

NORTH WEST GUIDELINE

Management of Neonatal Death



Ensuring optimal management for families who experience a neonatal death

To be used for neonatal deaths AT ANY GESTATION
in association with the North West Management of Neonatal Death
Integrated Care Pathway

Version 1 | January 2025

Guideline produced on behalf of the North West Regional Maternity Team

**In honour of all parents and families who have
experienced the death of their baby**

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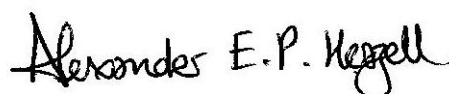
On behalf of the Greater Manchester and Eastern Cheshire (GMEC) and North West Coast (NWC) Strategic Clinical Networks, I would like to take this opportunity to thank the authors for their enthusiasm, motivation and dedication in the development of version 1 of the North West Management of Neonatal Death Guideline and Integrated Care Pathway (ICP). I would like to thank Sarah Fullwood, Project Manager for her support throughout the process. I would also like to thank members of the GMEC SCN Perinatal Loss Special Interest Group and North West Neonatal Operational Delivery Network for their valued contributions and to acknowledge the input from all who reviewed and commented on the draft versions of the documents. Your helpful suggestions have been incorporated into the final guideline and ICP. Special thanks to Sarah West for her invaluable help and for the finishing touches to produce the final documents.



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No conflicts of interest have been declared by the members of the guideline development group.

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Summary

The death of a baby after birth at any gestation is traumatic for parents, who deserve to be cared for with empathy and compassion. The death of a baby can be a traumatic event for everyone involved, including staff. Care provided and your role as supporter, counsellor, friend, advocate, carer, and clinician is pivotal to the family's experience and subsequent memories of this time. What we do for families during this time will last a lifetime so it is important that we get it right. This guideline and associated Integrated Care Pathway align with the principles of the Sands National Bereavement Care Pathway¹.

Purpose

The purpose of this guideline is to help staff to deliver optimal care for women and their families who experience a neonatal death at any gestation.

Scope

This guideline is available to be adopted across the North West (and anywhere else that may find this useful) in order that parents and their families receive compassionate and high-quality care if they experience a neonatal death. Please note that appendices are geographically orientated and may need editing for localisation.

Responsibilities

Midwives, obstetricians, neonatal nurses, neonatologists, perinatal histopathologists, bereavement teams, medical examiners.

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5.1. Guidance

A neonatal death is defined as a baby born with signs of life at any gestation who dies within 28 days ².

- Early neonatal death – a baby who dies within the first 7 days of life
- Late neonatal death – a baby who dies within 8-28 days of life

From 2013 to 2020 there was a year-on-year reduction in the total number of neonatal deaths. However, 2021 saw an increase. There were 1,151 neonatal deaths in 2021, compared with 1,051 neonatal deaths in 2020 and 1,158 in 2019. In 2021 the neonatal mortality rate was 1.65 deaths per 1,000 live births³.

The most common causes of neonatal death were congenital anomalies, extreme prematurity, neurological causes, cardio-respiratory causes and infection, with 77% of all neonatal deaths having a primary cause of death within one of these five groups. There was an increase in the proportion of deaths and the neonatal mortality in all groups in 2021 compared to 2020³.

The neonatal mortality rate is lowest in mothers from the least deprived quintile of residence (1.29 per 1000 births) and highest in mothers in the most deprived quintile (2.15 per 1000 births)³. There is wide variation in neonatal mortality rates by ethnicity. Babies of white ethnicity have the lowest neonatal mortality rate of 1.68 per 1000 births, compared to 2.22 per 1000 in babies from Asian ethnicity and 2.94 per 1000 for babies of black ethnicity³.

Congenital anomalies accounted for a significant proportion of neonatal deaths, 32.6% in 2021. Extreme prematurity accounted for 14.2% of neonatal deaths in 2021 compared to 10.8% in 2020. 14.0% of neonatal deaths were due to neurological causes. Cardio-respiratory causes continue to make up around 9% of neonatal deaths. Infection was the primary cause of death in 7.7% of neonatal deaths³.

When a baby dies on the delivery unit or the postnatal ward, women and their families will be cared for by the obstetric and midwifery bereavement teams. When a neonatal death happens within newborn services, parents will be cared for by the neonatologists and neonatal bereavement teams. This guideline has been written by a multidisciplinary team of professionals working in maternity and neonatal units across the North West. This guideline is written to support an integrated care pathway to facilitate optimal care following a neonatal death at any gestation and in any situation where healthcare professionals may find it useful.

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5.2. Breaking Bad News

This is a very sensitive situation best managed by a senior clinician, supported by the nurse or midwife caring for the family. Clinicians should ideally have completed training in breaking bad news and sensitive communication. National Bereavement Care Pathway training modules are available at

<https://www.e-lfh.org.uk/programmes/national-bereavement-care-pathway/>.

Parents remember for a long time the way in which the news of their baby's death was given to them. Therefore, plenty of time must be allowed so that information is not given in a hurried fashion. If the woman is unaccompanied, an immediate offer should be made to call her partner, relatives, or friends. If English is not the first language of a family ideally a face-to-face interpreter should be used. A warning must be given to the interpreter as to the content of the conversation.

The Sands leaflet 'Sensitive and effective communication' gives some helpful advice: <https://www.sands.org.uk/sites/default/files/Sensitive%20and%20Effective%20Communication.pdf>. Discussions should be culturally sensitive and should aim to support maternal/parental choice. Consider contacting the on-call lay chaplain or appropriate religious leader for emotional support or/and religious care.

Parents should be offered written information to supplement discussions ([Appendix 1](#)). Naturally, parents want to know why their baby has died. This may not be known at this stage, but parents must be assured that it is not their fault and that investigations may be helpful.

Practice Points For Sharing Bad News

- The discussion should take place in a suitable environment, ensuring privacy.
- Offer refreshments to the family.
- Do not be afraid to show and say how sorry you are. Parents appreciate it if you show your emotions.
- Partners should be included in all discussions, unless the mother declines.
- Plenty of time must be allowed when breaking the news of the baby's death.
- Ensure you know the baby's name (and gender).
- Ensure you know the parents' names.

Parents who have experienced baby loss report that indifferent attitudes from doctors and midwives and insensitive remarks and actions are remembered for a long time after the loss of their baby. Conversely, just a few thoughtful, heartfelt, caring words and letting parents know how sorry you are can last a lifetime.

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5.3. Psychological Support Following Neonatal Death

The death of a baby can be associated with short term and chronic anxiety and depression not only in the mothers but also the co-parent, siblings and other family members such as grandparents. Feelings of grief and loss (bereavement reactions) are very common and expected. It is important to ensure that the family is well supported throughout the hospital stay and beyond, with as much continuity of care and carer as possible. Every woman who suffers a neonatal death is at risk of depression, but those with psychiatric illness or from a vulnerable social group are at particular risk. As soon as practically possible, involve your Trust's bereavement midwife, specialist nurse or counsellor to provide ongoing support.

