
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

Neonatal Death

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 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).

'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 also be used by independent healthcare establishments and other bodies that organise and provide care for women and families experiencing a childbearing loss.

The Core Group gratefully acknowledges the support and contribution of the Department of Health and Social Care (DHSC) and Teddy's Wish to the development of the NBCP.

More detail on the terminology is given at 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 dies neonatally

A. Delivering difficult news

Delivering difficult news

- Prepare parents for difficult news and inform parents something may be wrong as soon as it is suspected.
- Prepare yourself for giving difficult news by gathering information and consulting with colleagues, if possible.
- Find an appropriate place or, if in the delivery room/neonatal unit, offer a separate private space once the news has been given.
- Ask the parent(s) whether they would like a support person present.
- Use clear, straightforward language, no euphemisms or jargon.
- Give parents time to absorb news and answer any questions you are able to, within your scope of practice.
- Give parents information about what happens next, provide written information and named contact with contact details (see Contact card, available at www.nbcpathway.org.uk).
- Consider onward transport needs.
- If there is one or more surviving sibling from a multiple birth, do not focus solely on them. Acknowledge the baby who has died.

Place of care

- If being cared for on an open-plan unit, be aware of the possible interactions between different families in the unit.
- If a single family room is being used, ensure that parents do not feel alone or abandoned, while ensuring that they are given space if this is what the family request.
- Be aware that some parents may need to make special arrangements to enable them to stay at the hospital for any length of time – provide information and support if necessary.
- Let parents know about the financial support available to them through benefits, the health service or local charities.

If the mother is ill

- If the mother is in the same hospital but is unable to walk to the neonatal unit, and her physical condition allows, bring her to the unit in a wheelchair or hospital bed.
- If the baby has to be transferred to a regional unit and the mother cannot be moved with them, ask staff at the referring hospital to phone the regional unit regularly to check the baby's progress and pass on the information.
- Provide digital pictures or videos of the baby to help ensure the family has updates on the baby's progress (though always give difficult news face to face).

A. Delivering difficult news continued

Talking to parents about their baby's condition

- Give parents clear, understandable, consistent and honest information about all tests, developments and interventions.
- At the end of formal discussions, give parents a time when they can meet with staff again.
- Give parents designated members of staff (including a named nurse) who take the main responsibility for checking that they feel informed and listened to, and who are present when sensitive and difficult issues and decisions are discussed with them.

Withholding or withdrawing life sustaining treatment

- Fully explain the baby's condition and options for care, including parents' options for symptom control and taking the baby home or to a hospice.
- Offer information about local resources available to support parents.
- Decision making is a process – another appointment should be arranged for parents to discuss their baby's care further with a senior member of their care team.

Making decisions about critical care

- Offer parents the opportunity to participate in all important decisions about the care of their baby, including critical care decisions.
- Communicate openly and honestly with parents about their baby's condition from the time of diagnosis.
- Parallel or anticipatory planning may be helpful – care plans can be discussed by staff and parents for active treatment while also planning for palliative or end-of-life care should it become necessary.
- During discussions about critical care, treat parents as full partners and always with respect and dignity.
- See also NHS, BAPM and Bliss guidance: www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e08/
www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2017/04/Neonatal-Critical-Care-Quality-Indicators-140617-Final-2.pdf
www.bapm.org/news/new-%E2%80%9Cneonatal-service-quality-indicators%E2%80%9D-developed-bapm-and-endorsed-bliss-out-now
www.bliss.org.uk/health-professionals/bliss-baby-charter/

A. Delivering difficult news continued

Palliative care

- Before life-sustaining treatment is withdrawn, have a private, face-to-face discussion with parents to discuss the options for their baby's care and give adequate time for parents to ask questions and talk about their views and feelings.
- Explain in detail the process of moving to palliative care and reassure parents that this does not mean that care is being withdrawn from their baby.
- Before their baby starts to receive palliative care, discuss with parents:
 - The time and place for the withdrawal of life-sustaining treatment; offer information about the options for taking the baby home or to a hospice to receive palliative care (even if the baby is not expected to live for long)
 - Transfer to a neonatal unit or hospital closer to the parents if the baby has been transferred to a unit that provides specialist neonatal care
 - The possibility of the baby receiving palliative care on the postnatal ward if the mother is ill and still in hospital
 - Whether or not they want to be present when life-sustaining treatment is withdrawn or their baby dies, and that they can change their mind
 - Whether or not they want to have a dedicated member of staff available to be with them or nearby when life-sustaining treatment is removed
 - The possibility of them inviting family members or close friends for support
 - The baby's possible physical reactions to the change in care; explain that the baby may gasp or change colour when the ventilator is removed
 - Any spiritual or religious needs or requirements

Care for parents around the time of their baby's death

- If parents want to hold their baby before the death and while they are dying, gently suggest how they could comfort their baby by holding them.
- Offer to take photographs of family members spending time with or holding the baby.
- Let parents be alone with their baby in quiet and privacy for as long as they want after their baby's death.

