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



Termination of Pregnancy due to Fetal Anomaly (TOPFA)

Bereavement Care Pathway

Led by



In partnership with:































nbcpathway.org.uk

NBCP for use in England from September 2025



About the NBCP

The National Bereavement Care Pathway, led by a multi-agency Core Group of baby loss charities and professional bodies, has been developed in order to improve bereavement care and reduce the variability in provision for families experiencing miscarriage, ectopic pregnancy and molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months.

This quick reference guidance has been prepared to assist all healthcare professionals and staff who are involved in the care of a woman or birthing person terminating a pregnancy because of a fetal anomaly. Other documents are available that describe the pathway for the other childbearing losses

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.

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

"All the staff were wonderful from the moment we were given the initial news at the 12-week scan – caring, supportive, kind, professional. It helped us enormously."

Bereaved parent



Bereavement care standards

These nine standards for bereavement care underpin the NBCP guidance. A Trust that meets these standards is considered to be providing good bereavement care.

Trusts should audit their service provision against these standards to identify gaps in the care they provide, and develop plans for improvement. A self-assessment tool is available for all Trusts in England to conduct this audit, see nbcpathway.org.uk.

Implementation of these standards via the pathway will help Trusts to meet the elements of the Care Quality Commission's assessment framework for maternity.

Parent-focused standards

- 1. All bereaved parents and families are provided with **personalised care**.
- 2. All bereaved parents and families have the opportunity to use an appropriate, available and accessible bereavement room.
- 3. All bereaved parents and families are offered opportunities to **make memories**.

Communication and learning standards

- 4. All bereaved parents and families are informed about and, where needed, referred for emotional support and for specialist mental health support.
- 5. A **system** is in place to clearly **signal** to all health care professionals and staff that a parent has experienced a bereavement.
- 6. Bereaved parents and families are confident that **learning** from their baby's death will take place and are fully informed throughout.

Staffing standards

- 7. Bereaved parents and families receive their care from an **appropriately staffed** team.
- 8. All staff involved in the care of bereaved parents and families receive the training and resources they need to provide high-quality bereavement care.
- 9. Healthcare staff are effectively **supported** to care for bereaved parents and families.

The NBCP bereavement care standards are cited extensively in national reviews, policy and clinical guidance. A full list of citations is available on the website.

A self-assessment form is available to help you assess the quality of care in your Trust against the nine bereavement care standards. Your bereavement lead should have one of these, otherwise contact us via bereavementcare@sands.org.uk.

Terminology

The NBCP editorial panel acknowledges that language matters, and that it is complex and continually changing.

We encourage all staff to follow the principle of asking the person they care for how they would like to be referred to and to mirror the language used by families when speaking to them about their experiences. The guidance below outlines important points on language use throughout the pathways:

- ➤ The terms 'healthcare professionals' and 'staff' are used throughout to denote all of those professionals working with bereaved parents.
- Throughout the pathways we use the additive language 'women and birthing people' to include individuals who do not identify as women.
- The term 'baby' (or 'babies' in the case of multiple pregnancies) is used throughout the pathways to refer to the first trimester of a pregnancy through to the neonatal period. In earlier losses many people will prefer to conceptualise their baby and will develop strong attachments to them from the moment they discover that they are, or were, pregnant. However, some people will be more comfortable with terminology such as 'fetus' or 'pregnancy' and will not find the term 'baby' to be appropriate in their situation. While we have used the term 'baby' throughout the guidance, it is important to recognise that not everyone who experiences a perinatal bereavement will want to refer to their loss using this language. The language preferences of those people experiencing a loss should always be mirrored when communicating with them.
- The term 'parents' is used to refer to expectant and bereaved people and partners. Many people will consider themselves parents from the time they discover they are, or were, pregnant. However, not everyone who experiences pregnancy loss or the death of a baby will want to be referred to as a parent. Therefore, when using this guidance staff should be sensitive to the individual preferences of those they are caring for.
- We recognise that who a 'family' is may involve different structures and diverse experiences. Where 'family' or 'families' are referred to in this document, we advise healthcare professionals to consider that there is not one type of bereaved family but to ensure that the individual is given opportunity to explain who they consider their family or support structure to be.
- 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, while others may be with a friend or family member, or may have more than one partner. As such, ask rather than assume who is in the room and what their relationship to the woman or birthing person is.
- 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, birthing people and families experiencing a childbearing loss.