Place of care

Whilst in hospital the parents should be cared for with respect and dignity, ideally in a single room or bereavement suite to ensure privacy during this difficult time. Ideally, these parents should be cared for in a different environment from mothers with healthy babies. Efforts should be made to provide continuity of care and carer. The partner/family should be able to remain with the mother as long as she wishes.

Bereavement Care

The bereavement specialist midwives or nurses should be informed of any neonatal deaths which occur within the maternity unit at the earliest opportunity. The role of the bereavement midwives/nurses should be discussed with the parents, who should be given the opportunity to meet with the team. The bereavement midwives or nurses may be able to support families following the diagnosis of poor prognosis and following the death of their baby and can provide support via telephone or email if this is preferred. This should be family led, as some families may find this difficult whereas others will want this support at the earliest opportunity. In all cases parents should be given appropriate contact details for the bereavement team.

Spiritual care

Health care professionals caring for grieving families should ask if there are any religious customs which are important to the family. Parents may want the opportunity to see their own religious leader or a member of Pastoral Care Chaplaincy Services. This should be facilitated by the maternity unit staff and offered to all families even if they do not have a specific faith.

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For more information on religious practices and customs see⁴

<https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2017/06/NWNODN-Religious-Practices-.pdf>

If caring for a Jewish family please see [Guidance on Neonatal Death for Jewish Parents](#), published by the Jewish Community in Manchester, together with Misaskim, Tommy's and Manchester University Foundation Trust in 2022⁵.

See page 31 for a list of [support organisations](#). Some Trusts hold an annual remembrance service which parents should be informed about and may wish to attend.

5.4. Multiple Pregnancies

Multiples make up approximately 3% of pregnancies in the UK with numbers rising significantly over the past 20 years due to the increasing use of assisted conception techniques such as IVF. Clinicians should be aware that the perinatal mortality rate is higher in multiple pregnancies than singleton pregnancies.

Clinicians should appreciate the complexity and mixed emotions of couples who experience the death of a baby from a multiple pregnancy. Parents will require support throughout the neonatal period as they face the difficult challenge of feeling anxious about the prognosis for surviving multiple whilst simultaneously dealing with the bereavement. Parents who have lost a twin born prematurely often remain in hospital for weeks or months while the surviving twin is cared for on the neonatal unit.

Parents may want to talk about the baby who has died and to acknowledge that they were twins, triplets or higher order multiples. Some parents may wish to take photographs of the babies together so this should be discussed and offered. It is important that staff are aware of the circumstances surrounding the baby's death and know the baby's name and gender.

The Butterfly Project supports families when a baby dies from a multiple pregnancy. Their guideline for professionals '[Bereavement from a multiple pregnancy](#)' was published in May 2016. The Neonatal Research Network⁶ www.neonatalresearch.net/butterfly-project have developed two concepts:

1. A small sticker of a butterfly that can be placed on the medical notes of the surviving twin to highlight the loss to professionals caring for the surviving baby and the family.

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2. A butterfly symbol that is placed inside of, or next to the incubator or cot of any surviving babies. Parents often like to write the name of the baby who died on the card. Remember to individualise care – some parents may not wish for this.

Parents may also wish to access the Twins Trust resources⁷

<https://twinstrust.org/bereavement.html>

5.5. Management of a Baby Born with Signs of Life Where Active Survival-Focused Care is not Appropriate

The baby should be treated with dignity, respect and love and comfort care should be provided. Wrap the baby to keep the baby warm and provide the option of family holding the baby. If the family do not wish to see or hold the baby place the baby in an appropriate size Moses basket in an alternative and private environment. A healthcare professional should remain with the baby and the time of death should be clearly documented.

5.6. Signs of Life and Confirmation of Death

National clinical guidance was released in November 2020 from MBRRACE-UK⁸ for the determination of signs of life following spontaneous birth **before 24+0 weeks of gestation where, following discussion with parents, active survival-focussed care is not appropriate**. A short training video which explains the new guidance very clearly is available at [Home | Signs of life | MBRRACE-UK](#).

Before 24+0 weeks, the midwife/nurse or other attending health care professional may observe for visible signs of life in the first minute whilst holding or wrapping the baby and handing them to the parents (if the parents wish to hold the baby). Subsequent observation for signs of life should be discreet and respectful. Assessment should be based on persistent, readily evident, visible signs. Listening for a heartbeat with a stethoscope or palpation of the umbilical cord within the first minute is not necessary.

Evident signs of life after birth would include one or more of the following:

- **easily visible heartbeat seen through the chest wall**
- **visible pulsation of the cord after it has been clamped**
- **breathing, crying or sustained gasps**
- **definite movement of the arms and legs.**

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Since fleeting reflex activity including transient gasps, brief visible pulsation of the chest wall or brief twitches or involuntary muscle movement can be observed in babies that have died shortly before birth MBRRACE-UK recommends that such fleeting reflex activity observed only in the first minute after birth does not warrant classification as signs of life².

Babies born with signs of life should be seen by a doctor at the earliest opportunity, so that in the event of a live birth and subsequent death, a neonatal death certificate may be issued to the mother. In England and Wales, a medical certificate of cause of death may only be signed by a registered medical practitioner and cannot be signed by a midwife or other attending health care professional.

Once the midwife or parents feel there are no longer any signs of life, it is the responsibility of a registered doctor to confirm and to certify the death of the baby. Therefore, it is best practice for midwives to request the presence of an obstetric/neonatal ST3 or above (as appropriate).

Confirmation of Death

Doctors should assess the baby as per the Academy of Medical Royal Colleges Code of Practice for the Diagnosis and Confirmation of Death, 2010⁹. The doctor must document in the maternal records and baby's records when they have confirmed the baby's death. The time of death is documented as the time the doctor verified the death by following the steps below.

Religious, cultural and spiritual needs as well as any Advance Care Plans in place must be taken into consideration.

Recommended equipment:

- Pen torch
 - Stethoscope
 - Watch with second hand
 - Appropriate PPE
1. Once cardiorespiratory function has ceased and there are no signs of life, the patient should be observed by the person verifying death for a minimum of five minutes.
 2. Check the absence of carotid, femoral and radial/brachial pulses for at least one minute.

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3. Check the absence of respiratory movements and sounds and the absence of heart sounds using a stethoscope to listen to both sides of the chest, for a total of one minute.
4. Check the patient's pupil reaction with a pen torch. Pupils should be fixed, dilated and unresponsive to light. Both eyes should be checked.
5. Using a finger and thumb, perform a trapezius squeeze. No motor response should be observed.
6. If there is any uncertainty, this process should be repeated after a minimum of 5 minutes.
7. Confirm the death to persons important to the patient and offer appropriate support.
8. Document verification of death using appropriately in the patient's record. The time of verification is recorded as the actual time of death.

Important Notes

It may not be possible to complete every step at very early gestations.

If a parenteral infusion is in place, syringe pump/IV pump must be stopped at the time of death and drugs infused and drugs yet to be infused accurately recorded.

