

Perinatal Palliative Care and Bereavement Guideline

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Approved by Neonatal Unit Development Meeting	9th April 2025
Approved by Perinatal Directorate meeting:	2nd May 2025
Approved at Medicines Safety Committee	14th May 2025
Date of Review: This is the most current document and is to be used until a revised version is available	2nd May 2028

This guideline is for use by the following staff groups:

Maternity and Neonatal Midwifery, Nursing and Medical Teams

Key amendments to this Pathway

Date	Amendment	Approved by:
NA	NA	NA

Contribution List

This key document has been circulated to the following for consultation.

- Neonatal Consultant team
- Bereavement Support Midwives
- Obstetric Consultant team
- Neonatal Clinical Nurse Educators
- Family integrated care lead
- Neonatal Nursing team & ANNP
- Midwifery team
- Neonatal and Paediatric Lead Pharmacist
- Medical examiner
- Acorns Children's Hospice
- Orchard community nursing team
- Parents of babies who received palliative care and bereavement support

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1. Introduction

The loss of a baby in pregnancy or shortly after birth is an immense trauma for the family involved. What happens to them and the care they receive during this time will stay with them forever, the memory of this will become entwined with the memory of their child. As such the provision of sensitive, high-quality care is imperative.

The National Bereavement Care Pathway (NBCP) for Pregnancy and Baby Loss was launched in 2017. The NBCP seeks to increase quality and reduce the inequity in the bereavement care provided by healthcare professionals after the loss of a baby or pregnancy at any gestation. There are 9 key standards which run through the 5 NBCP pathways and are embedded within this pathway.

The British Association of Perinatal Medicine (BAPM) published 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine' in July 2024 and this provides a basis for which this pathway is built upon.

2. Objectives

This pathway aims to provide guidance and support to all staff involved in caring for the baby and their family during the antenatal and postnatal period, whilst complying with professional and national standards. Our aims are that the women and their families experiencing the death of a baby or a baby that is dying are provided with sensitive, supportive, high-quality personalised care. Principles of Family Integrated Care (FIC) should be followed to ensure the families wishes and beliefs are at the forefront of all decisions made.

Palliative care is not synonymous with end-of-life care but rather represents an active and total approach to care which can be delivered from the point of diagnosis and alongside treatments directed at survival. It includes symptom management and parallel planning, but also empowering parents to be involved in decision making and the care of their baby.

3. Policy Scope

The pathway is intended as supportive guidance for all healthcare professionals working in perinatal medicine across antenatal, intrapartum and neonatal services. The focus is perinatal: on provision of care for babies with potentially life-limiting conditions and their families, before and after birth. However, parts of the pathway (particularly relating to babies transitioning to community care) will overlap with paediatric palliative care.

Acknowledging uncertainty and discussing palliative care can be challenging for perinatal teams. We recognise that sometimes using the terminology 'palliative' can itself be a barrier for both parents and health care professionals. This pathway offers a framework which is aligned with contemporary paediatric palliative care.

4. Definitions

4.1 Intrauterine Death (IUD)

The absence of cardiac activity in the baby while in-utero.

4.2 Miscarriage

A baby born before 24 completed weeks of pregnancy with no signs of life. Where an intrauterine death is diagnosed on ultrasound before 24 weeks (RCOG, 2005).

4.3 Stillbirth

A baby born after 24 completed weeks of pregnancy with no signs of life.

4.4 Neonatal death

A death that occurs in a 'live born' baby before the age of 28 completed days of life, this can be further split into an early or late neonatal death. An early neonatal death is the death of a live born baby before 7 completed days of age. A late neonatal death is the death of a live born baby after 7 completed days but prior to 28 completed days of age (MBRRACE, 2016). A 'live born baby' is a baby of any gestation that shows signs of life following complete expulsion from the mother, regardless of whether or not the cord has been cut.

A death after 28 days but before 1 year of age is termed an '**infant death**'.

4.5 Bereavement Suites

At Worcestershire Royal Hospital, there are two bereavement suites on delivery suite that are able to be used by families, 'Snowdrop Suite' and 'Forget Me Not Suite'. These rooms are situated just off delivery suite away from the noise to give privacy to families. In addition, there are side rooms and a parent flat available on the neonatal unit and they can be made private if the family wish to remain close to the neonatal unit or the baby is receiving active care.

4.6 Palliative care

Refers to an active approach to the care of patients with '**life-limiting conditions (see 6.1)**' from the time of diagnosis through to death and bereavement. It embraces physical, emotional, social and spiritual needs and focuses on the enhancement of quality of life, and support for the patient's family (Together for short lives).

Palliative care is an umbrella term which encompasses the full spectrum of '**supportive care**' and '**end of life care**'. This broader definition of palliative care includes a common approach to the holistic care of babies and their families with '**potentially life-limiting conditions (see 6.1)**'. This includes many babies who are not receiving end of life care, those for whom the outcome is not certain and some who may recover fully and live a normal lifespan.

4.7 End of life care

Refers to the care of a patient in the dying phase, including symptom management, decision-making about appropriate treatments, and family support.

4.8 Supportive care

Refers to an approach to care which aims to support patients and families to live as well as possible by providing high quality pain and symptom control alongside practical and psychological support. Supportive care is provided for patients in the setting of uncertain outcome, for example patients who may recover but also are at risk of dying.

5. Duties and Responsibilities

Palliative care is very much ‘everyone’s business’ and can and should be delivered by existing perinatal teams with support from community and specialist services where required.

Perinatal Palliative care team includes:

- Lead neonatal consultant
- Fetal medicine obstetric consultant
- Neonatal nurses
- Bereavement midwives
- Family integrated care lead
- Neonatal psychologist
- Network paediatric palliative care consultant – available for discussion 24/7

Key responsibilities to families include:

- Specialist support navigating a pregnancy with an uncertain or poor prognosis, individualised to each family’s needs. To include spiritual, social, financial as well as the care planning processes
- Supporting transition from obstetric & midwifery care to neonatal services and if required to paediatric services
- Parallel planning from time of diagnosis by supporting management and optimisation of life whilst also planning for the possibility of deterioration or death
- Symptom management
- Empowering parents to be central to their child’s care through family integrated care principles. Celebrating the joys in the ‘everyday’ whilst navigating uncertainty
- Grief and bereavement support through memory making activities and follow up after discharge

Additional responsibilities to include leading and supporting service development, education and co-ordination of care.

6. Procedures

6.1 Recognition of which babies will benefit from palliative care

1. Diagnosis of a life limiting condition before or after birth. This may be 'certain' that life is not sustainable, such as anencephaly or trisomy 13; or may be 'potentially' life limiting for example:
 - a. 'Extremely high risk' and 'high risk' extreme prematurity or severe growth restriction
 - b. Infants with univentricular congenital heart disease
 - c. Infants born with severe brain injury and high risk of severe disability e.g. Sarnat III hypoxic ischaemic encephalopathy or bilateral grade III or IV intraventricular haemorrhage
 - d. Post-natal exome sequencing which indicates a diagnosis with potential to lead to death in early childhood

See **Appendix A** for full list of examples.

2. Multidisciplinary team and family views. Babies may be at risk of dying even if there is no specific diagnosis as in example 1 above. Team members and parents should be encouraged to share concerns of an uncertain prognosis and consider palliative care needs for the baby at any stage in their journey.
3. 'The surprise question'. Clinical team to proactively ask 'would it be a surprise if this baby died?' If the answer is 'no' then this should prompt the team to actively consider a palliative approach to care.

'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice by the Royal College of Paediatrics and Child Health', state 3 sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, or because treatments cannot provide overall benefit:

1. When life is limited in quantity - If treatment is unable or unlikely to prolong life significantly it may not be in the baby's best interests to provide it. These comprise:
 - a. Brain stem death, as determined by agreed professional criteria appropriately applied
 - b. Imminent death, where physiological deterioration is occurring irrespective of treatment
 - c. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life, by life sustaining treatments confers no overall benefit.
2. When life is limited in quality - This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- a. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
 - b. Burdens of the baby's underlying condition. Here the severity and impact of the baby's underlying condition is sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
 - c. Lack of ability to benefit; the severity of the baby's condition is such that it is difficult or impossible for them to derive benefit from continued life.
3. Informed competent refusal of treatment – This doesn't apply in perinatal decision making.