Finally, because this is a pathway focused on improving outcomes for women, birthing people and 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: termination of pregnancy for fetal anomaly (TOPFA)

When a woman or birthing person decides to end a pregnancy her decision should be supported and she should expect high quality, individualised and well-coordinated care.

A. The decision to end a pregnancy after a prenatal diagnosis

This pathway provides guidance on care for women and birthing people and their partners who have made a decision to have a termination of pregnancy because of the implications of scan findings or other antenatal test results. We are assuming that the parents have experienced high quality care up to this point and had access to all the information and support they needed to come to a decision.

We expect all units to have carefully co-ordinated care pathways in place to provide support to women and birthing people and couples whether they decide to continue or end their pregnancy, whatever the diagnosis. For parents continuing when they know their baby is going to die, it will be helpful to also consult the Neonatal Death pathway.

B. Choice of method

It is important to offer women and birthing people a choice between surgical and medical termination when possible. Staff should be aware and ready to make any necessary adaptations for parents with an identified disability to ensure that parents fully understand. Staff should also ensure that if an interpreter is needed, this is arranged prior to the discussion.

Surgical termination of pregnancy

- Give parents clear information about what will happen, including information about any medical procedures and general anaesthetic.
- Discuss with parents their individualised care plan.
- Inform parents that they can change their mind about their management option, and let them know whom to contact and their contact details. Be clear about timelines if there are necessary cutoffs (such as what gestational age is the cut off for the offer of surgical termination of pregnancy at your hospital)
- Inform parents sensitively about the surgical procedure, including information such as the baby is not removed intact so there will not be a baby to see or hold following the procedure.
- Inform parents about the potential risks of the procedure.
- Discuss with parents how place of care (independent sector or NHS hospital) may affect the available treatment options for them
- Inform parents that a full post-mortem examination will not be possible, but some structural investigations and genetic testing are possible, but would need to be arranged before the procedure.
- Be clear about whether anyone can attend with the woman or birthing person, and if so, who.
- Let the woman or birthing person know that she will be alongside women and birthing people ending unwanted pregnancies.
- Provide the partner or support person with emotional support.
- Be aware that some women and birthing people will want to take the remains away with them.
- Provide parents with the time to take in information and ask as many questions as necessary.

- Explain to the woman or birthing person what she can expect regarding bleeding and pain after the procedure.
- Provide information about infection, and when to contact a healthcare professional.
- Sensitively discuss reducing infection risks and barrier contraception methods.
- Provide parents with written information, including about pain relief and physical and emotional care.
- Ensure all staff seeing parents before, during and after the procedure are aware of the baby's death and communicate sensitively.
- Ensure continuity of carer where possible.
- Make sure the woman or birthing person has made arrangements to get home safely after the procedure.
- Offer parents contact details for support organisations.
- Provide a named contact with contact details (a template contact card is available from nbcpathway.org.uk).
- Be prepared for questions about future fertility.
- Accurately complete all necessary paperwork, including the previous pregnancy loss form (a template is available from <u>nbcpathway.org.uk</u>). With consent from the woman or birthing person add this to her notes and explain why you have done
- 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.
- Be aware that NHS Trusts have some specialised surgical termination services (run through six regional centres) designed for women and birthing people who cannot safely be treated in independent sector clinics.
- Discuss with parents their individualised care plan.

B. Choice of method continued

Additional considerations for women and birthing people seeking care via the independent sector

- Before speaking to a woman or birthing person about their options via the independent sector **BPAS** (British Pregnancy Advisory Service) or MSI Reproductive Choices or NUPAS (National Unplanned Pregnancy Advisory Service), ensure that you are fully informed about the care offered by these providers, including where they are located and whether your Trust has a contract with them (BPAS clinics often offer visits for NHS staff to see the clinic space and meet their staff).
- Find where the nearest clinic is that can give gestation-appropriate treatment (a limited number of clinics offer surgical procedures after 18 weeks). Acknowledge that it might feel difficult to travel for this procedure.
- Prepare the woman or birthing person for the clinic environment - without offering personal views.

- Provide parents with the time to take in information about all of their options and the potential implications and ask as many questions as necessary.
- Ensure clear communication is established between the clinic and yourself/your unit.
- Be clear with the parent and the clinic about who is responsible for providing what care, including aftercare.
- Let the parent know whom to contact within the hospital regarding ongoing care needs.