In cases where the death is being reported to HM Coroner:

- Leave infusion lines in place (capped and taped gently to the deceased)
- Leave endotracheal (ET) tubes in place
- Remove medication syringe/s and syringe pump/IV pump
- Leave catheters and drains in situ, spigot the tubes and apply new drainage bags after recording volumes at the time of death
- **If you wish to remove any infusion lines, drains, tubes etc in the case of a child death, you must seek express approval from HM Coroner prior to doing so.**

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5.7. Referral to the Coroner or Medical Examiner

Clinicians are asked to refer to the Chief Coroner's Guidance No. 45 Stillbirth and Live Birth Following Termination of Pregnancy (February 2023)¹⁰. Guidance no. 45 applies to England and Wales and is written with a view to achieving consistency in Coronial practice. It is intended to "help coroners understand and apply the current law relating to stillbirth, and live birth following termination of pregnancy, to promote consistency in the scrutiny of unnatural neonatal deaths".

<https://www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/>

Please also refer to the RCOG position statement on Guidance no. 45, published as a resource for all healthcare practitioners (HCPs) involved in abortion care, to inform standards of clinical practice, mitigate potential variations in care, and to ensure that no unnecessary barriers are introduced for those accessing abortion care¹¹.

<https://www.rcog.org.uk/media/ny1pc5ml/position-statement-coroners-guidance-no-45.pdf>

Coroner

When a death is reportable to the coroner this must be done as a priority. A medical doctor should not write or issue the MCCD until the coroner has given their instruction to do so.

Where a doctor has not witnessed the baby showing signs of life but signs of life have been observed by either the midwife /nurse and/or the parents, a doctor must notify the coroner before a neonatal death certificate can be issued. **The coroner must be notified of all babies born with signs of life following a termination of pregnancy.** The coroner must be notified of all neonatal deaths where the cause of death is unknown.

Full list of deaths which should be reported to the coroner¹²:

In all cases of termination of pregnancy

- Uncertified deaths
- Death where there are parental concerns
- Neonatal or obstetric team feel unable to determine a cause of death.
- Two consultants are unable to agree what to put on the MCCD.
- One consultant believes that referral is required (in which case the reason for referral should be documented on the Coroner referral form)

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- Death following and possibly related to medical or surgical intervention, e.g. cardiac tamponade following central line insertion, or collapse following an operation where no other cause of death is determined
- Death linked to clinical incidents or error
- Death where the original diagnosis of a disease or condition was delayed or erroneous
- Hypoxic Ischaemic Encephalopathy
- Hospital-acquired infection

Please also check local coroner reporting criteria. An example of a Coroners Referral form can be found in [Appendix 2](#). The coroner will advise on an individual case basis whether a coronial review of the death is required.

Only once the coroner has given instruction that they no longer need to investigate the death will they send instruction to issue a Medical Certificate of Cause of Death (MCCD). This form will also be sent to the registrar's office informing the registrar that they are aware of the death, but no further investigation is necessary, and permission has been given to the doctor to issue the MCCD. The doctor completing the MCCD needs to make sure the cause of death on the MCCD matches the Part A certificate. **MCCD APC 2 should be completed for neonatal deaths in the first 28 days of life, whereas APC 1 should be completed for neonatal deaths after 28 days of life.** Once the MCCD has been completed it can be issued to the family and registration of the death can take place.

Coroner's Inquest

If an inquest is requested by a coroner, they may ask for a post-mortem examination. Cases can be required to go to the Coroner's court and parents should be supported through this. In these instances, the coroner will release the relevant paperwork for registration and the funeral. The parents cannot register the death until further clarification from the coroner has been given. They can, however, register the birth.

Medical Examiner

On 9th September 2024 the Death Certification Reforms came into effect and it is now a statutory requirement for all deaths in any health setting in England and Wales **which are not investigated by a coroner** to have independent scrutiny by an NHS medical examiner. It is the responsibility of the doctor who would be completing the Medical Certificate of Cause of Death to complete the referral to the Medical Examiner. A doctor who has seen the baby at any time in life can complete the MCCD and must send this to the Medical Examiner who can countersign it^{13, 14, 15}.

Please check your local medical examiner referral process.

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Medical examiners are able to highlight issues, refer to clinical governance and may be able to add to the PMRT questions raised by families. They are also able to advise on whether a case will need referral to the coroner or not.

The role of the medical examiner is:

1. to provide a proportionate independent review of care in the last illness
2. help the qualified attending physician (QAP) decide on the cause of death and complete a medical certificate of cause of death (MCCD)
3. to speak to the family and discuss the cause of death and any questions they may have, and give them an opportunity to raise any concerns or issues regarding care.

The Medical Examiner will review the referral form and proposed cause(s) of death, then perform rapid appropriate scrutiny of medical records and contact the referring doctor to discuss the case. If no concerns are raised, the attending medical team will be asked to complete the Medical Certificate of Cause of Death (MCCD) in the usual way. **MCCD APC 2 should be completed for neonatal deaths in the first 28 days of life, whereas APC 1 should be completed for neonatal deaths after 28 days of life.** Any issues or suggested actions that are raised during this process will be discussed with the attending medical team. The designated Bereavement Midwife/Nurse or member of the bereavement team will give the parents of the deceased child the opportunity to discuss concerns about care with the Medical Examiner if they wish. The role of the Medical Examiner is not to investigate cases or replace the child death review processes that already exist but to provide an early opportunity to highlight potential issues or concerns of bereaved families.

5.8. Registration and Certification

An incident report should be completed on the Trust's incident reporting system for neonatal deaths at all gestations.

When a baby is born with signs of life and subsequently dies, by law, two registrations are required, regardless of gestation; a live birth and subsequent neonatal death. **In this situation there is a legal requirement for a burial or cremation** (please see Section 13 Further Management of Baby Including Transfer and Funeral Arrangements).

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Registration of live birth and neonatal death:

- The live birth is required to be registered within 6 weeks (42 days).
- If not married, both parents must attend the registration if they wish both of their details to be on the birth certificate.
- If the parents are not married and the mother does not wish the father's details to be on the certificate she may choose to attend alone.
- Further guidance about who can register a birth can be found at [Register a birth: Who can register a birth - GOV.UK \(www.gov.uk\)](https://www.gov.uk/register-a-birth)
- If this was a multiple pregnancy, all births need to be registered before the death(s) can be.
- Once the MCCD has been completed the registration of the death should be done within 5 days of the death.
- Parents are requested to bring their passports or valid identification.
- If the parents are registering the death, they may be able to do the birth registration at the same appointment following discussion with the registrars.
- There may be extenuating circumstances in which a health professional registers the birth and death on behalf of parents. This is known as registering as the informant and can be arranged via local registry office if required.

5.9. MBRRACE Notification, PMRT and CDOP

MBRRACE-UK is a national collaborative programme of work involving the surveillance and investigation of maternal deaths, stillbirths and infant deaths. Neonatal deaths eligible for notification at: <https://www.mbrpace.ox.ac.uk>² include:

- **Early neonatal deaths** – death of a live born baby (born at 20 weeks gestation of pregnancy or later or 400g or more where an accurate estimate of gestation is not available) occurring before 7 completed days after birth.
- **Late neonatal deaths** - death of a live born baby (born at 20 weeks gestation or later or 400g or more where an accurate estimate of gestation is not available) occurring between 7 and 28 completed days after birth.
- **Terminations of pregnancy** - from 20⁺⁰ weeks which resulted in a live birth ending in neonatal death.