Life-limiting conditions are those for which there is no reasonable hope of cure and from which the baby will die.

Life-threatening conditions are those for which curative treatment may be feasible but can fail. These will include:

- babies with advanced progressive incurable disease
- babies whose death is expected in the foreseeable future
- babies in whom there is a risk of death from a sudden acute crisis in the condition
- babies in whom sudden catastrophic events have produced a life-threatening situation
- babies in whom the prospect of survival is small, for example, some extremely premature infants

6.2 Disagreement in diagnosis - Second opinion

If there is disagreement amongst the multi-disciplinary team (MDT) or between the team and the parents, then the family's lead consultant should seek second opinion from a colleague.

If families do not accept second opinion following clinical assessment:

- Discuss with clinical director or clinical lead
- Discuss with families the option of a further opinion from consultant neonatologist from a NICU within our neonatal network (usually BWH)
- Lead consultant may wish to seek advice from Trust's legal advisers via medico-legal department or on-call manager

6.3 Communication

Once an infant has been recognised as having the potential to benefit from palliative care it is important that this is communicated with family members and with other health care professionals in a way that effectively communicates prognostic information but that also responds to the emotions generated by the conversation. This will often

involve acknowledging that there is uncertainty and will require iterative conversations with families about their understanding of the illness and the prognosis, their hopes and fears, and what matters most to them as the trajectory of the illness becomes clear.

Communication with families about palliative care, parallel planning, and end of life care is a key skill for perinatal professionals. It should be sensitive to the needs and cultural background of families. In many cases, it will take place over a number of conversations.

Starting a conversation with questions can be helpful:

- Tell me about your baby (Tell me about your family)
- What do you understand about your baby's condition?
- What is most important for you and your family?
- What are your fears for your baby? What is worrying you the most?
- What do I need to know about you and your family to help you best?

The following phrases can be helpful to introduce the concept of palliative care:

- For our sicker babies and those whose future is uncertain, we try to provide extra support for both baby and parents. Whilst we work hard to ensure that baby's symptoms are well controlled and that we have carefully thought about and made plans for the future, if possible, we also want to provide the family as much help as we can at a difficult time.
- Sometimes we involve our colleagues from the palliative care team. This is life-long supportive and holistic care (that means that it covers a wide range of different areas). The palliative care team have special expertise in looking after babies and their families when we have a worry that the baby may not survive.
- Some families find the term scary, but actually 'palliative care' is just about providing the best possible comfort and quality of life for a baby, however long they are with us, whether that is a short time, or even for many years.
- It is normal for us to refer families to palliative care services for extra support in this type of situation.

Advance care planning (ACP) can then be introduced as follows:

- When we aren't sure what is going to happen, some parents find it helpful to hope for the best as well as make plans for the worst/plans for the rest.
- It can be helpful to talk about what might happen, as well as what we think is most likely.
- For example (make this situation specific - e.g. when the breathing tube is removed), it is hard to know what will happen next and sometimes it helps to think of this in advance and make plans.

- I don't know how long you will have with (your son/daughter). It might be only a very short time, but sometimes it is longer.
- Because we are not sure exactly what is going to happen, it can be important for us to have several different plans. We might need a 'plan A' for what we think is most likely, but then a 'plan B' in case that doesn't happen. Sometimes we need a plan C and D as well. How does that sound?

Below are some questions which may be helpful to ask families:

- Is there anything related to your culture or religion that we should know about so that we can care for you and your baby?
- Spirituality and faith are important to a number of the families that I meet. Do you have beliefs that you would like those caring for you and your baby to know about? Do other people in your family share the same beliefs?
- Is there anything we can do that would help you feel connected to your faith community? Is there anyone you would like us to call?
- Would it help to talk to a chaplain or other religious leader?
- When life is particularly challenging, different sources of support can be helpful for different people. What about you? Is there anything that you need that could be of comfort or support to you at this time?

It is important to document the discussions and hand this information over between professionals. This can be done using the ACP document (hard copies available on the neonatal unit – in the drawers). See **Appendix B**.

<http://cypacp.uk/document-downloads/care-plan/generic/>

This is not a legal document, does not need to be signed and can be amended as many times as required.

Face-to-face discussion with both parents should take place in a quiet room away from the neonatal unit. Give them the option of inviting other family members or a close friend to be with them. Ensure that parents have privacy, and adequate time and opportunity to discuss their views and feelings and to ask questions.

Arrange for an interpreter to be present if needed—avoid interpretation by family members or children.

6.4 Involvement of teams

Initial conversations with parents are best limited to essential team members such as the lead consultant and midwife or neonatal nurse caring for the women or baby. Ideally these should be started in the antenatal period where possible and a link person identified to provide continuity and reduce the number of times parents are having to hear the information and be asked to give their interpretation and thoughts. Starting the advance care plan (ACP) in pregnancy helps with this and provides a start point for

subsequent conversations to avoid covering difficult conversations which families do not want to have multiple times with different professionals.

As conversations develop and families are ready it is helpful to involve additional team members such as community teams:

- Bereavement midwives
- Orchard community nursing team if planning to take the baby home
- Acorns if considering use of respite, symptom management or end of life care
- Allied healthcare team including physiotherapy, occupational therapy, dietetics, speech and language, pharmacy to assess and support symptom management and equipment needs
- Psychology support from neonatal psychologist
- Specialist palliative care support from the West Midlands Palliative care team
- West Midlands Single point of contact - 24hour a day support through Acorns for healthcare professional advice and support for palliative care needs on 0330 094 1718 (currently until 30th May – likely to be extended)
- GP
- Health Visitor

Families should be given details of a lead consultant or midwife to speak to if they have questions or are not happy with the care they and their baby are receiving.

6.5 Medical management

Rationalise medications and ensure medications are discontinued if not needed for symptom management.

Prescribe medication on drug chart if an inpatient or use the 'WMPPCN drug administration document for babies, children and young people requiring symptom management' if going home with Orchard. **Appendix C**

Pain relief and comfort care:

- Consideration should be given to relief of pain and discomfort for infants receiving palliative care. This includes the type of medication, the dose, route of administration and the likely duration of need. Consideration should also be given to the use of formal tools to assess pain, such as the N-Pass pain tool.
- Should the infant have intravenous access in place, this route is preferable in the immediate period after discontinuation of life-sustaining care.
- If an infant is already receiving analgesic medication, this should be continued. If opiates are to be initiated, an initial bolus dose should be given before commencing an infusion so that adequate analgesia is achieved promptly. The dose may be increased or reduced depending on ongoing assessment of distress and development of tolerance. Parents should be made aware that opiates while relieving pain and distress also suppress respiratory drive and may hasten death.
- If the intravenous route is not available and adequate analgesia cannot be achieved through oral medication, a subcutaneous infusion may be necessary. Intramuscular medication is never appropriate. For rapid symptom management, buccal medication can be considered, usually in addition to longer acting medication via the enteral route or subcutaneous infusion.
- Non-narcotic analgesia such as paracetamol and oral sucrose or expressed breast milk (EBM) may be used for less severe pain or in combination with narcotic analgesics.
- Refer to **Appendix C** for a list of suggested medications and doses including morphine.
- Non-pharmacological interventions may be used in conjunction with analgesic medications. These include a calm environment with minimal noise and light stimuli, skin to skin care and comfort holding, non-nutritive sucking with a pacifier using EBM/ sucrose, music, and positioning with arms and legs flexed close to the trunk using a blanket or rolls, and massage.
- Assist the parents to hold their baby & support continued suckling at the breast or use of EBM if the mother wishes.