Medical termination of pregnancy

- Discuss the arrangements, including place of birth, medication, pain relief, timings and memory making, including the option of seeing and holding the baby. Respect the parents' decisions.
- Discuss pain relief options that will be available.
- Provide information about what to expect during labour and birth.
- Provide information about mifepristone and prostaglandins and how they are used. It is important that this information is comprehensive.
- Discuss the risk of complications, including retained placenta (in 10 – 20% of cases, women and birthing people will need to have surgery to remove the placenta).
- Discuss the possibility of the baby showing signs of life at birth. UK guidance is available to support health care professionals in the assessment and documentation of signs of life in extremely preterm births. It is important to know that if a baby does show signs of life, the coroner will need to be informed.
- Discuss feticide and whether the parent will need to travel for this procedure.
- Explain why they are being offered this procedure.
- Enable the woman or birthing person to have a partner or support person with her at all times.
- With the woman or birthing person's consent, keep the partner or support person informed.
- Provide the partner or support person with emotional support.

- Explain to the woman or birthing person what she can expect regarding bleeding and pain after the procedure.
- Provide information about infection, and when to contact a health professional.
- Sensitively discuss barrier contraception and reducing infection risks.
- Ensure all staff seeing the parents before, during and after labour and birth are aware of the baby's death and communicate sensitively.
- Ensure continuity of carer where possible.
- Provide a named contact in case parents change their minds or have any questions.
- Accurately complete all necessary paperwork, including the previous pregnancy loss form (a template is available from nbcpathway.org.uk). With consent from the woman or birthing person 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.
- Discuss exactly where termination will take place and how this may affect pain relief options.



B. Choice of method continued

Additional considerations for selective termination or multifetal pregnancy reduction

- Women and birthing people undergoing termination in the context of a multiple pregnancy should be cared for at a tertiary fetal medicine centre.
- Give full information about the procedures offered, depending on the gestation.
- Discuss the risks to other babies for each procedure.
- Give parents time to consider the available options.
- Offer parents support around this decision.
- Give parents a named contact and the details of support organisations.
- Discuss the potential side effects of drugs that may be offered to prevent premature labour.

- Acknowledge any difficulty for the parents in having a dead baby remaining in the womb beside the living baby or babies.
- Where possible, reassure parents that fetuses that have died will remain in the uterus but will not harm the surviving baby or babies.
- Tell parents about what to expect during the remainder of the pregnancy, labour and birth.
- Tell the parents there are unlikely to be any visible remains after the birth of the surviving baby or babies if the procedure is carried out in early pregnancy.
- All women and birthing people undergoing third trimester selective reductions should have access to expert psychological support, for example, a perinatal psychologist.

C. Next steps

Memory making (dependent on termination method)

- Acknowledge where there are no physical remains and be aware of how this may affect opportunities for memory making, if this is something parents would like to do.
- Consider the condition of the baby when offering memory making options.
- Do not make assumptions about what parents may want based on the gestation of their pregnancy loss, the anomaly diagnosed or the decision to end a wanted pregnancy.
- Offer parents the opportunity to see and hold their baby. Offer to describe the baby's appearance first.
- Let parents know they can change their mind, but respect a decision when one has been made.
- Complete an informed choice form to ensure parents are provided with options but do not feel pressured. Give parents time to reflect and decide what they want.
- Discuss with parents:
 - Washing and dressing the baby
 - Photographs
 - Hand and foot prints
 - Certificate of birth (a template certificate is available from nbcpathway.org.uk)
 - Taking the baby or remains out of the hospital environment (a template form is available from 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.

- Parents should be informed that they can request an official Baby Loss Certificate for a loss before 24 weeks at any time through the <u>UK Government website</u>
- That, where appropriate, parents are offered empathetic religious or spiritual care.

Post-mortem examination and histology

- Ensure staff discussing post-mortem examination consent with parents are trained to do so.
- Explain that there are other tests available, such as blood tests and an examination of the placenta.
- Allow enough time for discussing postmortem examination consent.
- 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.
- Let parents know they can change their mind, but respect a decision when one has been made.
- 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 gynaecology/maternity who will be responsible for following up on results.
- Prepare parents for significant wait times for some test results.