Individual maternity units may choose to report neonatal deaths over 28 days but this is not mandatory. These deaths are not counted in the perinatal mortality figures for the MBRRACE-UK report. Each maternity unit will have a designated person

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responsible for reporting relevant deaths to MBRRACE-UK, for example the bereavement midwife or pregnancy loss co-ordinator. MBRRACE-UK notifications should be completed within 2 working days².

Perinatal Mortality Review Tool (PMRT)

The majority of neonatal deaths will fulfil the criteria of the Perinatal Mortality Review Tool (PMRT)^{16,17} <https://www.npeu.ox.ac.uk/pmrt>. Those deaths which meet the criteria will have a multidisciplinary review. Parents should be told about this perinatal review process, given a letter of explanation, and be invited to be part of the process. Parental questions should be invited and if there are none initially, parents should be asked a second time. Both dates should be recorded in the maternal records. Parents will be supported throughout the process by the bereavement midwives. Trust governance and Duty of Candour processes should be followed.

Criteria for PMRT:

- All neonatal deaths from 22+0 gestation to 28 days after birth
- Babies who die after 28 days following care on the neonatal unit
- Excludes termination of pregnancy
- Excludes babies with a birth weight <500g where the gestation is unknown

PMRT reviews for neonatal deaths must involve all care providers, so if antenatal care was provided in a different unit than the one where the death occurred these providers should be notified and conduct their own review.

Child Death Overview Panel (CDOP)

It is a statutory requirement to notify the Child Death Overview Panel (CDOP) of all child deaths 0-17 years of age within 24 hours (or the next working day) of the death¹⁸.

It should be noted that this requirement specifically excludes “planned terminations of pregnancy carried out within the law”. This is the case, regardless of the gestation of the fetus¹⁰.

At present, the clinician (obstetrician, neonatologist or bereavement midwife) is expected to complete the online **notification** of a child death form with as much information as possible. All child death notifications must be reported electronically via <https://www.ecdop.co.uk/GMCDOPS/live/public>. Once the notification is successfully submitted, a downloadable PDF is made available – this should be filed in the baby’s hospital notes. The system then alerts the local CDOP coordinator that a child death has been reported to the CDOP.

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From 8th January 2025, MBRRACE will be integrated with CDOP such that completing the MBRRACE notification will automatically notify the relevant CDOP and pull across relevant information from the MBRRACE notification.

Following on from the notification and depending on the child's underlying health conditions and circumstances leading to their death, the lead clinician will be asked to complete further details on the CDOP **reporting form**. The clinician will require an eCDOP account to do so. The local CDOP coordinator is responsible for creating eCDOP user accounts. Once a new user is created, they will receive an email and the user will need to confirm their account details and login with the temporary password received. The user will receive a request to complete a reporting form. The user will need to follow the link from the email as this is specific to the child's record. The user will then be asked to complete as much information as possible including the supplementary questions relating to the child's health conditions and cause of death.

The user can also upload additional documentation such as discharge summaries, death certificates, internal reports and any other relevant documentation. Once all the information has been entered, the user will need to save the form as final which will prompt a confirmation pop-up to appear. The user can then download a PDF version of the reporting form which should be filed in the baby's notes.

Please note that neonatal deaths which do not fit the MBRRACE reporting criteria still require the CDOP notification to be completed separately.

5.10. Care of Baby

The individual cultural and spiritual needs of each family should be identified and accommodated. Assistance should be given to facilitate the grieving process including empathic care, appropriate literature and contact telephone numbers.

Contact with baby

Parents should be given the opportunity to see, hold and spend special time with their baby whatever the gestation. Seeing and spending time with their baby is valuable if supported and family led. Some parents may wish to see and hold their baby immediately after birth, others may prefer to wait and some will decline; their decision should be respected. At earlier gestations parents should be prepared for their baby's appearance. Parents are free to change their minds and can ask for their baby to be brought to them whenever they feel ready. Parents may wish other family members to be given opportunity to see or hold the baby.

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Parents should be offered the use of a cooling cot or cuddle cot if available/appropriate to maintain the baby's skin condition. The use of the cooling cot can improve the quality of bereavement care as it allows parents to spend more time with their baby and enhances their lasting memories. <https://cuddlecot.com/cuddlecot/>

Deterioration of the baby's body following birth is likely to be increased the longer the baby is outside the fridge and not kept cool. It is difficult to predict the length of time any one family will want to spend with their baby. Therefore, it is important to ensure that parents understand that this is likely to affect the quality of the post mortem examination and investigations.

Staff should also make parents aware that the sex of the baby may not be easily identified at earlier gestations. Hence, in cases of uncertainty, the fetal sex should not be assigned. The parents may decide to choose a neutral name for baby.

Mementos

Mementos may include hand and foot prints or casts (though these may not be possible at earlier gestations), cord clamp, identity band in addition to items such as a phototherapy eye shield, oxygen saturation posey wrap or chest leads. Most parents welcome these mementos and they can be presented in memory boxes.

Many charities offer memory boxes to record and store mementos obtained (for example [4Louis](#), [Sands](#)). Faith specific memory boxes are also available. If parents are not ready to take mementos and/or photographs home, these can be sealed in an envelope so that they can look at them in their own time or can be stored in hospital records if the hospital has the facility to do this.

Photographs of baby

Photographs of the baby are valuable and can be taken with the parents' own camera, with the hospital digital camera, or by medical photography. If there is a multiple birth, offer to take photographs of the babies together and/or separately. Suggest different photos including family groups, photos of hands and feet and with baby dressed and undressed.

Taking photographs with the hospital digital camera requires parental verbal or written consent. Identification of the start and end of a series of photographs must be performed unless the Trust issues each family with an individual memory card.

An additional option is <http://www.remembermybaby.org.uk>, a charity that has volunteer professional photographers who photograph babies for parents.

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The medical illustration department can provide a photography service for bereaved families but should be informed that the baby has died. Verbal or written consent is required for this.

Please see Section 5.13, page 27, for further management of baby including transfer to the mortuary and funeral arrangements.

5.11. Postnatal Care of Mother

Clinical Care

Maternal care should be as per local obstetric guidelines with multidisciplinary input as required. A VTE risk assessment should be performed and low molecular weight heparin prescribed if required, taking into account the full clinical picture and any contraindications.

Psychological support

All parents and siblings should be offered bereavement support and counselling. As soon as practically possible, involve your unit's bereavement midwife, bereavement nurse or counsellor to provide ongoing support. They will also be able to offer continuity and psychological support in subsequent pregnancies. Information of [support organisations and groups](#) should be offered. If the woman has ongoing psychological concerns or a known psychiatric disease the General Practitioner and Health Visitor should be made aware of this.

Lactation

Suppression of lactation should be discussed if 18+0 weeks or over and cabergoline 1 milligram may be administered orally, unless there is severe maternal hypertension/pre-eclampsia or puerperal psychosis. Rarer contraindications include allergy to ergot alkaloids, pulmonary / pericardial / retroperitoneal fibrosis, cardiac valvopathy.