Seizures:

- If an infant is already receiving medications to control seizures before life-sustaining support is withdrawn, this should be continued. If death does not follow the withdrawal of life sustaining support, ongoing management of seizures should involve a consideration of the type of medication and route of administration.
- Refer to **Appendix C** for medications and doses.

Dyspnoea:

- Opioids and Benzodiazepines **Appendix C**
- Airflow/ oxygen

Secretions:

- Gentle suctioning and medications such as glycopyrrolate or hyoscine may be used to decrease respiratory and salivary secretions.
- Feed management may help with secretions.
- Refer to **Appendix C** for medications and doses.

Oedema:

- Feed management
- Furosemide **Appendix C**

Fluids and nutrition: (**Appendix D**)

- The goal of treatment is comfort, not usually the provision of nutrition.
- In those infants able to tolerate milk feeds their ongoing provision should be determined by their clinical condition and the cues that the infant demonstrates.
- Oral nutrition should only be withheld if it is felt that providing it will cause pain or discomfort. It may be appropriate to allow the infant to suckle at the breast or receive buccal colostrum/ expressed breast milk if able to do so.
- If vomiting is a problem, the volume of enteral feeds should be reduced appropriately.
- In those infants in whom the duration between the withdrawal of life-sustaining care and death is expected to be short, it is reasonable to cease all feeds if it is felt feeding could cause distress, and to discontinue intravenous hydration and nutrition.
- If death does not follow the withdrawal of life-sustaining care, or if palliative care is instituted in an infant where the provision of hydration and nutrition is the sole

intervention maintaining life, then considering stopping this is appropriate only if to do so will not result in hunger or distress to the infant. Any such decision should involve discussion with the parents.

- Any decision to continue to provide intravenous nutrition and hydration should be taken in the light of the pain and discomfort to the infant of continuing to provide fluid and nutrition (e.g. need for central or peripheral venous access).
- If the infant is discharged home or to a hospice for palliative care, arrangements to continue or discontinue medically provided fluids and nutrition will need to be made in advance and the parents supported accordingly.
- Gastrostomy, nasogastric and jejunostomy feeding will require parent training and community nursing support. This training should begin as early as possible to facilitate discharge home where parents choose to take their baby home to receive palliative care.
- The benefits of surgery to allow feeding either via the intravenous route or via the enteral route must be balanced against the burden of the intervention and the prolongation of death.

Non-pharmacological holistic management in partnership with parents:

- Developmental care with focus on sensory environment including noise, light, temperature, touch and smell.
- Minimising stress and pain
- Skin protection
- Sleep and rest
- Positioning and handling
- Optimising nutrition as above (**Appendix D**)

6.6. End of life care

If appropriate agree a time and location for withdrawal of life-sustaining treatment with the parents. This could be NNU, one of the bereavement suites, acorns or home. Explain what will physically happen to the infant, what to expect practically, and if the length of time until death is uncertain. If withdrawal of life-sustaining treatment is likely to lead to immediate death, explain that the infant may gasp and have colour changes to their face and body. Support parents to be present and hold their baby at the actual time that life-sustaining treatment is withdrawn. Be mindful that they may prefer not to, and also that they may change their mind. Ask the parents whether they would like siblings or family members to be with them.

Monitoring

- Invasive techniques such as invasive blood pressure monitoring should be discontinued. Cardiac and saturation monitors should also be turned off prior to disconnecting mechanical ventilation.
- The baby should be monitored for physical signs that suggest discomfort (crying, whimpering, panting, tachycardia, excessive secretions, dry mucous membranes).
- Blood tests and blood gas measurements should no longer be carried out.

Oxygen and ventilation

- Decide in advance which member of staff will be responsible for the actual removal of the endotracheal tube and turning the ventilator off.
- Aspirate the nasogastric tube & consider not feeding the infant just prior to extubation. Turn off the alarms of the ventilator and monitors prior to disconnecting these. Suction the endotracheal tube before removal.
- Withdrawal of less invasive forms of respiratory support such as nasal continuous positive airway pressure and nasal cannula oxygen may be appropriate if a baby is dying, and continued provision of respiratory support only serves to delay death.

Once life-sustaining support has been withdrawn, intermittent physical examination with auscultation of the heart rate should be continued by the nurse or doctor caring for the baby depending on the clinical condition of the baby or at parental request.

Ask if the parents would like their infant to be dressed in a special way, or if they have specific preferences, such as around bathing or anointing.

Ask if they would like photos to be taken and offer them the opportunity to take handprints and footprints. If parents do not want photos, offer to take some on a digital camera with individual SD card kept in a memory box and stored in case they decide

they would like them at a later date. There is also a charity called 'Remember My Baby' who provide a free photography service and will photograph palliative baby's as well as those who have already died.

Ask parents if they wish to keep any items such as blankets, hats or other items that were related to the baby's care. See later section **6.11** on memory making.

If the infant is one of a set of twins or other multiples, where possible take a photograph of the babies together with the family. This could be incubators or cots close together if that is the only way to do this if the other infant is very sick. Then provide a butterfly sticker & explain this is to ensure people are aware the remaining child was one of a multiple pregnancy.

Ensure the nurse who is allocated to the infant and family does not have another infant to care for. Ask the parents if they would like the nurse and/or doctor to be present behind the screen or in the room with them. If they prefer privacy explain how they can call the nurse and advise that he/she will return intermittently.

Let parents know that it is possible for their baby to remain with them after death if they wish and even to take their baby home. If a post-mortem examination is to be carried out, it is not advisable to keep the body outside of a cool room or mortuary for longer than 4–6 hours. Ask for use of 'Cold Cot' or if available 'Techni ice'.

Parents should be informed that it is possible to see their baby after the body has been taken to the mortuary and following the post-mortem, however the process for release of the body will need to be discussed with the mortuary. If the death should be referred to the coroner, the body must remain in the care of the Trust until such times as the coroner deems further investigation is not required.

Some parents may wish to take the baby home until the funeral or prior to return for post-mortem. There is no legal reason why they should not. For the protection of the parents and to avoid misunderstandings, staff should give them a completed "Consent letter to take baby's body home" form (**Appendix E**) and 'Taking Your Baby Home from Hospital' patient information leaflet (WAHT-PI-0847) to accompany the baby and a photocopy kept in the medical records. The SANDS information leaflet needs to be provided to the parents for extra information. The police should be informed on 101 and a police log number documented. The baby can be transferred in a car seat, lay in a Moses basket next to an adult, in a clear footwell if large enough or carried however parents should be advised that carrying the baby home provides less protection should they be involved in a car accident.

6.7 Location of care & transfer – Appendix F for flowcharts

The principles of palliative care should be consistently applied regardless of location.

Discuss with parents if they would prefer to stay in hospital in one of the bereavement suites on delivery suite, the neonatal unit with a screen for privacy or move to a side room or alternatively the parent flat just outside the neonatal unit.

If the mother is receiving care herself (for example after a caesarean section) consider providing palliative care on delivery suite in a private area that does not compromise her own care and provide nursing support for the infant.

If appropriate, offer palliative care to be provided outside of the hospital environment. Consider transfer to a hospice, especially if the duration between the withdrawal of life sustaining treatment and death is expected to be days rather than hours. Alternatively consider the possibility of transfer home.

When an infant is transferred to a hospice supported by a palliative care team, it is recommended that there is a designated senior neonatal doctor with whom the palliative care team can liaise after discharge. This is particularly important should there be a change in the infant's condition after discharge.

If the baby is ventilated and the family wish to transfer the baby to a hospice or to their home, this can only be done if there is sufficient support available at the chosen location to support extubation and provide ongoing care. Liaise with community nursing team to ensure services and support can be provided before discussing options with families. With regards to the transfer, the neonatal transport service (NTS) may be able to offer support, alternatively, the hospital medical team will try to facilitate this using the unit's neonatal unit transport incubator.

Tailor care to the individual needs of the infant and the family but be realistic. The family may change their mind regarding location of care at any time or the clinical situation may change thereby altering the possibilities of transfer. Parents should be advised that although baby may be expected to live for more than a few hours, death may occur during transfer and parents should accept this possibility before arrangements are made.

