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



**national bereavement
care pathway**
for pregnancy and baby loss

Miscarriage, Ectopic Pregnancy and Molar Pregnancy

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 a woman who has miscarried (up to 23+6 weeks) or had an ectopic or molar pregnancy, and her partner. 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 available from www.nbcpathway.org.uk

“Bereavement care recognises that parents’ experiences and feelings count, no matter how early the gestation.”

(Quote by bereaved parent, 2018)

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.

A self-assessment tool is available for all Trusts who sign up to the NBCP. more information can be found at nbcpathway.org.uk or by contacting the NBCP team at Sands.

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).

In time we are hopeful that the CQC will also include these elements within their inspection frameworks for other departments.

- 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 (appropriately equipped and ideally soundproofed) 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.

1 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: miscarriage (to 23+6 weeks), ectopic pregnancy and molar pregnancy

A. Diagnosis and delivering difficult news

- When consenting the woman for the scan, explain the potential need for a second opinion and/or repeat scan.
- Be aware that the parents may be anticipating bad or negative news because of signs or symptoms, an earlier assessment, a letter or phone call (re molar pregnancy) or a previous pregnancy. However, for many the news will come as a complete shock.
- Do not make assumptions about how the parents feel about the pregnancy or the news – communicate empathically and follow the parents' lead on terminology and language.
- If you suspect or identify a problem on examination and need to consult or confirm with a colleague outside the room, explain this before you leave the room. Be aware of your body language and non-verbal signals and sensitive to the woman's or couple's reaction.
- Find an appropriate place either to deliver the news and/or to explain it further. This might mean giving the news in the scan room but explaining next steps elsewhere.
- If the woman is alone for the diagnosis, ask her whether she would like someone else to be present for further explanation.
- Use clear, straightforward language. Avoid medical terms, abbreviations (e.g. ERPC) or euphemisms (e.g., 'not in your tummy').
- If the news is being given at an ultrasound scan, ask the parents if they want you to show them on the screen what you have seen. Ask the woman if she would like to get dressed and sit up or prefer to see the screen while you explain the findings.
- If the diagnosis is unclear – a pregnancy of unknown location or of uncertain viability or a suspected molar pregnancy – explain the need for further assessment and acknowledge how difficult the period of uncertainty can be.
- If one or more babies in a multiple pregnancy dies but one or more is still viable, be sensitive to the difficult feelings that the parents may have. The continuing pregnancy or pregnancies may still be at risk and even if continuing, may be no compensation for the baby/babies that died.
- If the pregnancy is heterotopic – one ectopic and one intrauterine – and the intrauterine pregnancy is viable, be sensitive to the difficult feelings that the parents may have. Depending on how the ectopic is managed, the intrauterine pregnancy may still be at risk and even if continuing, may be no compensation for the baby that died.
- If you are giving the diagnosis of molar pregnancy, ensure that you know whether the parents are expecting this news (e.g. from a letter or phone call). Be sensitive to the difficult feelings she/ they may have if they have already been coping with the diagnosis of miscarriage. Also be aware that molar pregnancy is uncommon and is a complicated diagnosis to understand.
- Give the parents time to absorb the news, and answer as many questions as you are able to, within your scope of practice.
- Give information about what happens next, provide written information, specific patient leaflets and a named contact with contact details (a template contact card is available from www.nbcpathway.org.uk).
- Offer a copy of the scan picture if there is one and offer to keep a printed copy in the notes if she/they would prefer.
- Check that the woman can get home or to the next appointment safely. Explain that the hospital will be unable to pay for a taxi, but that you could call a taxi or a friend on their behalf if they would like you to.
- It is not uncommon for women to pass their baby/pregnancy while on the toilet. Bedpans or similar should be provided in women's toilets in A&E, gynaecology and maternity settings.
- See NICE guidance NG126 for further information (www.nice.org.uk/guidance/ng126).