Some mothers choose to continue to express milk following the loss of their baby. While this option does not suit everyone, some families find comfort in continuing to express and donate. Healthcare professionals should discuss the option of milk donation with bereaved families to help make a decision that feels right for them.

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Further information can be found at

<https://www.milkbankatchester.org.uk/donationafterloss>, the North West human milk bank¹⁹. A free, two-hour Future Learn course is available to NHS staff. Lactation and Loss; Choices for Bereaved parents [Learninghub.nhs.uk/Lactation After Loss: Choices for Bereaved Parents](https://learninghub.nhs.uk/Lactation%20After%20Loss/Choices%20for%20Bereaved%20Parents).

Parents should be informed that there is a strict screening process. Sometimes the bank may be unable to accept milk if the mother has taken certain medications. Some medication may be safe when breastfeeding however may not be acceptable for donation purposes. Parents should also be informed that the milk bank is unable to accept milk if anyone in their household smokes. If a bereaved mother expresses a wish to donate, the first step is to contact the milk bank. They will talk the family through the donor recruitment process and answer any questions. Alternatively, parents can fill in the online screening form (link above).

Contraception

Contraception should be discussed and where possible be provided as per local policy before discharge home.

Further Resources

The North West Neonatal Palliative Care website is an excellent resource, with the relevant documents for management of neonatal death²⁰ [Support for Clinicians – North West Neonatal Operational Delivery Network](#)

5.12. Investigations Following Neonatal Death

If the cause of death is clear then further investigations may not be required.

Before offering any investigations, a history should be taken to appreciate the clinical presentation to guide investigations. Under-investigation impedes efforts at gaining an accurate diagnosis however unfocused investigation could yield results which were not contributory to the death, thus clinicians should consider the clinico-pathological correlation between abnormal investigation results and the clinical presentation.

Causes of neonatal death include fetal structural abnormalities, chromosomal abnormalities, fetal anaemia, hypoxic ischaemic encephalopathy, placental pathology and prematurity. Preterm birth may be iatrogenic due to pre-eclampsia or growth restriction or may be spontaneous due to infection, maternal uterine abnormalities and cervical insufficiency or incompetence.

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Initial Investigations to Consider:

1. Blood group / Kleihauer / anti-D

- a) FBC/G&S/antibody screen
- b) Kleihauer in all RhD negative women and if clinical suspicion in Rh D positive women to identify and quantify fetomaternal haemorrhage. This should be taken as early as possible, especially if trauma to the abdomen, antepartum haemorrhage, pale baby, known vasa praevia. As a Kleihauer is not routinely performed for Rhesus positive women, the clinical reason should be clearly documented on the request form and discussed with laboratory staff to minimise the chance of sample rejection in a Rhesus positive mother.
- c) If the mother is Rh negative give appropriate dose of anti-D within 72hrs of birth if fetal genotype Rh positive or if unknown.

2. Maternal infection screen

If the mother has fever, flu-like symptoms, abnormal liquor (purulent or offensive), prolonged rupture of membranes:

- FBC, CRP, lactate
- Maternal blood cultures
- MSSU
- HVS
- Endocervical swabs
- Coronavirus swab
- Influenza swab

3. Fetal infection screen

- Swab from the baby's axilla
- Swab from the maternal surface of the placenta

4. External examination of the baby

External examination of the baby should be offered and detailed external assessment should be possible from 16 weeks.

See page 10 of the ICP.

5. Placental pathology (Appendix 4)

Placental histology should not be requested following termination of pregnancy.

Placental histology may be performed in cases which fulfil the referral criteria in the guidance published from the Royal College of Pathologists in 2022²¹

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<https://www.rcpath.org/static/ec614dfa-007c-4a93-8173cb202a071a72/a8b51280-edf3-4414-9197ab58d641bafd/G108-Tissue-pathway-for-histopathological-examination-of-the-placenta.pdf>

Referral criteria for placental histopathology which may be relevant to an early neonatal death include:

- severe fetal distress defined as: pH <7.05 or Base Excess \geq -12 or scalp lactate >4.8mmol/l
- preterm birth (less than 32+0 weeks' gestation)
- fetal growth restriction defined as: birthweight below 3rd centile or drop in fetal growth velocity of >2 quartiles or >50 percentiles
- abnormal umbilical artery Dopplers (absent or reversed end diastolic flow)
- fetal hydrops
- early-onset (<32 weeks) severe pre-eclampsia requiring iatrogenic delivery
- caesarean peripartum hysterectomy for morbidly adherent placenta
- severe maternal sepsis requiring adult intensive care admission and/or fetal sepsis requiring ventilation or level 3 NICU admission (following swab taken from the placenta for microbiology at delivery)
- massive placental abruption with retroplacental clot
- monochorionic twins with TTTS

Swabs and cord samples (if required) should be taken **prior to** placing the placenta in formalin (in accordance with local policy) with the excess drained off prior to transport. If the placental histopathology referral criteria are fulfilled, the appropriate placental pathology request form should be completed and sent with the placenta as per local policy ([Appendix 4](#)).

In Greater Manchester, Lancashire and South Cumbria histopathological examination of the placenta is carried out by the perinatal histopathology service at Royal Manchester Children's Hospital (RMCH). For Cheshire and Merseyside, placental histology is carried out at Alder Hey Children's Hospital.

The placenta may show an unexpected positive finding that may have implications especially in cases such as recurrent pregnancy loss as part of an undiagnosed autoimmune spectrum. Chronic histiocytic intervillitis (CHI) is a rare, inflammatory condition of the intervillous spaces, characterised by extensive maternal infiltration of inflammatory cells and fibrin deposition^{22,23,24}. It is associated with pregnancy loss in all trimesters and fetal growth restriction and has a very high recurrence rate of 75-90%. It is a histological diagnosis, characterised by CD68 immunostaining. See section on [Follow Up Visit](#) for the details of the recommended medication regime in a subsequent pregnancy.

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6. Post mortem examination (Appendix 5)

Where there is no Coronial involvement and a MCCD can be offered a post mortem examination can be offered to women who experience a neonatal death (hospital post mortem – see local guidance).

When a death has been reported to the Coroner, the Coroner may request a post-mortem to ascertain cause of death. Please note that legally, the Coroner's request for a post-mortem examination to be performed overrides parental choice. If the Coroner makes the decision not to perform a post-mortem examination as part of their investigation, parents can request a hospital post-mortem. Gestation should not determine whether a post-mortem is offered, though parents and clinicians should understand that the information gained at early gestations might not be as helpful. This requires informed written consent from an appropriately trained individual. The parents should be provided with a post-mortem patient information leaflet, for example²⁵

<https://www.sands.org.uk/sites/default/files/Deciding%20about%20a%20post%20mortem%20LINKED.pdf>

To request a neonatal post mortem at RMCH the following should be sent:

- Completed perinatal hospital PM referral form (gives maternal details, history)
See [Appendix 5 for consent forms and help sheet.](#)
- Copy of neonatal discharge/death summary for neonate details
- MCCD as provided by clinician
- Reason for consented PM as discussed with family
- Completed consent form for hospital PM

Other Selective Investigations (only perform if there is a clinical indication):

1. Maternal blood

- HbA1C
- Viral screen (toxoplasmosis, rubella, cytomegalovirus, syphilis and herpes)
- Parvovirus B19 (especially if baby has hydrops)

2. If fetal anomaly diagnosed or chromosomal abnormality suspected

Offer fetal chromosome analysis (with the exception of an isolated neural tube defect). If parents accept, they should sign the relevant box on page 6 in the ICP. Place 2-3cm of umbilical cord in a leak-proof, dry, sterile, plastic container, or sterile saline if stored overnight (not formalin).

