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A pathway to improve bereavement care for parents in England after pregnancy or baby loss

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**national bereavement**  
**c a r e p a t h w a y**  
for pregnancy and baby loss

# Termination of Pregnancy due to Fetal Anomaly (TOPFA)

## 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 terminating a pregnancy because of a fetal anomaly. Other documents are available that describe the pathway for the other childbearing losses (see [www.nbcpathway.org.uk](http://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' and sometimes 'remains' are used throughout. Not everyone will want these words to be used, though, and healthcare professionals should use the words preferred by the individual. We refer to 'Trusts', but we hope that the pathway will be used by independent healthcare establishments and other bodies that organise and provide care for women and families experiencing a childbearing loss.

**More detail on the terminology is available from [www.nbcpathway.org.uk](http://www.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.”

**(Quote by bereaved parent)**



# 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](http://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: termination of pregnancy for fetal anomaly (TOPFA)

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

## A. Diagnosis and delivering difficult news

- When possible, 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. If over the phone, check the woman is able to speak.
  - Ask the woman whether she would like her partner or a support person present, or if she has brought children to a scan whether she would like them to leave.
  - Use clear, straightforward language, with no euphemisms or jargon.
  - Do not make assumptions about how the woman feels about a diagnosis, or any decisions she may make – communicate empathically and follow the parents' lead on language (for example, using 'baby' or 'fetus').
  - Give parents time to absorb the news and answer any questions you are able to, within your scope of practice; refer where needed.
  - If a diagnosis is made during a scan give the woman an opportunity to see the screen, and offer to show them what you have seen.
  - Offer the woman a scan photograph.
  - Offer the woman supportive, non-directive communication.
- Provide accurate information about the diagnosis, including what it might mean for the pregnancy and for the baby.
  - Give information about what can happen next, including information about continuing and ending the pregnancy.
  - Acknowledge that uncertainty and delays for subsequent scans or investigations can be difficult.
  - Explain any reasons for a delay for further care (for example, further scans).
  - Where a referral to a different unit and travel is required, explain the reason for this.
  - Provide accurate information about choice of method of termination (surgical or medically managed and where procedures can take place under NHS contracts).
  - Provide written information and a named contact with contact details (a template contact card is available from [www.nbcpathway.org.uk](http://www.nbcpathway.org.uk)).
  - Check the woman can get home safely – offer a taxi if necessary.
  - Offer the woman the contact details for support organisations.
  - See NICE guidance C154 for further information ([www.nice.org.uk/guidance/cg154](http://www.nice.org.uk/guidance/cg154)).

## B. Choice of method

It is important to offer women a choice between surgical and medical termination when possible.

### Surgical Termination of Pregnancy

- Give parents clear information about what is happening, 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 who to contact and their contact details. Be clear about timelines if there are necessary cut-offs (such as when your hospital stops offering the surgical method).
  - Inform parents sensitively about the surgical procedure, i.e. if the baby is not removed intact 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, and if so, who.
  - Let the woman know that she will be alongside women ending unwanted pregnancies.
- Be aware that some women 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 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 has made arrangements to get home safely after the procedure.
  - Offer the woman the contact details for support organisations.
  - Provide a named contact with contact details (a template contact card is available from [www.nbcpathway.org.uk](http://www.nbcpathway.org.uk)).
  - Be prepared for questions about future fertility.

## B. Choice of method continued

### Additional considerations for women seeking care via the independent sector

- Before speaking to a woman about her options via the independent sector (British Pregnancy Advisory Service [BPAS] or Marie Stopes UK), 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 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 who to contact within the hospital regarding ongoing care needs.



## B. Choice of method continued

### 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.
- Provide information about what to expect during labour and birth.
- Provide information about mifepristone and prostaglandins and how they are used.
- Discuss the risk of complications, including retained placenta.
- Discuss the possibility of the baby showing signs of life at birth.
- Discuss feticide and whether the parent will need to travel for this procedure. Explain why they are being offered this procedure.
- 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.
- Explain to the woman 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 [www.nbcpathway.org.uk](http://www.nbcpathway.org.uk)). With consent from the woman add this to her notes and explain why you have done this.

## B. Choice of method continued

### Additional considerations for selective termination or multifetal pregnancy reduction

- Women 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 undergoing third trimester selective reductions should have access to expert psychological support, for example, a perinatal psychologist.



## C. Next steps

### Memory making

- Acknowledge where there are no physical remains and be aware of how this may affect opportunities for memory making, if this is something they 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 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](http://www.nbcpathway.org.uk)).
- 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 [www.nbcpathway.org.uk](http://www.nbcpathway.org.uk))
  - Taking the baby or remains out of the hospital environment (a template form is available from [www.nbcpathway.org.uk](http://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.

### 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. This could be particularly relevant for earlier losses, where a post mortem examination is not possible.
- Allow enough time for discussing post mortem 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 timescales 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.

## C. Next steps continued

### Registration and certification

- 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 form [www.nbcpathway.org.uk](http://www.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.

### 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 team.
- Record all decisions made by the woman in her medical records, including where information is declined or no decision is made.
- See also HTA guidance on disposal of pregnancy ([www.bit.ly/2gEDOfT](http://www.bit.ly/2gEDOfT)) and RCN guidance on managing disposal of remains ([www.bit.ly/2Nm7o5o](http://www.bit.ly/2Nm7o5o)).

## 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 mother's consent, promptly inform primary care staff that the woman has experienced the death of her baby.
- Inform primary care staff where the mother will be staying when they leave the hospital.
- Before discharging the woman, give her 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.