B. Next steps

Making decisions about clinical care: early miscarriage

- Give clear information about what is happening, including information about management options or recommendations (including risks), if appropriate.
 - Discuss how place of care (home or in hospital, gynaecology or maternity ward) may affect the management options available to them.
 - Explain any reasons for a delay in further care (e.g., further scans, booking theatre time).
 - Transfer a woman admitted through an emergency department to a ward or offer support to go home as quickly as possible, with information about accessing, and/or an appointment for further treatment or assessment.
 - Provide clear information about possible pain and bleeding, and the possibility of passing the baby or remains, before the next appointment.
 - If the woman opts for expectant management or medical management at home, explain honestly what she can expect regarding pain and bleeding during and after the miscarriage. Offer analgesics or advice on over-the-counter options.
 - In all cases, advise that the woman may miscarry while on the toilet and offer information regarding pregnancy remains (see guidance for miscarriages that occur at home, available from www.nbcpathway.org.uk).
 - If methotrexate is offered, explain the need for compliance with the treatment and the potential need for additional treatment in some cases.
- Provide written information and give time for decision making wherever possible.
 - Inform the woman that she can usually change her mind about the management option, and provide the contact details for who to be in touch with if she does.
 - Ensure all staff seeing the parents during and after the process of miscarriage are aware of what is happening and communicate sensitively, using appropriate language and terminology.
 - Ensure continuity of carer where possible
 - Offer to tell the parents what they might expect their baby or pregnancy remains to look like, depending on gestation and management method.
 - Discuss how the woman/couple will travel home afterwards.
 - Provide information about signs of infection, and when to contact a healthcare professional. Advise on reducing infection risks, avoiding sexual intercourse and use of tampons until bleeding has stopped.
 - Offer to provide verbal and/or written information about trying again and/or contraception.
 - Ask the woman if she would like the pregnancy loss form completed and added to her notes to alert staff in any future pregnancy or pregnancies (a template form is available from www.nbcpathway.org.uk).
 - Ask the 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.

B. Next steps continued

Ectopic pregnancy

- Give clear and understandable information (verbally and in writing where possible) about management options, risks, benefits and any recommendations, and allow time for discussion and decision making wherever possible.
 - Be sensitive to the feelings the parents may have about the loss of the baby, risks to the woman and implications for her fertility. Provide information about organisations that can offer further support.
 - Recognise that they may have already been coping with the diagnosis of miscarriage.
 - If the woman opts for expectant management, explain the need for continued monitoring and further appointments, and advise on the potential need for treatment in some cases. Provide a contact name and/or number so the woman or couple can ask questions or seek advice at any time.
 - If the woman opts for medical management, explain that the options are not suitable for all women, the process for testing and the need for continued monitoring and further appointments; advise on the potential need for repeat treatment or surgery in some cases. Provide a contact name and/or number so the parents can ask questions or seek advice at any time.
 - If surgical management is advised/ opted for, clearly and sensitively explain the steps for hospital admission, pre-operative preparation and surgical routes including any recommendations (keyhole, open, possible outcomes for the affected fallopian tube). Provide a contact name so that the woman or couple can ask questions or seek advice.
- Offer to tell the parents what they might expect the remains of their baby or pregnancy to look like, depending on the gestation and the type of management used.
 - Provide information about pain relief, signs of infection and heavy bleeding, and when to contact a healthcare professional.
 - If a woman has opted for medical or expectant management, provide information about how to reduce risk of and signs of rupture and provide a contact name and number so that the woman can contact a healthcare professional, if needed.
 - Advise on reducing infection risks, avoiding sexual intercourse and use of tampons until bleeding has stopped.
 - Offer to provide verbal and/or written information about the return of the woman's menstrual cycle, sex and trying again and/or contraception.
 - Ask the woman if she would like the pregnancy loss form completed and added to her notes to alert staff in any future pregnancies (a template form is available from www.nbcpathway.org.uk).
 - Ask the 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.

B. Next steps continued

Molar pregnancy

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- Give clear and understandable information regarding the recommendation for surgical management if this is needed, recognising that this may be the woman's second procedure.
 - Give clear information about the follow up process, why it is needed and what it will involve. Provide contact details of the specialist centre to which the woman will be referred, so the parents can ask questions or seek advice at any time.
 - Be sensitive to the feelings the parents may have regarding the loss of their baby, the possible risks for the woman's health and implications for future pregnancies. Provide information about organisations that can offer further support.
 - Provide information about signs of infection, and when to contact a healthcare professional.
- Advise the parents on reducing infection risks, avoiding sexual intercourse and use of tampons until bleeding has stopped.
 - Tell the parents that the follow up centre will advise them not to conceive until follow up is complete, and offer to provide verbal and/or written information about contraception.
 - Ask the woman if she would like the pregnancy loss form completed and added to her notes to alert staff in any future pregnancies (a template form is available from www.nbcpathway.org.uk).
 - 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 he/she did.

B. Next steps continued

Late miscarriage/second trimester (from 14 to 23+6 weeks)

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- In which ever way the woman enters the care environment, ensure she is offered an appropriate care environment based on her expressed needs and wishes (for example, gynaecology, maternity).
 - Discuss the arrangements, including place of birth, pain relief, timings and memory making.
 - Provide written details of where care will be provided and prepare the parents for what to expect during labour and birth.
 - Provide a named contact in case the woman changes her mind or has any questions.
 - Ensure all staff seeing the parents during labour and birth are aware of the baby's death and communicate sensitively.
 - Ensure continuity of carer where possible.
 - Women are likely to need additional emotional support during labour.
- 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 baby/pregnancy loss form.
 - 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.