If a decision to institute palliative care has been made in the antenatal period offer parents the opportunity to meet the bereavement support midwives, consider birth choices appropriate to the level of care that their baby may require and the opportunity to visit a hospice.

Perinatal Referral for Acorns Hospice care

Children's Hospices are funded and run independently. They are not part of the NHS and are funded by charities. Each hospice has their own admission criteria and fundamentally follow 'Together for Short Lives' (TFSL, 2024) categories of care.

Acorns children's hospice has a dedicated team to provide specialist palliative care for life limited and life threatened babies, children's and young people and support for their families. This support is offered from three hospices based in Worcester, Birmingham and Walsall, as well as in the family home and community. The care is supported by West Midlands palliative care consultants Dr Christine Mott and Dr Yifan Liang.

It is important to not offer hospice care to families prior to contacting a hospice to see if support/transfer is possible in order to provide realistic expectations.

For Worcestershire support contact Acorns for the Three Counties: **01905 767 676**.

They are able to accept end of life referrals at any time of day and would prefer you to ring as soon as you know of a potential referral. However, admissions are only accepted in daytime hours, unless previously arranged with hospice and permission given by on call manager. All other referrals are reviewed at a weekly review panel.

Referral forms are accessed via Acorn's website. [Homepage - Acorns Children's Hospice](#). Email form to: Referrals@acorns.org.uk

Criteria for referral

Early referral is beneficial so that families can access the support available for as long as possible before the child dies. Acorn's hospice accepts antenatal referrals, which allows families to receive support from the point of diagnosis in utero and become familiar with the hospice setting. Hospice staff can attend meetings, help to source equipment and make all possible preparations, with the hope that the parents will get the most out of the time they do get with their baby. They are very happy to speak with families and arrange visits to the hospice before the baby is born so they have information about the services and full range of options available.

Acorns will accept babies for end-of-life care but unfortunately can no longer accept babies who have already died.

Acorns have cold cot facilities that can be used in the special bedroom to allow the family to spend additional time with their baby after death. The length of time is not specified but depends on a number of factors and is guided by the nursing team and funeral director. Cooling cots or mats can be provided for the home, and the Acorns family team can support this.

Together for Short Lives (TFSL, 2024) divides children with palliative care needs into four categories:

Category 1: Life threatening conditions for which curative treatment may be feasible but can fail.

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.

Category 2: Conditions where premature death is inevitable.

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

Category 3: Progressive conditions without curative treatment options.

Treatment is exclusively palliative and may commonly extend over many years. Examples: batten disease, mucopolysaccharidoses.

Category 4: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.

Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode. Families need to be referred to Acorns by a paediatrician, nurse or midwife.

How to Transfer

Where possible an MDT discharge planning meeting should take place with the unit who are to support the transfer using a paediatrician/ neonatal nurse.

For Hospital to Hospice Transfer:

1. Parents own vehicle
2. NTS vehicle
3. Ambulance with hospital medical team

One or both parents/carers can travel with them providing sufficient seating is available within the ambulance/NTS vehicle. They must understand that they are not to interfere with any care provided on route and that if their baby deteriorates, the plan of care will be followed. If the mother is accompanying her baby, she must be safe to travel and fully discharged from obstetric care.

The transport team and/or NTS crew have the right to refuse transfer of the parent if deemed necessary at any point.

If the baby is receiving any form of respiratory support the following considerations need to be made prior to transfer:

- Is a ventilator/CPAP required for transfer?
- Do you think the baby is going to die quickly once the respiratory support is removed?
- If respiratory support is to continue for the transfer, then an ambulance/NTS must do the transfer.
- If the plan is to transfer on respiratory support, then the plan should include decisions about when to stop the support following arrival at the hospice and carry out a compassionate extubation or remove CPAP there.
- To support in compassionate extubation on arrival at the hospice, a clear plan needs to be in place and an agreement as to which transferring staff member will be available to stay for this.
- A doctor or other suitably qualified practitioner from the referring unit will accompany the transport team, or meet them at the destination, to manage this in a controlled and unrushed manner.
- The referring unit staff will need to organise return transport back to their place of work.

If deterioration is likely or expected during the transfer, or if concerns are raised by any individual, a senior doctor who knows the patient should accompany the Transport Practitioner and baby. If deterioration is not expected during the transfer and the baby is stable, the transport team and the referring consultant should be in agreement as to who must travel with the baby.

The transport staff will discuss and agree with the family prior to departure what action should be taken in the event of deterioration during transfer, aiming to follow the end-of-life care plan where possible, but also to facilitate some time at the hospice and avoid a death in transit. Any changes to the plan which are applicable during transfer should be documented.

The baby should be transferred to the predetermined receiving site. No diversion to alternative destinations should be made, unless it is part of the agreed plan of care.

Observations and times should be recorded during transfer in the usual way.

If death occurs during transfer, the following will need to be done:

- Note the time and location and document in the transport record
- Proceed as in the care plan (normally this would be to the destination)
- Medical team to inform parents on arrival, if they are not already aware
- Medical team to discuss with Medical Examiner, who can advise if referral to coroner is required – this is usually only when death is in any way unnatural.

- Verification of death is completed at receiving site by appropriate person. Death certification is completed by the Medical Practitioner in liaison with a Medical Examiner. Details of the medical examiner will be required by acorns prior to transfer. Any doctor who has cared for the baby can complete the death certificate. The GP needs to be informed of the planned discharge and expected death.

Documentation

Advance Care Plan (ACP). <http://cypacp.uk/document-downloads/care-plan/generic/>

Appendix B completed by the referring consultant in conjunction with parents prior to transfer.

Paper copies of the ACP's are available in the set of drawers on the neonatal unit.

Care is agreed between parents and Health Care Professionals. Orchard shares copies of the ACP with Riverbank, GP, WMAS (West Mids Ambulance Service) and any other relevant team. Parents will keep the main copy.

This Plan of Care form is a document recognised by the referring and receiving hospitals and the ambulance service to ensure that resuscitation is not commenced inappropriately. If this form is not completed, and the baby deteriorates the ambulance personnel are required to resuscitate.

Advanced Care Planning should be completed for any baby being transferred to home or hospice for end-of-life care. The ACP must be discussed with parents. A clear plan for management of deterioration or death in transit needs to be documented.

Transfer to home:

If parents wish to take their baby home for end-of-life care support, Orchard Service is commissioned as the provider of end-of-life care at home as a 24/7hr service in specific cases. Orchard should be contacted to support and facilitate the transfer home. The same transfer considerations and documentation need to be completed as documented in 'How to transfer' and 'documentation' above.

Parents taking their baby home following death should be provided with "Consent letter to take baby's body home" form and 'Taking Your Baby Home from hospital' patient information leaflet (WAHT-PI-0847) to accompany the baby and a photocopy kept in the medical records (**Appendix E**). The SANDS information leaflet needs to be provided to the parents for extra information. The police should be informed on 101 and a police log number documented. The baby can be transferred in a car seat, lay in a Moses basket next to an adult, in a clear footwell if large enough or carried however parents should be advised that carrying the baby home provides less protection should they be involved in a car accident.