### 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.
- Use the Maternity Bereavement Experience Measure (MBEM) to capture parent feedback ([www.bit.ly/2DQ3MJz](http://www.bit.ly/2DQ3MJz)). Be clear with parents that this feedback mechanism is not a review of the baby's death, nor the complaints process.
- Be clear with parents about whether they will receive any follow-up contact about this after submitting their feedback.
- See also NICE Postnatal Care Quality Standard 37 ([www.nice.org.uk/guidance/QS37](http://www.nice.org.uk/guidance/QS37)) and RCGP guidance on Palliative & End of Life Care ([www.bit.ly/2AzB5Pz](http://www.bit.ly/2AzB5Pz)).

### 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 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 template contact card is available from [www.nbcpathway.org.uk](http://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).

## 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 baby's death.
- With consent from the parents, ensure the mother's notes have a baby loss summary sheet attached (a template form is available from [www.nbcpathway.org.uk](http://www.nbcpathway.org.uk)).
- Discuss with the woman or couple the difficult emotions they may experience to reassure them that feelings of grief and loss 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.
- Do not refer to 'post-abortion' counselling services unless you are confident they are completely non-judgemental 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 mother.
- see also NICE guidance on antenatal/postnatal mental health ([www.nice.org.uk/guidance/qs115](http://www.nice.org.uk/guidance/qs115)) and Public Health information on Maternal Mental Health ([www.bit.ly/2Noa0Qw](http://www.bit.ly/2Noa0Qw)).

## E. Subsequent pregnancy

### Preconception

- Familiarise yourself with the parent's notes.
- With consent ensure the mother's notes are marked with a pregnancy or baby loss form (a template form is available from [www.nbcpathway.org.uk](http://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 (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).
- 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 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.

## F. Staff care

### Staff care

- Recognise your own support needs.
- Identify your own training needs or seek advice from colleagues or peers.
- Communicate these needs with management and colleagues; other staff may have similar needs.
- Ensure you are aware of the support systems in place within your Trust.
- Ensure a good level of self-care.

### 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.
- 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.



# Useful contacts

## National contacts:

### Action on Pre-Eclampsia (APEC)

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

[www.action-on-pre-eclampsia.org.uk](http://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](http://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](http://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](http://www.bereavementadvice.org)

### Bereavement Care Network

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

[bereavement-network.rcm.org.uk](http://bereavement-network.rcm.org.uk)

### Bliss

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

[www.bliss.org.uk](http://www.bliss.org.uk)

### British Pregnancy Advisory Service (BPAS)

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

[www.bpas.org](http://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](http://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](http://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](http://www.tcf.org.uk)

### Contact a Family

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

[www.cafamily.org.uk](http://www.cafamily.org.uk)

### Cruse Bereavement Care

Offers support to bereaved people and training for professionals.

[www.cruse.org.uk](http://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](http://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](http://www.ectopic.org.uk)

### Federation of British Cremation Authorities (FBCA)

Professional organisation of burial and cremation authorities in the UK.

[www.fbca.org.uk](http://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](http://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](http://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](http://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](http://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](http://www.hta.gov.uk)

## Infertility Network UK

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

[www.infertilitynetworkuk.com](http://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](http://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](http://www.stillbirthalliance.org)

## Jobcentre Plus – Bereavement Services Helpline

Provides information about benefits claims.

Telephone: **0345 608 8601**

[www.gov.uk/contact-jobcentre-plus](http://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](http://www.lullabytrust.org.uk)

## Marie Stopes International

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

[www.mariestopes.org.uk](http://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](http://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](http://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](http://www.miscarriageassociation.org.uk)

## Money Advice Service

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

[www.moneyadvice.service.org.uk](http://www.moneyadvice.service.org.uk)

## Multiple Births Foundation (MBF)

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

[www.multiplebirths.org.uk](http://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](http://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](http://www.namm.org.uk)

# Useful contacts

2

## 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](http://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](http://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](http://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](http://www.ourmissingpeace.org)

## Perinatal Institute for maternal and child health

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

[www.perinatal.org.uk](http://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](http://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](http://www.gro.gov.uk/gro/content)

Scotland: National Records for Scotland

[www.nrscotland.gov.uk/registration](http://www.nrscotland.gov.uk/registration)

Northern Ireland: General Register Office

Northern Ireland (GRONI)

[www.nidirect.gov.uk/gro](http://www.nidirect.gov.uk/gro)

## Relate

Offers relationship support to help people strengthen their relationships.

[www.relate.org.uk](http://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](http://www.remembermybaby.org.uk)

## Sands, the stillbirth and neonatal death charity

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

[www.uk-sands.org](http://www.uk-sands.org)

## Samaritans

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

Telephone: **116 123 (UK)** or **116 123 (ROI)** for free.

[www.samaritans.org](http://www.samaritans.org)

## Tamba Bereavement Support Group

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

[www.tamba.org.uk/bereavement](http://www.tamba.org.uk/bereavement)

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

[www.tamba.org.uk](http://www.tamba.org.uk)

## Together for Short Lives

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

[www.togetherforshortlives.org.uk](http://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](http://www.ukamb.org)



### Winston's Wish

Offer support to bereaved children, their families and professionals.

[www.winstonswish.org.uk](http://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](http://www.workingfamilies.org.uk/articles/miscarriage-stillbirth-and-neonatal-death-your-rights-at-work)

### Other

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# Supporting documents

The following supporting documents are available from [nbcpathway.org.uk](http://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



For more information visit:  
**[nbcpathway.org.uk](http://nbcpathway.org.uk)**

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Sands (Stillbirth & Neonatal Death Charity)  
Victoria Charity Centre  
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**Sands (Stillbirth and Neonatal Death Society)**  
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Charity Registration Number: 299679  
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