B. Next steps continued

Memory making

- Recognise that some parents will appreciate the offer of some kind of memory making and others will not. Do not make assumptions about what they might want based on the gestation of their pregnancy loss, though there are likely to be limited options with early loss.
 - Be sensitive to the condition of the baby or pregnancy remains when offering memory making options.
 - If there are no pregnancy remains (for example, after a complete miscarriage), ask the parents if they would like to consider memory making or marking the loss in some way, such as with a certificate of loss.
 - Depending on the condition of the baby or remains, offer the opportunity to see and perhaps hold the baby. Offer to describe the baby's appearance or what the remains look like first.
 - Let the parents know they can change their minds, but respect a decision when one has been made.
 - Make clear any time frame for making that decision.
 - Allow time for all these decisions.
 - Complete the informed choice form to ensure the parents are provided with options, but that they do not feel pressured (a template form, 'Creating memories – offering choices', is available from www.nbcpathway.org.uk).
- Depending on the diagnosis and/or condition of the baby or remains, discuss with parents:
 - Seeing and/or holding their baby or baby's remains, in a suitable container if needed
 - A memory box, or items for a box if one is not available
 - A copy of the scan image, if still in the notes or not already taken
 - Taking the baby or remains out of the hospital environment (a template form is available from www.nbcpathway.org.uk)
 - Certificate of birth or loss (a template certificate is available from www.nbcpathway.org.uk)
 - Photographs of the baby or remains
 - Hand and footprints
 - Other memorials
 - Where there is a death in a multiple pregnancy, discuss with the parents the options around future memory making with siblings.

B. Post mortem, registration and disposal of remains/funeral

Post mortem examination and histology

- Ensure staff discussing post mortem examination consent with parents are trained to do so.
 - Offer testing other than a full post mortem examination, such as an examination of the placenta and blood tests. This could be particularly relevant for earlier losses, if testing is offered.
 - Allow a minimum of one hour for discussing post mortem consent.
 - Seek consent for histological examination at the time of obtaining consent for surgery, where possible, explaining what it is, why it is done and options regarding subsequent sensitive disposal and funerals.
 - Ensure discussion takes place in a quiet, private place.
 - Inform the parents if the post mortem examination will take place at a different hospital (or if the histology examination will be at another location), and explain where and why.
- All transport arrangements and handling of the baby or remains must be respectful; the baby's body or remains must be labelled and tracked.
 - During the consent process, inform the parents of the likely time scales for the return of the baby's body or pregnancy remains and how and when results will be communicated.
 - Identify a named contact within both pathology and maternity/gynaecology who will be responsible for following up on the results.
 - Ensure that the parents understand that routine histology will not provide information about a possible cause of miscarriage/ectopic pregnancy/molar pregnancy or identify the baby's gender.
 - This is possible only through post mortem testing or fetal karyotyping.

Certification and Registration

- Offer to provide a 'certificate of loss' or 'certificate of birth' from the hospital.
- Offer to provide a letter confirming that the pregnancy was lost or the baby was born dead before 24 weeks.
- If the miscarriage occurred at home, refer to the guidance for miscarriages that occur at home (available from www.nbcpathway.org.uk).
- If a baby was born after 24 weeks' gestation but it is known or can be proven that the baby died before 24 weeks, the death cannot be recorded or registered as a stillbirth.

C. Post mortem, registration and disposal of remains/ funeral continued

Sensitive disposal and funerals

- Offer to provide the parents with information about options for what happens to their baby/the remains of their baby. Recognise that some women will not want this information nor feel capable of making decisions.
- If the parents do not want the information, explain that the hospital will take care of this but that they can get back in touch if they change their minds (and provide the time frame for doing so).
- Verbal and/or written information should include:
 - The choices they have if they want the hospital to make arrangements and the costs, if any
 - The choices they have if they want to manage the arrangements, including information on local funeral directors if available
 - The time frame for making and communicating that decision
 - The hospital process if they do not make or communicate that decision within that time frame
- Bear in mind and support where possible different personal, religious and cultural needs. Assumptions must not be made.
- Discuss the options for urgent burial and cremation where appropriate.
- Offer to refer the 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 (<https://bit.ly/3JZ5O8K>) and RCN guidance on managing disposal of remains (<https://bit.ly/3QGTg80>).
- Make sure that women 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 with the woman ongoing physical symptoms she may experience, such as bleeding and pain, and when to contact a healthcare professional.
- After second trimester miscarriage, discuss lactation and milk suppression and consider providing information about the option of milk donation.
- With her consent, promptly inform primary care staff that the woman has experienced a miscarriage, ectopic or molar pregnancy.
- Provide information on continuing care/ follow up/early scanning for ectopic or molar pregnancy and additional information where appropriate (e.g. gestation, one of multiples).
- If the woman is not going to her own address, with her consent, inform primary care staff where the woman will be staying when she leaves the hospital.
- Before the woman/couple leaves the hospital, give them 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 and explain what to expect from this appointment.
- Discuss the location of the follow up appointment and who can attend.