Check list for transfer outside of the hospital (home or Acorns)

- 1) Referral accepted by hospice and/ or Orchard service
- 2) Referral discussed with Palliative care consultant (Dr Christine Mott/ Dr Yifan Liang) who will oversee the provision of care whilst in the hospice
- 3) Drugs prescribed for transfer with baby to hospice (TTO and on WMPPCN drug administration document to include medication which may be required e.g. pain relief, buccal midazolam, etc. A five-day supply is required by the hospice.).
- 4) Method of transfer - Ambulance / NTS contacted if they are doing transfer.
- 5) Is a trans-warmer needed for transfer (consider for babies <2.5Kg)
- 6) Documentation to be completed. ACP, Medical notes, nursing notes and completed Badgernet discharge letter with copies to GP, members of the team providing palliative care, community midwifery team and the parents.
- 7) The babies lead neonatal Consultant should be informed of the transfer and made aware that they may be contacted to provide secondary level clinical advice until transfer of care to another professional has occurred.
- 8) GP should be informed for support with ongoing care.
- 9) Any equipment which might be needed at home or hospice (e.g. oxygen, suction etc.) would need to be arranged by the referring unit, community team or hospice and installed in advance.
- 10) Any enteral feeds/ feeding equipment required. The hospice will require one week supply of these.
- 11) Ensure that the plan is discussed and agreed with the parents.
- 12) The staff member going on the transfer will need to be rostered to undertake the transfer and beyond to allow the parents maximum support when they reach their destination.
- 13) A detailed handover from the neonatal team to those members of the team providing the transfer and again at the receiving end should be undertaken.
- 14) Hospice staff aware of expected arrival time.

6.8 Certification

Miscarriage <24/40.

When a baby has been born with no signs of life before 24 weeks, a non-viable Midwife certificate (purple form) which is included in the bereavement packs must be completed by the midwife at delivery. This is the legal paperwork required for the family to be able to arrange a burial or cremation. The back of the paperwork must be filled in, including the parent's information and signed by the mother and the partner if the funeral arrangements are to be arranged with the hospital contracted funeral directors. This should be kept in the patient's records to be scanned to Badgernet and sent to the bereavement support midwives. The purple form should be placed in an envelope and sent to the Mortuary with the baby. There is no option to proceed with a burial or cremation without this paperwork signed by both the delivering midwife and the parents. Not completing the paperwork can delay arrangements and cause further distress.

There is now provision to allow the certification of babies born before the 24th week of pregnancy. Families can self-register on www.gov.uk/request-baby-loss-certificate for a certificate which acknowledges their baby/pregnancy loss. This certificate is not a legal document. Alternatively, the memory boxes used have 'acknowledgement of life' certificates that can be completed by midwives or the family.

Stillbirth >24/40. No signs of life – Obstetric or Neonatal doctor or midwife depending on who is present at delivery – stillbirth certificate.

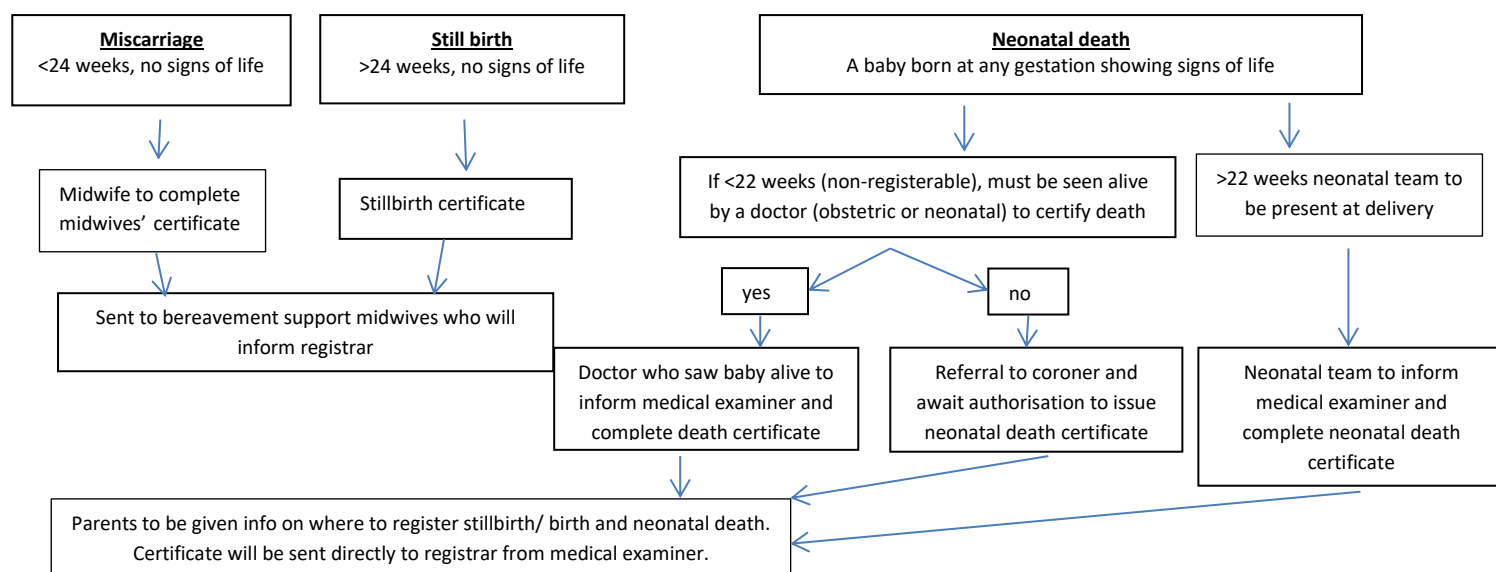
Neonatal death <22 weeks (non-registerable) must be seen alive by obstetric team to complete certificate. If not, then will need referral to coroner. Neonatal team are unlikely to be involved in these babies but can complete certificate if were present.

Neonatal death >23 weeks neonatal team at delivery and responsible for death certificate.

All deaths need referral to the medical examiner before death certificate can be issued.

All babies that show signs of life at delivery irrespective of gestation are registered as a live birth and issued with a hospital and an NHS number.

From 8th January 25, all neonatal deaths (babies born alive at 20 weeks gestation or greater who die up to 28 days after birth) will only need to be notified to MBRRACE-UK; a separate notification for CDOP will not be required as the electronic form will be shared via cascade. Notification must be completed by the bereavement midwives within two working days of death via: <https://www.mbrrace.ox.ac.uk/>



Additional information can be found in the 'Registration of births' SOP on the intranet. This explains the baby loss certificate that parents can register for as well as other kinds of certificates above.

Stillbirth considerations:

- Resuscitate as necessary if not known to be intrauterine death.
- Once death declared communicate this with parents and offer for them to hold their baby. Care will be co-ordinated by the midwifery team (WAHT-TP-094 guideline), usually in the bereavement suites and at an appropriate time memory making options will be discussed as per 'Making memories' (**Section 6.10**)
- The baby should be kept cold in the 'cold cot' or Techni ice if available when not being held by their family. Once family leave the hospital or if baby's condition is deteriorating, sensitive discussion with the family should take place about transfer to the Mortuary. Babies should never be placed in a freezer.
- Bereavement support to be provided and offer of post-mortem
- A Midwife or doctor may complete both the medical certificate of stillbirth (under the desk on Delivery Suite) and the stillbirth certificate blue form, for cremation/burial. Neither of these needs to be signed by the parents. They should ideally be completed by those who attended the delivery.

The family should be supported to see the baby. Studies have shown that seeing and holding their baby facilitates an adequate grief response, with earlier acceptance. It is well documented that couples who accept an offer to see and hold their child do not

regret the decision; many often speak fondly of the experience. However, the family's wishes should be respected and if they choose not to see the baby, the option of taking photographs and/or foot/handprints should be offered. They should be made aware that they can change their mind, and this can be facilitated in the hospital or at the chosen funeral directors.

Photographs can be taken and printed or kept on a secure SD card, if parents do not wish to see them at present, they should be encouraged to take them home in an envelope to keep for when they feel ready. Professional photos can be provided for stillborn babies by the Charity 'Remember My Baby'.

Parents often wish to know the sex of the baby for identity and naming. It may be difficult to tell the sex of the baby in the presence of dysmorphism. If there is any doubt, it is better to await the results of the post-mortem or karyotype (if performed). Wrong assignment of fetal sex can be very distressing. Below 20 weeks do not determine the gender of the baby; the parents may if they wish after sensitive counselling regarding the similarity in appearance at younger gestations and the possible results at a later date if genetic testing is performed.

6.9 Investigations to be considered after unexpected death

Always discuss with a consultant if it is necessary to take samples of blood or tissue after death in order to make a diagnosis, this should be clearly explained to the parents.