Do not send cord samples routinely or if prenatal testing by chorionic villus sampling (CVS) or amniocentesis has been performed and a result obtained.

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Do not send purely for fetal sexing. See [Appendix 6](#) for full referral criteria. If in doubt contact the cytogenetics service. For Greater Manchester, St Mary's Hospital, 0161 276 6553. For Cheshire and Merseyside, Liverpool Women's Hospital 0151 702 4229.

Genetic examination of the baby should be offered (with the exception of isolated neural tube defects such as spina bifida or anencephaly or other abnormalities which are unlikely to have a genetic cause). This should be discussed with clinical genetics. For Greater Manchester this is St Mary's Hospital 0161 276 6506. For Cheshire and Merseyside, this is Liverpool Women's Hospital 0151 702 4228/4229. The post mortem consent form should be used to obtain consent for this examination. The baby should be transferred dry to the mortuary who will arrange transfer to the appropriate hospital by the trust contracted funeral directors.

Please note parental chromosomes should be obtained **only if**:

- Fetal chromosomal analysis shows an unbalanced translocation
- Fetal chromosome analysis fails with a fetal abnormality on ultrasound or post mortem
- If suggested by the genetics team on the fetal chromosome report

5.13. Further Management of Baby Including Transfer and Funeral Arrangements

Funeral arrangements

There is a legal requirement for a cremation or burial where a baby is born with signs of life and subsequently dies. Please refer to local policy and national guidelines regarding registration of neonatal deaths.

Discuss the available options with the family. If the parents would like the hospital to help them with the funeral arrangements, refer to local hospital policy. Document what arrangements are likely to be carried out. Parents are entitled to the Child Funeral Fund for England and should be informed of this²⁶. The burial or cremation must take place in England. It is not means-tested. <https://www.gov.uk/child-funeral-costs>. The Children's Funeral Fund for England can help pay for:

- burial fees
- cremation fees, including the cost of a doctor's certificate
- coffin, shroud or casket (up to a cost of £300)

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Taking baby home

Occasionally the family may wish to take their baby home. The parents' wishes should be supported. Parents should be warned that the condition of their baby may deteriorate rapidly. This is especially important if they wish to have a post mortem. **If a coroner's referral has been made or a coroner's post mortem ordered, the request to take the baby home needs to be discussed with the coroner. Inform the parents that the baby cannot be released from the hospital until the coroner's release form is received.** The baby must be taken home in an appropriate casket or Moses basket. The transport home must be appropriate i.e. private not public transport. The mortuary must be informed if the parents are taking their baby home. **Local policy should be followed and relevant paperwork completed.**

Some hospices offer the use of a cold room facility. This allows the family to stay with the baby and say goodbye in a supportive environment. This is a place where babies can lay at rest after their death until the day of their funeral. See page 12 [Hospice Information \(neonatalnetwork.co.uk\)](http://neonatalnetwork.co.uk).

Transfer of baby to the mortuary

Inform the parents where the baby will be taken once they go home.

Allow parents the time they wish to spend with their baby before transferring the baby to the mortuary. Parents should be asked if they want to take their baby to the mortuary and should be supported to do so.

Prior to transfer, ensure the baby has been appropriately identified and that all relevant funeral paperwork has been completed. Ensure two name bands are completed stating "baby of (mother's name), mother's hospital number, date and time of giving birth as well as the hospital the baby was born at". Attach one name band to the baby.

If the parents have given their baby personal items (teddy etc.) they should remain with the baby, they can be labelled using identification bands. Prior to transfer to the mortuary some Trusts wrap the baby in a sheet or place in infant body bag, ensuring that all body parts including the face are covered.

Arrange transfer and if parents wish to accompany their baby, notify the anatomical pathology technician (APT) first. A member of maternity staff must accompany the family. The baby should be transported in a Moses basket or pram.

If a baby is transferred to the mortuary and there is no further contact from the family, the Trust should make every effort to contact the family. If this is not possible, please follow the Trust's local abandonment policy.

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After discharge

After the parents have returned to their home environment, they should be supported to return to hospital to see their baby if they wish. Follow local policy to advise the parents who they should contact to make arrangements (e.g. bereavement office, bereavement midwife, mortuary).

When such a request is received:

1. Obtain the parents' contact number
2. Check whether the baby is still on hospital premises, especially if transferred out for post-mortem.
3. Viewings are arranged on an individual basis.
4. Give the parents the name of the person who will meet / accompany them.
5. Check that the baby is lying peacefully; (clothes and hat for the baby if the parents wish at later gestations).

5.14. Other Postnatal Considerations

All outstanding appointments with midwifery, ultrasound or medical staff should be cancelled to avoid potential upset. A letter should be sent to the mother's GP to explain that she has had a pregnancy loss. A letter should also be sent to the co-parent's GP and other relevant professionals involved in the family's care if they consent (this could be school, social worker etc).

If the woman booked at another Trust, please inform their bereavement midwife of the neonatal death.

Antenatal screening results

There should be a robust method of communication with the screening midwife. First and second trimester screening results should still be communicated to the mother in the event of a neonatal death. This must be done sensitively, for example by letter expressing condolences.

Follow up

Follow up for parents who have had a neonatal death is a key element of care, with an opportunity to assess maternal recovery from the event, both physical and psychologically, as well as to convey information about investigations performed. It is

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also a chance to put in place a management plan for future pregnancies if that may be considered. In some circumstances it may be useful for a joint appointment with the neonatal team.

Discuss with the mother, when and where the postnatal follow up should take place. An appointment with the appropriate consultant obstetrician and / or neonatologist should be offered, maintaining continuity where possible. Explain to the parents that it may take 12 weeks or more to receive investigation results including the post mortem report and PMRT report, if applicable. If the parents have given the baby a name, healthcare professionals should use the baby's name in all discussions with the family thereafter.

Preparation is essential for any such consultation, for parents who have been through the experience of having a neonatal death should not have the additional trauma of an unprepared consultation. It is recommended that parents see a consultant obstetrician and are supported where appropriate by a bereavement midwife. In some cases of neonatal death, it may be necessary for the consultant neonatologist and or consultant geneticist to be present at this meeting.

At postnatal follow up appointments, clinicians should enquire about the psychological well-being of both parents and offer additional help if appropriate. Particular care should be taken with women with a history of a psychiatric disorder and other vulnerable groups of women. A high standard of communication across all health professionals such as psychiatrist, GPs and Health Visitors is required. If the parents do not wish to return to see the consultant, it is good practice to send a letter to the family and the mother's GP.