D. Discharge and aftercare continued

Feedback

- Discuss with the parents the opportunity to give feedback about the bereavement care they received.
- Be clear that this feedback mechanism is not a review of the causes of their loss.
- If the parents give consent to be contacted for feedback, let them know how and when they will be contacted about this.
- Document consent to participate in giving feedback.
- Use the Maternity Bereavement Experience Measure (MBEM) to capture feedback (<https://bit.ly/3SRnMxN>).

Ongoing emotional support

- If the woman consents, ensure all appropriate hospital and community healthcare staff have been informed of the baby's death.
- Discuss with the parents the difficult emotions they may experience to reassure them that feelings of grief and loss are common.
- Provide information about the emotional support available via your Trust, primary care colleagues and via local and national support organisations (see Useful contacts).
- Offer contact with the chaplaincy team.
- Bear in mind and facilitate where possible different personal, religious and cultural needs. Assumptions must not be made about the parents' knowledge of or adherence to their own faith requirements in the event of miscarriage, ectopic pregnancy or molar pregnancy.
- Allow sufficient time for all follow up appointments (refer to local policies, where they exist).
- Make sure you know to whom you can refer for a mental health assessment and where appropriate, treatment.
- If the partner consents and provides details, ensure handover of care to the GP or health visitor for the partner as well as the woman.
- See also NICE guidance on antenatal/postnatal mental health (www.nice.org.uk/guidance/qs115) and Public Health information on Maternal Mental Health

E. Subsequent pregnancy

Pre-conception

- Familiarise yourself with the woman's notes.
- Support the parents to make informed choices around if/when to try for another baby.
- Discuss what, if anything, the parents can do that might reduce the risk of another loss.
- Listen to and acknowledge any fears and concerns.
- It is important not to offer false reassurance and to be aware that statistical probabilities may not provide comfort.
- Be clear about the available support from staff and other organisations.
- Ensure that partners are offered support.

Antenatal care

- With consent, ensure the previous history is disclosed on the ultrasound request to avoid miscommunication.
- If possible, offer the option of an additional ultrasound scan or scans, appropriate to the timing of the previous loss.
- Staff should explain reasons for additional tests with their benefits and any risks in declining. This is important for early scans where women have previously experienced ectopic pregnancy.
- Women with a previous loss should be offered regular contact with staff, emotional support and screening for mental health difficulties.
- If possible refer the woman to another unit or another consultant if requested, or offer a different scan room, if available.
- Outline any additional antenatal support offered. Allocate extra time for these appointments.
- Remind the woman that she can bring a support person to attend these appointments.
- Discuss and acknowledge (where appropriate) certain stages, events or dates during the pregnancy that may be particularly difficult (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

Labour and birth

- Be prepared for the parents' emotional reactions, regardless of the gestation at which previous losses occurred.
- Be sensitive to the mixed feelings the parents may have after a live birth. They may be thinking of the baby or babies lost in previous pregnancies or earlier in this pregnancy. Show understanding and empathy.
- Let the parents know mixed feelings are normal and be ready to talk about the baby or babies who died.

Care in the community

- Offer the parents a telephone call and/or house visit when they are back at home.
- Allow enough time to offer emotional support as well as to check the mother's physical health.
- Discuss how or if to talk about the baby who died or the pregnancy loss with existing and subsequent siblings.
- Give the parents the contact details of a healthcare professional they can contact for information and support and offer referrals where necessary (see Useful contacts).
- Offer contact with the chaplaincy team.
- Bear in mind and facilitate where possible different personal, religious and cultural needs. Assumptions must not be made about the parents' knowledge of or adherence to their own faith requirements in the event of miscarriage
- Give the parents the contact details of local and national support organisations (see Useful contacts).

F. Staff care

Staff care - please see full guidance for greater details

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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/mbrance-uk

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

www.mbrance.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.twustrust.org/bereavement

Together for Short Lives

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

www.togetherforshortlives.org.uk

United Kingdom Association for Milk Banking (UKAMB)

Supports human milk banking and aims to provide safe and screened donor breastmilk for premature and sick babies.

www.ukamb.org

Useful contacts

Winston's Wish

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.
- 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

www.sands.org.uk



Sands (Stillbirth and Neonatal Death Society)
Company Limited by Guarantee Number: 2212082
Charity Registration Number: 299679
Scottish Charity Registration Number: SC042789