the pathway will be used by independent healthcare establishments and other bodies that organise and provide care for women and families experiencing a childbearing loss.

More detail on the terminology is available from 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)



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.

1 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 ‘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.

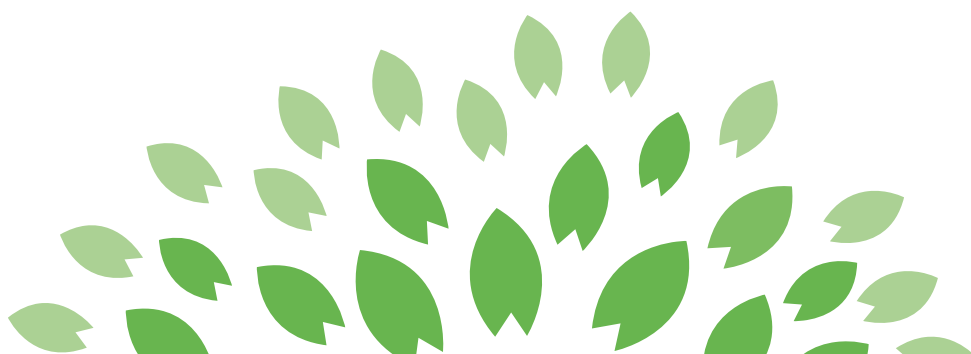
When talking with families

- 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.

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.
 - Support the family with practical arrangements, such as how they will get home or to somewhere else they would prefer to stay.
 - 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

Mementos

- 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.

Coroners and post mortem examination continued

- 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.

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 if they are particularly struggling with issues such as sleep, or re-living the time when their baby died.
- Remember the GP is 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).

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.

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 (for example, a bereavement lead or community midwife).
 - Counselling services available via the care provider.
 - Access to counselling and further support via secondary care (for example, 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.

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 able to input into the process if they want. 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/learning-from-deaths-information-for-families/

D. Subsequent pregnancy


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



E. Staff care

Staff care

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

Useful contacts

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

Bereavement Care Network

Online network for bereavement care professionals who offer or are interested in care for parents when a baby dies.

www.bereavement-network.rcm.org.uk

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/hm-revenue-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 a Family

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

www.cafamily.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

Fertility Network UK

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

www.fertilitynetworkuk.org

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/funeral-payments

Useful contacts

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 (HFEA)

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

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

Marie Stopes International

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

www.mariestopes.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/mbrance-uk

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

www.mbrance.ox.ac.uk

Miscarriage Association

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

www.miscarriageassociation.org.uk

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.moneyadvice.service.org.uk

Multiple Births Foundation (MBF)

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

www.multiplebirths.org.uk

National Association of Funeral Directors

Provide 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

Useful contacts

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

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.gro.gov.uk/gro/content

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, the stillbirth and 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.uk-sands.org

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

Tamba 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.tamba.org.uk/bereavement

(Part of the Twins and Multiple Births Association (Tamba))

www.tamba.org.uk

Together for Short Lives

Offers support for families with children who have life-threatening 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

Offer 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.

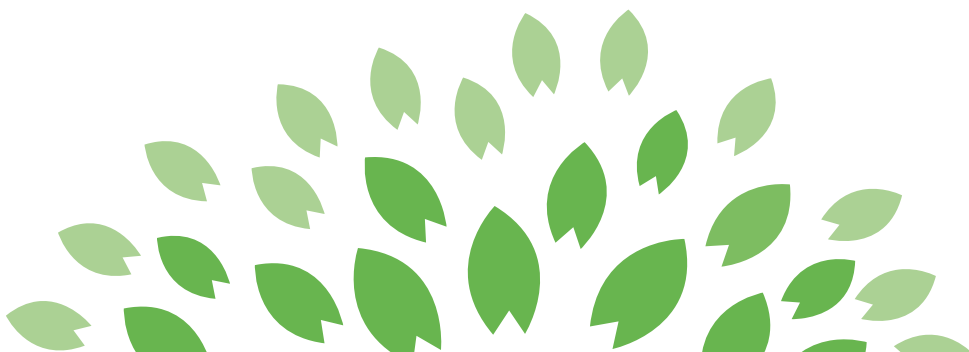
www.workingfamilies.org.uk/articles/miscarriage-stillbirth-and-neonatal-death-your-rights-at-work

Other

Supporting documents

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

- Best practice in bereavement
- Terminology





For more information visit:
nbcpathway.org.uk

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Sands (Stillbirth & Neonatal Death Charity)
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