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5.15. Follow Up Visit

Prior to Consultation – Preparation is Key

1. Ensure all results are available
2. Notes of any case review are available
3. The PMRT report is available to share with the parents (if applicable)

At Consultation

1. Results of investigations
2. Consider whether further investigations are required:
 - a. antiphospholipid antibody screen if severe maternal vascular malperfusion on placental histopathology²⁷
 - b. maternal anti-Ro/SSA and anti-La/SSB antibodies if hydrops fetalis and post mortem shows endomyocardial fibroelastosis/AV node calcification
 - c. maternal alloimmune anti-platelet antibodies (blood samples are required from mother and father) if fetal intracranial haemorrhage is demonstrated on post mortem examination
3. Cause of neonatal death, if known
4. Pre-pregnancy plan for next pregnancy
 - a. Smoking status
 - b. Alcohol intake and substance use
 - c. Folic acid advice
 - d. BMI optimisation
 - e. Any psychological issues
 - f. Other medical issues
 - i. Medications
 - ii. Pre-pregnancy medical conditions
5. Pregnancy plan for next pregnancy
 - a. Who to contact when pregnant
 - b. Book under Consultant Obstetrician
 - c. Consider whether aspirin or LMWH are indicated
 - d. Consider referral to specialist clinic such as Fetal Medicine Unit, Rainbow clinic, Preterm Labour clinic depending on the underlying obstetric history and cause of death.

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- e. If Chronic Histiocytic intervillitis (CHI) discuss with Rainbow Clinic for commencement of aspirin 150mg at night, low molecular weight heparin, prednisolone 20mg daily and hydroxychloroquine 200mg twice daily at 7 weeks gestation following an early viability scan, followed by close ultrasound surveillance. Prednisolone is weaned down by 5mg/week from 17/40 if the uterine artery Dopplers are normal.
 - f. Offer continuity of care
 - g. Offer extra ultrasound scans for reassurance
 - h. Discuss an individual plan for the birth
6. Consider extra precautions for postnatal depression
 7. Write a letter to the parents as well as communicating with their GP

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5.16. Support Organisations and Groups

National

ARC Antenatal Results & Choices

Support for parents whose baby is diagnosed with a fetal abnormality in pregnancy.

Helpline: 0207 713 7356 (available Tuesday & Thursday evenings 8pm to 10pm).

Website: www.arc-uk.org/

Bliss for babies born sick or premature

Family support helpline offering guidance and support for premature and sick babies.

Website: www.bliss.org.uk/

Child Bereavement UK

Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Helpline: 0800 028 8840

Website: www.childbereavementuk.org

Child Death Helpline

For all those affected by the death of a child.

Helpline: 0800 282 986 or 0808 800 6019

Website: <http://childdeathhelpline.org.uk/>

Cruse Bereavement Care

For adults and children who are grieving.

Helpline: 0808 808 1677

Website: <https://www.cruse.org.uk/get-help>

Daddies with Angels

Advice and support to male family members following the loss of a child/children.

Website: <https://www.daddyswithangels.org/>

Finding Rainbows

Support for parents who have experienced child loss

Helpline: 07340 799387

Email: finding.rainbows@outlook.com

Website: <https://www.findingrainbows.org/>

Jewish Bereavement Counselling Service

Supporting Jewish individuals through loss and bereavement

Helpline: 020 8951 3881

Email: enquiries@jbcs.org.uk

Website: www.jbcs.org.uk

Lullaby Trust

Bereavement support to anyone affected by the sudden and unexpected death of a baby.

Helpline: 0808 802 6868

Website: <http://www.lullabytrust.org.uk>

Petals Baby Loss Counselling Charity

Free counselling service to support women, men and couples through the devastation of baby loss.

Helpline: 0300 688 0068

Website: www.petalscharity.org

Sands Stillbirth & Neonatal Death Charity

Support for families affected by the death of a baby before, during or shortly after birth.

Helpline: 0808 164 332

Website: <http://www.uk-sands.org>

Twins Trust

Bereavement and special needs support groups

Email: enquiries@twinstrust.org

Website: www.twinstrust.org/bereavement

The Compassionate Friends UK

Offering support to bereaved parents and their families

Helpline: 0845 123 2304

Email: info@tcf.org.uk

Website: www.tcf.org.uk

Tommy's

Information and support for parents on coping with baby loss. Bereavement-trained midwives available Monday to Friday, 9am to 5pm

Helpline: 0800 0147 800

Website: <https://www.tommys.org/>

Winston's Wish

Support for bereaved children, families and professionals.

Helpline: 08088 020021

Website: <https://www.winstonswish.org/>

Regional

Children of Jannah

Support for bereaved Muslim families in the UK, based in Manchester.

Helpline: 0161 480 5156

Email: info@childrenofjannah.com

Website: www.childrenofjannah.com

Lighthouse Therapy Service

Post Infant Loss Support Service covering Merseyside

Website: <https://www.lighthousetherapyseices.co.uk/>

Listening Ear

Free self-referral counselling to help deal with anxiety, bereavement and depression.

Helpline: 0151 488 6648

Email: enquiries@listening-ear.co.uk

Website: <http://listening-ear.co.uk/>

North West Forget Me Not's & Rainbows

Support any member of the family who has been affected by the loss of a baby, during pregnancy, at birth or afterwards.

Facebook: [nwforgetmenotsandrains](https://www.facebook.com/nwforgetmenotsandrains)

Once Upon A Smile

Children's bereavement support

Phone: 0161 711 0339

Website: www.onceuponasmile.org.uk

Dad Matters

Supporting Dads to have the best possible relationships with their families.

Website: <https://dadmatters.org.uk/index.html>

Liverpool Bereavement Services

Provide 1:1 counselling for people who are struggling to cope with a loss.

Website: <https://liverpoolbereavement.com/>

Love Jasmine

Supports for families directly affected by the loss of a child providing practical, emotional and respite support and promote self-care to improve the emotional wellbeing of the whole family.

Phone 0151 459 4779 (Mon-Fri 930 – 1700)

Or call/text 07566 225 253

Website: <https://www.lovejasmine.org.uk/>

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Appendix 1 - Patient Information

- [sands.org.uk/support/how we offer support/sands bereavement support book](https://sands.org.uk/support/how-we-offer-support/sands-bereavement-support-book)
- [How we offer support | Sands - Saving babies' lives. Supporting bereaved families.](#)
- [Twins Trust | Information](#)

Appendix 2 - Coroner / Medical Examiner Referral Forms

Greater Manchester and Eastern Cheshire please use

[GM Medical Practitioners - Referring a Death to the Coroner](#)

For other areas please refer to local policy

Example letter for parents explaining the role of the Medical Examiner

[Medical Examiner Information Leaflet for Parents](#)

Appendix 3 - Deciding about a post mortem examination: Information for Parents

Patient information

- [sands.org.uk/Understanding Why Your Baby Died \(March 2023\)](https://sands.org.uk/Understanding-Why-Your-Baby-Died-(March-2023))
- [sands.org.uk/understanding why your baby died/post mortem examination](https://sands.org.uk/understanding-why-your-baby-died/post-mortem-examination)

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Appendix 4 - Placental Pathology

Greater Manchester and Eastern Cheshire, Lancashire and South Cumbria

- [MFT Placental histology information sheet](#)
- [Request Form for Histopathological Examination of Placenta](#)