C. Next steps continued

Next steps continued

- Offer to provide the parents an unofficial 'certificate of birth' from the hospital.
- Ensure the abortion notification form is completed and sent to the Chief Medical Officer.
- If pre-24 weeks, provide a letter confirming the baby was born dead before 24 weeks.
- The death will be formally registered as a termination.
- If delivery occurs at home following the initial stage of the medical termination, refer to guidance for miscarriages that occur at home (available from nbcpathway.org.uk).
- If a baby was born after 24 weeks' gestation but it is known or it can be proven the baby died before 24 weeks', they should not be registered as a stillbirth.
- If the baby is born dead after 24 weeks' gestation, provide the parents with a medical certificate of stillbirth.
- If a baby is born alive following a termination of pregnancy at any gestation and subsequently dies, both the birth and death of the baby must be registered.
- Where appropriate, staff should inform parents about the coronial process.

Sensitive disposal and funerals

- Provide parents with legal requirements and options.
- Discuss Trust and other local options.
- Bear in mind and facilitate where possible different personal, religious and cultural needs. Assumptions must not be made.
- Discuss with parents options for urgent burial and cremation where appropriate.
- Offer to refer parents to the chaplaincy
- Record all decisions made by the woman or birthing person in her medical records, including where information is declined or no decision is made.
- The HTA and Royal College of Nursing provide further guidance on managing disposal of remains.
- Make sure that women and birthing people who are treated outside of the hospital context are made aware of the options for disposal and funeral arrangements.



D. Discharge and aftercare

Discharge and aftercare

- Discuss lactation, milk donation and milk suppression.
- Discuss ongoing physical symptoms, such as bleeding and pain, and when to contact a healthcare professional.
- With the woman or birthing person's consent, promptly inform primary care staff that the woman or birthing person has experienced the death of her baby.
- Inform primary care staff where the woman or birthing person will be staying when they leave the hospital.
- Before discharging, give parents the contact details for primary care staff, secondary care staff and also local and national support organisations (see Useful contacts).
- 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.
- Staff should also provide information on when the woman or birthing person can return to physical activities and exercise. As appropriate, staff should provide information on pelvic floor muscle exercises.
- Ensure that the woman or birthing person's physical health and recovery needs are met. Resources on physical recovery that are sensitive to loss are available from The PABL Project https://thepablproject.com/].
- If there is any need for interpreting or translation services, then best practice should be followed and this arranged prior to any meetings.

Feedback

- Discuss with parents the opportunity to give feedback about the bereavement care they received.
- If they give consent to be contacted for feedback, let them know how and when they will be contacted about this.
- Document whether parents have consented to give feedback.
- Ensure the <u>Maternity Bereavement</u> <u>Experience Measure (MBEM)</u> is adapted for those parents who have experienced TOPFA.
- Be clear with parents about whether they will receive any follow up contact about this after submitting their feedback.
- See also <u>NICE Postnatal Care Quality</u> <u>Standard 37</u> and <u>RCGP guidance</u> on Palliative & End of Life Care.

Care in the community

- 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 check the woman or birthing person'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 template contact card is available from nbcpathway.org.uk).
- Offer parents contact with the chaplaincy team.
- Give parents the contact details of local and national support organisations (see Useful contacts).

D. Discharge and aftercare continued

Ongoing emotional support

- With consent from the parents, ensure all hospital and community healthcare staff have been informed of the loss.
- With consent from the parents, ensure the woman or birthing person's notes have a baby loss summary sheet attached (a template form is available from nbcpathway.org.uk).
- Discuss with the parents the difficult emotions they may experience to reassure them that feelings of grief, loss and guilt 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, which should have contacts with religious and spiritual advisers of all local faiths and spiritual organisations.
- Do not refer to 'post-abortion' counselling services unless you are confident they are completely nonjudgemental and without anti-abortion bias.
- 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 good follow up care by the GP or health visitor for the partner as well as the woman or birthing person. See also NICE <u>guidance</u> on antenatal/postnatal mental health.

E. Subsequent pregnancy

Pre-conception

- Familiarise yourself with the parent's notes.
- With consent ensure the woman or birthing person's notes are marked with a pregnancy or baby loss form (a template form is available from 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 (such as smoking cessation, weight loss and regular exercise programmes that are available in the local area, and taking folic acid and vitamin D supplements).
- Discuss with parents what testing might be available to them in a subsequent pregnancy, dependent on diagnosis.
- Listen to and acknowledge parents' fears and concerns.
- It is important not to offer false reassurance and to 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.