In sudden death of unexpected cause please follow 'Investigation of Sudden and Unexpected Deaths in Children Under 18 Years' WAHT-CG-512

Bloods to consider if not already taken when baby alive:

- Biochemistry – U&E, LFTs, Bone profile, Mg, Glucose, lactate, 3-OH butyrate, FFA, Amino acids, acylcarnitine, Inherited metabolic diseases, carnitine
- Haematology – FBC & clotting
- Microbiology – blood culture/ PCR
- Genetics – Microarray. Consider WGS (whole genome sequencing) if negative microarray and genetic diagnosis suspected
- Consider toxicology

Additional investigations to be discussed with consultant:

- Lumbar puncture for CSF – send for microbiology (MC&S & PCR), protein, glucose and stored sample for additional neuro-biochemical test if needed
- Naso-pharyngeal and/or throat swab for Extended Respiratory Panel & PCR
- Urine for microscopy (MC&S), biochemistry (Amino and organic acids, oligosaccharides) and consider toxicology
- Consider skin biopsy for fibroblast if considering neurometabolic disorder (see below)

Post-mortem

Post-mortem consent should be obtained by a neonatal consultant, obstetrician or midwife trained in gaining consent.

- The best time to broach the issue of post-mortem is after the baby's death.
- If parents raise the issue of post-mortem examination themselves, discussion before the baby's death is acceptable.
- A post-mortem examination should be offered to all parents of baby's that die even if the cause of death appears obvious. Except in the case of a confirmed Trisomy prior to the baby's death. This may identify unexpected problems. The person taking consent should be trained to do this and the parents provided with written information (SANDS leaflet).
- Post-mortem examination can reveal valuable information which would help in the planning of future pregnancies. Evidence suggests that even when a likely prenatal diagnosis is reached, the post-mortem significantly changed the cause of death in 12% and found new information in 26% of cases.

- It is important to explain to the family that the post-mortem will be performed by a dedicated perinatal pathologist, and that this therefore requires the baby being moved to another hospital – usually in Birmingham, sometimes further afield. The baby is always treated with dignity and respect.
- Complete a 'Post-mortem Consent form' (**Appendix H**) and provide the 'Parents Considering Giving Consent for a Post-mortem' patient information leaflet (WAHT-PI-0559).
- The baby is returned directly to the funeral director once the post-mortem is complete. This may take 2-3 weeks.
- Parents should be informed of timescales for results which may take 4-6 months for non-coronial post-mortems.
- They should be informed how baby will look like on their return. They will be bathed and redressed as per the families wishes to hide any incision marks to be as respectful as possible. Property such as teddies/blankets will always be kept with their baby
- If after appropriate senior discussion the post-mortem is declined it should be clearly documented in the case notes.

External post-mortem

In some cases, where a full post-mortem is not required or parents do not consent to full post-mortem, a pathologist may be able to examine the baby externally for dysmorphic features. This can only be done at a specialist centre such as Birmingham Women's Hospital and not at WRH.

What can be offered to parents who do not wish to have a post-mortem?

- Consent for any of the following examinations should be obtained from the parents with the relevant explanation, information and discussion being provided by an experienced perinatal clinician.
- **Fetal imaging:** In cases where a genetic syndrome is suspected and the parents decline a post-mortem, they may accept fetal imaging with MRI, or whole-body CT.
- **Placental Histology & Cytogenetics:** Families usually consent to histological examinations of the placenta which often offers valuable information on inflammatory or infective causes. Placental abnormalities may be associated with fetal demise. Placental tissue and umbilical cord can also be sent for karyotyping and cytogenetics it is important to ensure it is in dry pot with **no formalin**. A few drops of sterile saline can be added to keep the tissue moist. The placenta or cytogenetics sample should be sent from WRH pathology reception on the courier service to BWH Mon-Thurs before 1pm. If sampling takes place over the

weekend, then the appropriately packaged sample should be kept refrigerated. The placenta should be sent whole with a completed clinical information for perinatal post-mortem form. (**Appendix H**)

- **Skin biopsy:** Sterile urine bottle, with sterile transport medium. As it is critical to keep the biopsy moist if the medium is unavailable, use sterile saline. Do not use iodine or betadine to clean biopsy site. Alcohol, Phisoderm or a similar product is acceptable. Excise biopsy with sterile forceps and blade. Immediately place the biopsy carefully into the collection container with the medium and close the container. Label the container with the location of the skin biopsy/biopsies (if more than one, please keep in separate containers and label which one is from which site), patient name, date, and time. Keep container at room temperature and send as soon as possible to the laboratory. Need to inform lab as the sample will need to be transferred in a specialised medium from lab and should be received in BCH within 24 hours.

Organ donation

Some parents may wish to donate their baby's organs. It is important to establish if this is possible and if not, then to explain why this is the case. The UK Organ and Tissue Donation have a specialist nurse available 24/7 on 03000 20 30 40 for discussion of eligible babies. Heart valves (Tissue donation) can potentially occur from 32 weeks CGA and solid organ donation from 37 weeks CGA.

When to refer to coroner

If a baby dies unexpectedly following delivery or following a medical or surgical procedure during the neonatal period, including planned termination of pregnancy, or if there is any suspicion about why the baby died, for example if the mother has been involved in an accident or is a victim of violence the doctor must report the death to the coroner. If you need to discuss with the coroner's office, please call 01905 766066. If unsure, please discuss with the Medical Examiner.

An online referral form must be completed by the consultant and sent to the coroner. This is available through the coroner's portal on the intranet or:

www.worcestershire.gov.uk/council-services/births-deaths-marriages-civil-partnerships-and-citizenship/death-registration-services/coroners-service

The coroner will then decide if a post-mortem needs to be carried out to ascertain a cause of death. If the coroner decides not to perform a post-mortem, the family can decide to consent for post-mortem themselves. If the coroner decides a post-mortem is required, the family are assigned a coroner's officer to keep them informed of what is happening and the coroner will arrange for the baby to be transferred to a hospital

where coronial post-mortem can be performed. From this, the coroner will then decide if there is a cause of death or to open an inquest.

6.10 Memory making

Hand and footprints can be taken with parental consent and inserted in the memory box. It is advisable to take several prints rather than one set. Acorn's hospice also has hand and foot casts and resin mementos and are happy to support providing these memory making activities on the unit/ delivery suite.

Families can also be offered a lock of hair from the baby, the towel the baby was wrapped in, clay hand and footprints, foot casts (above 24/40), the cot card and duplicate name bands.

Parents should be offered the option to take part in any memory making activities with their baby. They can bath and dress their baby in their own clothes or clothes provided by delivery suite.

Photographs can be taken with the digital camera available on delivery suite with an individual memory card with the parents' consent. Ideas for photographs include:

- the baby's hands and feet (including soles)
- head with and without hat
- face and side profile
- wrapped in blanket with teddies
- held by parents or family.

Further examples can be seen on the 'Remember My Baby' website discussed below.

Parents can also take their own photographs with their own camera if they wish.

If parents do not wish to see the photos, they should be encouraged to take them home in an envelope to keep for when they feel ready.

There are memory boxes available on the neonatal unit or delivery suite.

6.11 Spiritual / pastoral support

Support should be offered taking into consideration different faith, cultural and spiritual needs of the family. See *'Chaplaincy (Spiritual and Pastoral Care)'* pages on A-Z pages of Trust Intranet.

Some families may appreciate the option of having the baby blessed and named. Offer services of the hospital chaplain, their own minister or religious advisor. The chaplain can be contacted through switchboard (24 hours on-call chaplain service).

The family should be given information regarding the options for cremation or burial which can be organised by the hospital, or some families may wish to arrange the funeral themselves, and the bereavement support midwife or chaplain can aid the family in planning either of these. Most funeral directors offer funerals of babies free of charge.

All professionals caring for bereaved parents should be aware of differing cultural requirements.

