
A pathway to improve bereavement care for parents in England after pregnancy loss or the death of a baby



Stillbirth

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 stillborn baby. 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 is stillborn

A. Diagnosis and 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.
- Find an appropriate place.
- Ask the parent(s) whether they would like a support person present.
- Use clear, straightforward language, with 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 contact details for a named health professional (a template contact card is available from www.nbcpathway.org.uk).
- Check the parents can get home safely – offer a taxi if necessary.
- If there is one or more surviving sibling from a multiple pregnancy, do not focus solely on them. Acknowledge the baby who has died. Recognise the challenge that the parents face in celebrating the arrival of one baby and the tragic death of the other baby or babies.

B. Delivery and birth

If the baby shows signs of life when born, see section on coroners in the full neonatal death pathway

Death before the onset of labour

- Discuss the birth plan, including place of birth, method of delivery, pain relief, timings and memory making.
- Provide written details of where care will be provided and prepare parents for what to expect during induction, labour and birth.
- Provide a named contact in case the parents change their mind or have any questions.
- Ensure all staff seeing parents during labour and birth are aware of the baby's death and communicate sensitively.
- Ensure staff are sensitive to sounds e.g. newborn healthy babies, that may be upsetting for bereaved parents to hear.
- Ensure continuity of carer where possible.
- Consider onward transport needs.

Death during labour

- Be open and honest about the situation.
- Introduce any new members of staff.
- If a change in staff or place of care is needed, talk to the parents and try to accommodate their wishes as far as possible.

B. Delivery and birth continued

In general

- Enable the woman to have a partner or support person with her at all times.
- With the woman's consent, keep the partner or support person informed.
- Provide the partner or support person with emotional support.
- Accurately complete all necessary paperwork, including the previous stillbirth form for the woman's notes (a template form is available from www.nbcpathway.org.uk). With consent from the woman, add this to her notes and explain why you have done this.
- 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.
- Consider bereavement care principles in the context of management of other types of delivery.

C. After the birth

Memory making

- Offer parents the opportunity to see and hold their baby. Offer to describe the baby's appearance.
- Let parents know they can change their mind, but respect a decision when one has been made.
- 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).
- Give parents time to reflect and decide what they want.
- Consider the condition of the baby when offering memory making options.
- Discuss with parents:
 - Washing and dressing the baby
 - Photographs
 - Hand and foot prints
 - Certificate of birth (a template certificate is available from www.nbcpathway.org.uk)
 - Taking the baby out of the hospital environment (a template form is available from www.nbcpathway.org.uk)
 - Memory box
 - Other memorials
- Where there is a death from a multiple pregnancy, discuss with parents the options around memory making with siblings.

C. After the birth 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.
- Tell 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, inform parents of the likely time scales for the return of the baby's body and the results.
- Identify a named contact within pathology and maternity who will be responsible for following up on results.
- Ensure any small objects or keepsakes such as a hat or cuddly toy that parents sent with the baby are returned following the investigation.
- 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.

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. Do not make assumptions.
- Discuss the options for urgent burial and cremation with parents 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.

Registration and certification

- Provide parents with the medical certificate certifying stillbirth.
- Provide information about the registration process, including where and how to register, and who can register. Inform the parents that a stillbirth must be registered within 42 days.
- Provide written information.
- Ensure parents have any other information the registrar will need.

D. Discharge and aftercare

Discharge and aftercare


- Discuss lactation, milk donation and milk suppression with the woman.
- Discuss with the woman ongoing physical symptoms she may experience, such as bleeding and pain, and when to contact a healthcare professional.
- Discuss place and time of leaving the hospital.
- With the woman's consent, primary care staff should be promptly informed that the woman has experienced the death of her baby.
- Inform primary care staff where the woman will be staying when she leaves the hospital.
- Before parents leave the hospital, give them the contact details for primary care staff, secondary care staff and also local and national support organisations (a template contact card is available from www.nbcpathway.org.uk).
- Offer all parents a follow up appointment.
- Ensure parents know what to expect from this appointment.
- Discuss location of the follow up appointment and who can attend.

Ongoing emotional support


- With consent from the parents, ensure all hospital and community healthcare staff have been informed of the baby's death.
- With her consent, ensure the woman's notes have a baby loss summary sheet attached (a template form is available from www.nbcpathway.org.uk).
- Discuss the difficult emotions parents may experience with them and let them know any feelings they have 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 (<https://bit.ly/3SRnMxN>).

D. After the birth continued

Review

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- Inform parents about the process of perinatal review and invite them to become involved in the review process.
 - 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.
 - 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.

Feedback

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- Discuss with parents the opportunity to give feedback about the bereavement care they receive.
 - If they give consent to be contacted for feedback, let them know how and when they will be contacted.
 - Document consent to participate in giving feedback.
 - Use the Maternity Bereavement Experience Measure (MBEM) to capture parent feedback (<https://www.sands.org.uk/maternity-bereavement-experience-measure-mbem>).
 - 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.

E. Subsequent pregnancy

Pre conception


- Familiarise yourself with the parents' notes.
- With consent, ensure the woman's notes are marked with a baby loss form (a template form for the notes 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 death.
- 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.
- 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.

E. Subsequent pregnancy continued

Delivery and birth

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- Be prepared for parents' emotional reactions during labour and at the birth.
 - 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

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- Offer parents a telephone call and/ or house visit when they are back in the community.
 - Allow enough time to offer emotional support as well as to 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 if needed. Offer referrals when necessary.
 - Give parents the contact details of a healthcare professional they can contact for information and support (a template contact card 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).

F. 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 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

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/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

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-expenses-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

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.msichoice.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

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

www.gov.uk/government/news/uk-first-parents-wholose-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 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

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-your-rights-at-work

Other

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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.
- Maternity Bereavement Experience Measure (MBEM).
- Previous stillbirth death form for notes.
- Terminology.



For more information visit:
nbcpathway.org.uk

www.sands.org.uk



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