B. After the death

Memory making

- Let parents know that memory making can begin before the baby dies, and sometimes before the baby is born.
- Discuss with parents:
 - Seeing and holding the baby
 - Washing and dressing the baby
 - Providing care for their baby (for example, changing nappies)
 - Kangaroo care
 - Photographs
 - Hand and foot prints
 - Introducing baby to friends and family
 - Taking the baby out of the hospital environment (a template form for taking a baby out of hospital is available from www.nbcpathway.org.uk).
 - Creating a memory book or box
 - Other memorials
- Consider the condition of the baby when offering memory making options.
- Give parents time to reflect and decide what they want.
- Complete the informed choice form to ensure parents are provided with options, but do not feel pressured (a template form, 'Creating memories – offering choices', is available from www.nbcpathway.org.uk).
- Where there is a death from a multiple pregnancy, discuss the options around memory making with surviving siblings.
- Enable parents to have additional people there to support them if requested.



B. After the death continued

Post mortem examination

- Ensure staff discussing post mortem examination consent with parents are trained to do so.
- Allow a minimum of one hour for this discussion.
- Ensure discussion takes place in a quiet, private place.
- Inform the parent if the post mortem examination will take place at a different hospital, and explain where and why.
- All transport arrangements and handling of the baby must be respectful; label and track the baby's body.
- During the consent process, tell parents the likely timescales for the return of the baby's body and the results.
- Identify a named contact within pathology and within the neonatal unit who will be responsible for following up on results.
- If parents decline a full post mortem examination, discuss other tests, such as an examination of the placenta and blood tests, as appropriate.
- 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 parents as appropriate.

Organ donation

- Neonatal organ donation may be an option in certain circumstances; while it is still quite rare, there have been positive outcomes for transplants from neonatal donors, and some parents may take comfort from knowing that their baby's organs will help another child.
- Ensure that you have links with the Clinical Lead for Organ Donation (CLOD) and/or Specialist Nurse for Organ Donation (SNOD) in your Trust, to understand more about how this may be communicated with, and consent sought from, parents of eligible babies.

B. After the death continued

Registration and certification

- Provide parents with the medical certificate of the death of their baby.
- If the death has been referred to the coroner, inform parents that the death cannot be medically certified until this referral has happened. Acknowledge the difficulty of any delays and sensitively discuss the process and realistic timeframes.
- Provide information about, and all necessary documentation for, the registration process.
- Provide parents with clear, written information.
- Ensure parents have any other information the registrar/funeral director/cemetery/crematorium will need.

Funerals

- Provide parents with information around the legal requirements and options.
- Discuss what is available through the Trust and other local options.
- Provide parents with written information, including:
 - The choices they have if they want the hospital to make arrangements
 - The choices they have and what they need to do if they want to manage the arrangements
 - The costs involved (if any)
- Bear in mind, and facilitate where possible, different personal, religious and cultural needs. Assumptions must not be made.
- Discuss options for urgent burial and cremation where appropriate.
- Offer to refer parents to the chaplaincy team.
- Record all decisions made by the woman in her medical records, including where information is declined or no decision is made.
- Details are emerging of a new Children's Funeral Fund, please see www.bit.ly/2zNolIV

C. Ongoing care for families

Ongoing emotional support

- With consent, refer parents for neonatal bereavement support.
- With consent from the parents, ensure all hospital and community healthcare staff have been informed of the baby's death.
- With consent from the mother, ensure the mother's notes have a baby loss summary sheet attached (a template form for previous neonatal death is available from www.nbcpathway.org.uk).
- Ask the father or same sex partner if he/she would like his/her GP to be informed about the loss so it can be added to his/her notes, and record his/her consent if he/she did.
- Discuss the difficult emotions parents may experience with them to let them know their feelings are normal.
- Provide parents with information about the emotional support available to them via your Trust, primary care colleagues and via local and national support organisations (see Useful contacts).
- Offer parents contact with the chaplaincy team.
- Allow sufficient time for all follow-up appointments (refer to local policies, where they exist).
- Make sure you know who can offer a mental health assessment and treatment to bereaved parents and the wider family.
- Ensure follow-up care by the GP or health visitor is arranged for the partner as well as the mother.
- See also NICE guidance on antenatal/postnatal mental health (www.nice.org.uk/guidance/qs115) and Public Health information on Maternal Mental Health (www.bit.ly/2Noa0Qw).