In Worcester Royal Hospital there is a 'Book of Remembrance' kept in the entrance to the prayer room in which parents can discuss with one of the chaplaincy team to make an entry if they wish.

The Bereavement Garden at Worcester Royal Hospital is a place for quiet during their hospital stay only and not for ashes to be scattered.

6.12 Transfer to the mortuary

A member of the portering staff and clinical staff (midwife or nurse) will escort the baby in a pram or Moses basket to the mortuary.

The check book has now been replaced by a 'Mortuary Transfer Checklist' (**Appendix I**). This form documents the journey of the baby and their property between departments and complies with HTA guidance. The form will stay with the baby until their discharge to the care of the funeral directors.

All babies should be wrapped in their own blankets in the first instance, taking care not to wrap too tightly as to cause trauma to the baby's skin from accompanying property. Babies should then be wrapped further in Gamgee roll secured with micropore ensuring that the baby is totally covered. An ID band or Addressograph label should be placed on the Gamgee roll for ease of identification.

If there is to be a post-mortem, the placenta should accompany the baby to the mortuary in a labelled dry pot with **no formalin** and further stored in a plastic bag. A few drops of sterile saline can be added to keep the tissue moist. The placenta or cytogenetics sample should be sent from WRH pathology reception on the courier service to BWH Mon-Thurs before 1pm. If sampling takes place over the weekend, or no post-mortem is to take place, then the appropriately packaged sample should be kept refrigerated on delivery suite. The placenta should be sent whole with a completed clinical information for perinatal post-mortem form. (**Appendix H**)

Tissue samples for cytogenetics, having been stored in the correct medium and container, should then be placed in a white bucket, correctly labelled, and kept in the fridge on delivery suite to be collected in the same way as the placentas.

Please note, if the baby is classed as a high infection risk or if the baby is born to a mother who is high infection risk, then the baby may need to be placed in a marked body bag on delivery suite or the neonatal unit. The bags are available from the mortuary staff if required – check with staff first and inform parents.

If the baby's parents have different surnames, the baby is labelled with the mother's details on a white label and the father's details on a red label.

On arrival to the mortuary, details must be entered in the register. The register logging in process should include details of both the baby and the placenta, with the date and time of admission into the mortuary. This will be done by the portering staff. Midwifery staff do not need to go past the first reception room.

Parents must be given details of how to arrange an appointment to come back and see their baby should they wish. This is usually facilitated by the bereavement support midwives.

6.13 Bereavement support

All families should be provided with information on how to access the bereavement team, and what support is offered. The bereavement midwives are available 7 days a week and will usually call the following day but will not often visit the first day home so please ensure a community midwife visit is requested if required.

Information is provided to all women experiencing bereavement. This may include:

- Available financial help, including maternity benefits
- Exercise and advice leaflets,
- Help for bereaved parents booklet
- Funeral options
- Information regarding post-mortem consent
- Support groups
- Trust 'bereavement support following the death of a baby' leaflet (see below)
- Trust 'lactation after loss' leaflet (available on the intranet)

It is important to note that a small number of women, their partners and possibly other family members may want at some stage to see a professional counsellor. A counsellor has a relationship that is different and preferably separate from the parent's relationship with other members of staff. The Bereavement team can sign post families to support that is local to them such as Cedar Tree, Lily Mae Foundation, Rose and Daisy Foundation etc.

For families known to the neonatal team, they have access to the neonatal unit psychologist for additional support.

South Worcestershire Bereavement Support Tel helpline: 01905 760934 (available for those women registered with a GP in Martley, Evesham, Worcester, Great Malvern, Droitwich, Pershore). www.bereavementsupportworcestershire.org.uk

Miscarriage Association, Tel. No. 01924 200799, Monday – Friday 9.00 a.m. – 4.00 p.m.

SANDS (Stillbirth & Neonatal Death Society) Tel. No. 0207436 7940 Monday – Friday 10.00 a.m. – 3.00 p.m.

Cedar Tree (Miscarriage/Stillbirth Counselling/Support) Tel. No. 01905 616166

'Bereavement support following death of baby' patient information leaflet WAHT-PI-0524 covers many of the topics above including spiritual support, care of the baby following death, mementos and photography, funeral arrangement and follow up.

6.14 Follow-up

When women are discharged to their community midwifery team, an electronic postnatal transfer of care form is required to be completed on maternity badger. This is sent electronically to their GP and placed on the postnatal clipboard to ensure the community midwife is notified of the discharge. Information must be documented with a plan for follow up. For example, if and when the community midwife needs to call or visit.

All women should be offered a follow up appointment when the results of investigations are reported; the bereavement team will keep in communication with the families to keep them informed of expected timescales of this appointment. This appointment will be with a member of the bereavement team as well as either their named obstetric and/or neonatal consultant, particularly when the baby has received care from the neonatal team.

For the majority of late miscarriages, stillbirths and premature births leading to neonatal death, specialist pregnancy loss bloods will be offered at around eight weeks post-delivery. If death has occurred due to pregnancy/labour complications it may be appropriate to consider bloods at the time of birth e.g. Kleihauer, FBC, infection screening – these can be found on the IUD profile under the obstetrics tab on ICE.

Test results will be used to inform future pregnancy management plans.

Specific behaviours such as folic acid supplementation, smoking cessation, weight loss and adequate blood glucose control in diabetics should be considered.

Clear documentation, including a letter to GP, should be prepared.

It may be helpful to write to the parents to summarise findings and management in future pregnancies, in case they chose to book elsewhere in future pregnancies.

The family should be provided with a contact number, usually for the Bereavement Team, in case they have further questions and to provide a contact for early notification of future pregnancies.

6.15 Staff support

All staff need an open and supportive environment in which the stress and difficulty of caring for families who have experienced the loss of their baby are acknowledged.

Staff should feel able to share their concerns, anxieties and worries in a psychologically safe space. It is usual to offer a 'hot' and 'cold' debrief following death of a baby.

Professional nursing and midwifery advocates (PNA/PMA's) are available for additional support where required. Managers have a particular duty to provide encouragement and support to those caring for bereaved families.

All staff can access support through their line managers, PMA's, the chaplaincy team, neonatal psychology support, trust psychology support and through occupational health. Some charities also offer support for staff involved in the unexpected death of a child such as 2wish.

6.16 DATIX, Duty of Candour & governance processes

A DATIX must be completed for all pregnancy losses above 22 weeks and neonatal deaths.

If concerns have been raised on the quality of care received, please highlight this in the Datix report and inform the governance team who will ensure the appropriate process is followed, including Duty of Candour if required.

For neonatal deaths:

- Rapid review should be started within 72hours by medical and nursing team and taken to weekly safety meeting – please liaise with the governance team for support (the template is on the Datix page on the intranet – no password required).
- Exception report needs to be completed and sent electronically to the West Midlands Perinatal ODN team.

The Bereavement Team will discuss with families any standardised reviews of their care that will take place, such as the Perinatal Mortality Review Tool (PMRT), Maternity and Neonatal Safety Investigation (MNSI formerly HSIB) or a Coroner investigation. In cases of sudden unexpected deaths this will be completed by the SUDIC nurses.

Families feedback will be gathered by the Bereavement Team to be fed into the review.

7. Appendices

Appendix A: Certain and potentially life-limiting conditions identified in the perinatal period ⁽¹⁾

This is not an exhaustive list and there may be many other diagnoses in which there is uncertainty about the expected outcome and delivering palliative care is appropriate. See main text for alternative ways in which babies with palliative care needs may be recognised.

Pregnancy related

- Very severe intra-uterine growth restriction.
- Prolonged preterm rupture of membranes from early gestation with oligohydramnios/anhydramnios.

Prematurity related conditions

- 'High risk or Extremely high risk' Extremely preterm delivery e.g., preterm infants at 22-23 weeks gestation (See diagram below).
- Extremely preterm infants with severe complications, e.g. severe necrotising enterocolitis, intraventricular haemorrhage, cystic periventricular leukomalacia, severe chronic lung disease.