E. Subsequent pregnancy continued

Antenatal care

- Parents should be offered regular contact with staff, emotional support and screening for mental health difficulties.
- Refer parents to another unit or another consultant if requested.
- Outline any additional antenatal support offered, including additional scans or appointments and why these have been offered. Not all parents will want this.
- Allocate extra time for these appointments.
- Remind women and birthing people 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 or birthing person's previous history before admission.

Labour and birth

- 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 or birthing person.
- 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.

F. Staff support

Staff support

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

Trusts should provide:

- A safe, compassionate workplace culture that normalises seeking support.
- Bereavement care training to all staff.
- A trauma-informed approach to staff support.
- Access to wellbeing services and opportunities for staff to debrief.
- Monitoring of staff wellbeing.
- Access to appropriate support for managers and senior staff.
- Managers should ensure that any staff that have a conscientious objection are managed in order to minimise the impact on care experienced by families.

Not all of these contacts will be appropriate for all pathways

National contacts:

Action on Pre-Eclampsia (APEC)

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

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.

arc-uk.org

Baby Mailing Preference Service (MPS) online

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

mpsonline.org.uk/bmpsr

Bereavement Advice Centre

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

bereavementadvice.org

Bliss

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

bliss.org.uk

British Pregnancy Advisory Service (BPAS)

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

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.

gov.uk/government/organisations/ hm-revenuecustoms/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.

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.

tcf.org.uk

Contact

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

contact.org.uk

Cruse Bereavement Care

Offers support to bereaved people and training for professionals.

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.

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.

ectopic.org.uk

Federation of British Cremation Authorities (FBCA)

Professional organisation of burial and cremation authorities in the UK.

fbca.org.uk

Footprints Baby Loss

Provides vital support to parents and families who experience the death of one or more of their twins or triplets before, during or after birth.

footprintsbabyloss.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.

nidirect.gov.uk/articles/funeral-expenses-payments

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.

gov.uk/funeral-payments

Gifts of Remembrance

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

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.

hfea.gov.uk

Human Tissue Authority (HTA)

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

hta.gov.uk

Infertility Network UK

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

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.

iccm-uk.com

International Stillbirth Alliance (ISA)

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

stillbirthalliance.org

Jobcentre Plus - Bereavement Services Helpline

Provides information about benefits claims.

Telephone: 0345 608 8601 gov.uk/contact-jobcentre-plus

Lullaby Trust

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

lullabytrust.org.uk

Miscarriage Association

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

miscarriageassociation.org.uk

MSI Reproductive choices

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

msichoices.org.uk

Woman or birthing persons 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.

npeu.ox.ac.uk/mbrrace-uk

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

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.

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.

nafd.org.uk

National Association of Memorial Masons (NAMM)

Sets standards for memorial stones and provides information for individuals who are choosing a memorial **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 birthing people and their families in the perinatal period and promote the effective use of resources by perinatal health services.

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.

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.

nowilaymedowntosleep.org

Our Missing Peace

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

ourmissingpeace.org

Parental Bereavement Leave

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

gov.uk/parental-bereavement-pay-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.

perinatal.org.uk

Rainbow Trust Children's Charity

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

rainbowtrust.org.uk

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

England and Wales: General Register Office

gov.uk/general-register-office

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

Northern Ireland: General Register Office Northern Ireland (GRONI)

nidirect.gov.uk/gro

Relate

Offers relationship support to help people strengthen their relationships.

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.

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

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. samaritans.org

The PABL Project

Provides resources on physical recovery that are sensitive to loss.

Thepablproject.com

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.

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).

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.

ukamb.org

Winston's Wish

Offers support to be reaved children, their families and professionals.

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.

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
- Application form for the individual burial or cremation of pregnancy remains
- Certificate of birth before the 24th week of pregnancy
- Contact card
- Creating memories offering choices
- Form for parents who take their baby's body home

- Funeral consent form for parents
- Guidance for miscarriages that occur at home
- Maternity Bereavement Experience
- Measure (MBEM)
- Previous pregnancy loss form for notes
- Medical form for cremation or burial
- Terminology

nbcpathway.org.uk



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

sands.org.uk