Cheshire and Merseyside

- [Saint Helens and Knowsley Cytology request form](#)
- [Alder Hey Request for Placental Histopathology](#)

Appendix 5 - Post Mortem Consent Form, Request Form

Greater Manchester and Eastern Cheshire, Lancashire and South Cumbria

Greater Manchester and Eastern Cheshire

- [Referral form for neonatal Post Mortem at RMCH](#)
- [MFT Post mortem consent form](#)
- [MFT Post mortem help sheet for consent form](#)

Cheshire and Merseyside

- [Alder Hey Post mortem consent form](#)
- [Alder Hey Examination of fetus request form](#)

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Appendix 6 – Cytogenetic Testing

Greater Manchester and Eastern Cheshire, Lancashire and South Cumbria

Current forms can be printed from

- www.ManGen.org.uk/useful-forms
- [Cytogenetics referral form](#)

Cheshire and Merseyside

Current forms can be printed from

- [Genetics referral form – Alder Hey](#)

Appendix 7 - Collecting Feedback from Families

Some units may wish to collect feedback from parents. The feedback from women and families will identify aspects of care that should always happen and potential improvements in maternity bereavement services.

Below is an example of a feedback questionnaire:

- [Example letter to parent](#)
- [Maternity Bereavement Experience Measure \(MBEM\)](#)

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Details of other relevant or associated documents (including links)

[Support for Clinicians – North West Neonatal Operational Delivery Network](#)

Supporting references & national guidance

1. Sands (2022) Neonatal Death Bereavement Care Pathway
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4. North West Neonatal Operational Delivery Network (2017)
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5. [Misaskim, Tommy's and Manchester University NHS Foundation Trust](#) (2022)
6. Neonatal Research Network (2016) www.neonatalresearch.net/butterfly-project
7. Twins Trust <https://twinstrust.org/bereavement.html>
8. MBRRACE-UK (2022) <https://www.npeu.ox.ac.uk/mbrance-uk/signs-of-life>
9. Academy of Medical Royal Colleges (2010). A Code of Practice for the Diagnosis and Confirmation of Death. https://www.aomrc.org.uk/wp-content/uploads/2016/04/Code_Practice_Confirmation_Diagnosis_Death_1008-4.pdf
10. Courts and Tribunals Judiciary (2023) Chief Coroner's Guidance No.45 Stillbirth, and Live Birth Following Termination of Pregnancy. <https://www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/>
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14. The Royal College of Pathologists (2022) National Medical Examiner's Good Practice Series No. 6 Medical examiners and child deaths. <https://www.rcpath.org/static/7fa7a9d6-ada5-4597-b16f4602c93d3e91/Good-Practice-Series-Child-Deaths.pdf>

15. The Royal College of Pathologists (2024) Death Certification Reforms. <https://www.rcpath.org/static/a78a8b4b-0c24-45ac-8422531e6218bcb8/Death-certification-reformschanges-from-9-September-2024Final.pdf>

16. MBRRACE-UK (2018) Perinatal Mortality Review Tool <https://www.npeu.ox.ac.uk/pmrt>

17. MBRRACE-UK (2018) Guidance for Trust and Health Boards https://www.npeu.ox.ac.uk/assets/downloads/pmrt/3b_Guidance%20for%20using%20the%20PMRT%20July%202018%20v6.pdf

18. HM Government (2018) Child Death Review Statutory and Operational Guidance (England) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1120062/child-death-review-statutory-and-operationalguidance-england.pdf

19. The North West Human Milk Bank <https://www.milkbankcatchester.org.uk/donate/donationafterloss>

20. North West Neonatal Operational Delivery Network (2023) North West Perinatal / Neonatal Palliative Care Guideline [Support for Clinicians – North West Neonatal Operational Delivery Network](#)

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Definitions / Glossary

Consultation with Stakeholders

Midwives, obstetricians, bereavement midwives, bereavement nurses, neonatologists, perinatal histopathologists working in the North West Regional Maternity Network and Neonatal Operational Delivery Network. Maternity and Neonatal Voices Partnership representatives.

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Equality Impact Assessment

Section 1: Equality Impact Assessment (EIA) Form

The EIA process allows the group to identify where a policy or service may have a negative impact on an individual or particular group of people.

Information Category	Detailed Information
Name of the strategy / policy / proposal / service function to be assessed:	Management of Neonatal Death, Version 1
Directorate and service area:	Obstetrics and Neonatology
Is this a new or existing Policy?	New
Name of individual completing EIA (Should be completed by an individual with a good understanding of the Service/Policy):	Dr Elaine Church, Consultant Obstetrician
Contact details:	Elaine.church@mft.nhs.uk

Information Category	Detailed Information
1. Policy Aim - Who is the Policy aimed at? (The Policy is the Strategy, Policy, Proposal or Service Change to be assessed)	Staff caring for families who experience a neonatal death in maternity or on the neonatal unit.
2. Policy Objectives	This guideline is written to support an integrated care pathway to facilitate optimal care following a neonatal death at any gestation and in any situation where healthcare professionals may find it useful.
3. Policy Intended Outcomes	To facilitate optimal care following a neonatal death at any gestation.
4. How will you measure each outcome?	
5. Who is intended to benefit from the policy?	Staff caring for and families who experience a neonatal death.
6a. Who did you consult with? (Please select Yes or No for each category)	<ul style="list-style-type: none"> Workforce: Yes Patients/ visitors: No Local groups/ system partners: Yes External organisations: Yes Other: No

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Information Category	Detailed Information
6b. Please list the individuals/groups who have been consulted about this policy.	Please record specific names of individuals/ groups: Midwives, obstetricians, neonatal nurses, neonatologists, perinatal histopathologists, bereavement teams across the North West Maternity Network and Neonatal Operational Delivery Network.
6c. What was the outcome of the consultation?	All comments received were considered and incorporated to improve the quality of the documents and to produce version 1.
6d. Have you used any of the following to assist your assessment?	National or local statistics, audits, activity reports, process maps, complaints, staff, or patient surveys: No

7. The Impact

Following consultation with key groups, has a negative impact been identified for any protected characteristic? Please note that a rationale is required for each one.

Where a negative impact is identified without rationale, the key groups will need to be consulted again.

Protected Characteristic	(Yes or No)	Rationale
Age	<i>No</i>	
Sex (male or female)	<i>No</i>	
Gender reassignment (Transgender, non-binary, gender fluid etc.)	<i>No</i>	
Race	<i>No</i>	
Disability (e.g. physical or cognitive impairment, mental health, long term conditions etc.)	<i>No</i>	
Religion or belief	<i>No</i>	
Marriage and civil partnership	<i>No</i>	
Pregnancy and maternity	<i>No</i>	
Sexual orientation (e.g. gay, straight, bisexual, lesbian etc.)	<i>No</i>	

A robust rationale must be in place for all protected characteristics. If a negative impact has been identified, please complete section 2. If no negative impact has been identified and if this is not a major service change, you can end the assessment here.

I am confident that section 2 of this EIA does not need completing as there are no highlighted risks of negative impact occurring because of this policy.

Name of person confirming result of initial impact assessment:

Dr Elaine Church, Consultant Obstetrician

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