Review

- Inform parents about the process of perinatal death review and invite them to become involved in the review process.
- Offer parents flexibility on the timing of when and how they contribute to the review process.
- Ensure the review looks at parents' clinical and emotional care, and covers the whole pathway of care, both antenatal and postnatal, with input from community healthcare professionals.
- Ask parents if they want to be informed of the outcomes of the review of their baby's death, and if they have any questions for the review to address.

Feedback

- Discuss with parents the opportunity to give feedback about the bereavement care they receive.
- If parents consent to be contacted for feedback, let them know how and when they will be contacted.
- Be clear with parents that this feedback mechanism is not a review of the baby's death, nor a complaints process.
- Be clear with parents about whether they will receive any follow-up contact about this after submitting their feedback.

D. Subsequent pregnancy

Preconception

- Familiarise yourself with the woman's notes.
- With consent, ensure the mother's notes are marked with a previous neonatal death form (a template is available from www.nbcpathway.org.uk).
- Support parents to make informed choices around if/when to try for another baby.
- Discuss what, if anything, parents can do to reduce the risk of another loss.
- Listen to and acknowledge parents' fears and concerns.
- Do not offer false reassurance and be aware that statistical probabilities may not be comforting.
- Be clear about the available support from staff and other organisations.
- Ensure that fathers and partners are offered support.

Antenatal care

- Offer regular contact with staff and emotional support and screening for mental health difficulties.
- Reassure parents that there will be continuity of care. This is of the utmost importance to those who have experienced a loss, to avoid having to repeat their story.
- Refer parents to another unit or another consultant if requested.
- Outline any additional antenatal support offered. Allocate extra time for these appointments.
- Remind parents they can bring a support person to attend these appointments.
- Discuss and acknowledge with parents (where appropriate) certain stages, events or dates during the pregnancy that may be particularly difficult for them (for example, discuss the birth plan and offer ward tour); consider a clinical alert to inform staff of the woman's previous history before admission.

D. Subsequent pregnancy

Labour and birth

- Be prepared for parents' emotional reactions during labour, at the birth and in the time that follows.
- Be available to offer support if needed.
- Offer support to any partners or birth supporters who are with the woman.
- Offer sensitive support to parents after their baby is born.
- Let parents know mixed feelings are normal and be ready to talk about the baby who died.

Care in the community

- Offer parents a telephone call and/or home visit when they are back in the community.
- Allow enough time to offer emotional support as well as check the mother's physical health.
- Discuss with parents how to talk about the baby who died with existing and subsequent siblings.
- Ensure ongoing care is available where it is needed. Offer referrals where necessary.
- Give parents the contact details of a healthcare professional they can contact for information and support (a contact card template is available from www.nbcpathway.org.uk).
- Offer parents contact with the chaplaincy team.
- Give parents the contact details of local and national support organisations (see Useful contacts).

E. Staff care

Staff care

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- 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



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/bmps

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/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

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

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

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.moneyadviceservice.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

Parental Bereavement Leave

Government scheme due to come into force on 6 April 2020 enabling parents who lose a baby or child to be entitled to parental leave.

www.gov.uk/government/news/uk-first-parents-who-lose-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.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.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.twustrust.org/bereavement

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

Useful contacts

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.

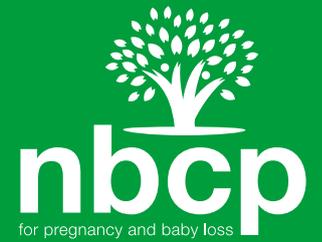
www.workingfamilies.org.uk/articles/miscarriage-stillbirth-and-neonatal-death-your-rights-at-work

Other

Supporting documents

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

- Best practice in bereavement
- 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

Lead organisation and © copyright:

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