Perinatal management of extreme preterm birth before 27 weeks of gestation
 A BAPM Framework for Practice

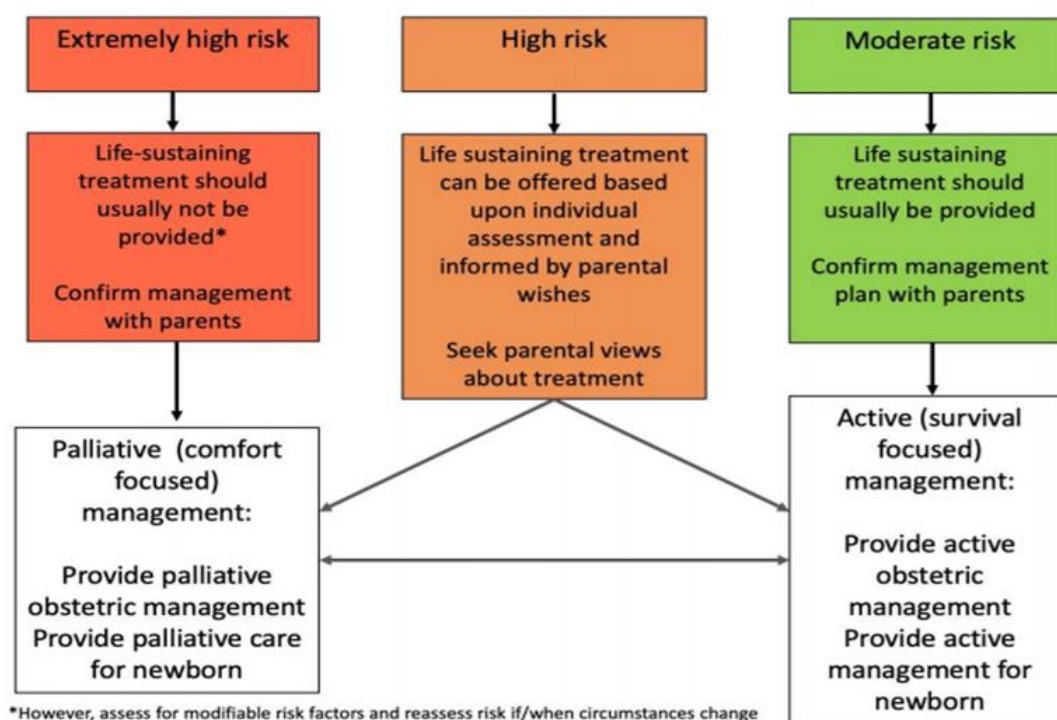


Figure 2. Decision-making around management of delivery, following risk assessment and after consultation with parents.

Multi-system

- Newborn infants with organ failure requiring escalation to extra-corporeal membrane oxygenation or dialysis or solid organ transplantation.
- Severe congenital skin disorder e.g. Epidermolysis bullosa, Harlequin fetus.
- Severe hydrops fetalis.
- Multiple severe congenital abnormalities (that may or may not be treatable) in the absence of a clear diagnosis.

Gastrointestinal

- Babies with short gut following bowel resection or long-term dependence on parenteral nutrition.

Neurological/Muscular

- Newborn infants with brain injury and high risk of severe disability, e.g. infants with severe (Sarnat III) hypoxic-ischaemic encephalopathy.
- Neonatal or fetal onset neuromuscular disorder, e.g. myotonic dystrophy, congenital myopathy, spinal muscular atrophy.
- Severe brain abnormality, e.g. Anencephaly, Craniorachischisis, Hydranencephaly, Holoprosencephaly, Iniencephaly, Lissencephaly.
- Vein of Galen malformation.

Genetic/ Chromosomal

- Severe chromosomal abnormality, e.g. Trisomy 13 and 18 (including mosaicism), triploidy.
- Post-natal exome sequencing indicates a causative diagnosis that has the potential to lead to death in early childhood.

Cardiac

- Severe congenital cardiac conditions that may not be amenable to surgery, or only with severe morbidity, e.g. single ventricle conditions.
- Severe fetal cardiomyopathy.

Airway/Respiratory

- Severe lung or airway abnormality (e.g. Alveolar capillary dysplasia, laryngeal or tracheal atresia).
- Newborns where there is a question about providing tracheostomy for long-term ventilation.
- Severe congenital diaphragmatic hernia.

Renal

- Bilateral Renal agenesis.
- Other severe disorders of renal system, e.g. severe multicystic dysplastic kidneys and oligohydramnios, urethral or bladder agenesis.

Skeletal

- Severe skeletal dysplasia (including osteogenesis imperfecta).
- Arthrogryposis with confirmed severe neuromuscular disorder.

Appendix B: Advance care plan



CYPACP-Version-5-A
ntenatal-with-ReSPe

Appendix C: Commonly used medications

The drug doses below are the most commonly ones used on the neonatal unit. They are listed in alphabetical order. Refer to the BNFC for infants older than 1 month of age.

For full list of medications and doses please see APPM (Association of Paediatric Palliative Medicine) Formulary 2024



APPM formulary 6th
edition 2024 Final 2024

Drug name	Indication	Dosage	Route
Chloral hydrate	Long term sedation*	20–30mg/kg up to max 50mg/kg 4 times daily	Oral/rectal
Diazepam	Seizures	300-400micrograms/kg as a single dose repeated once after 10 minutes if necessary 1.25–2.5mg as a single dose repeated once after 10 minutes if necessary	Intravenous Rectal (Not licenced <1yr)
Domperidone	Gastro-oesophageal reflux and stasis (avoid if known cardiac problems)	250micrograms/kg 3 times daily before feeds. Max dose 400micrograms/kg 3 times daily	Oral
Erythromycin	Prokinetic for gastrointestinal stasis	3 mg/kg 4 times a day	Oral or intravenous
Furosemide	Diuretic to help with oedema and improve renal output	0.5-2mg/kg once or twice daily 0.5-1mg/kg once or twice daily 0.1-1mg/kg/hr	Oral Intravenous Continuous infusion
Glycopyrronium bromide	Control of airway secretions and hyper-salivation	Sialanar 400micrograms/ml solution: 16micrograms/kg 3 times daily increased in steps of 16micrograms/kg every 7 days to maximum 80micrograms/kg 3 times a day. Continuous infusion 12micrograms/kg/24hrs to max 40micrograms/kg/24hrs	Oral (Not licenced if < 1month but can be considered) Intravenous/ subcutaneous

Hyoscine hydrobromide	Control of airway secretions and hyper-salivation	250micrograms (quarter of a patch to skin) every 72 hours (Not licenced if < 1month but can be considered)	Transdermal patch applied to hairless area of skin behind ear
Ibuprofen	Pain	5mg/kg every 12 hours	Oral
Lactulose	Constipation	2.5ml twice daily	Oral
Levetiracetam	Seizures	40mg/kg loading dose over 15minutes	Intravenous
		10-20mg/kg maintenance twice daily	Intravenous or oral
Midazolam	Seizures	150–200micrograms/kg loading dose over 5 mins 60micrograms/kg/hr increased in steps of 60 micrograms/kg/hr only after consultant review to a maximum rate of 300microgram/kg/hr It should be stopped if no response after 24hours.	Intravenous bolus then Continuous intravenous infusion
		300microgram/kg, repeat after 5-10minutes if required. Max 1.25mg/dose	Buccal
	Sedation	60microgram/kg/hr, adjusted according to response. After 24 hours reduce to 30microgram/kg/hr in neonates <32 weeks corrected gestational age	Continuous intravenous infusion for a maximum of 4 days
		500microgram/kg/ dose 30-60mins prior to procedure	Oral
		300microgram/kg/ dose 30-60mins prior to procedure	Buccal
	Terminal agitation	200microgram/kg/ 24hr	Continuous subcutaneous/ intravenous infusion
		150microgram/kg (max 600microgram/dose) given up to 6-8 hourly as required	Oral
		75microgram/kg (max 300microgram/dose) given up to 6-8 hourly as required	Buccal

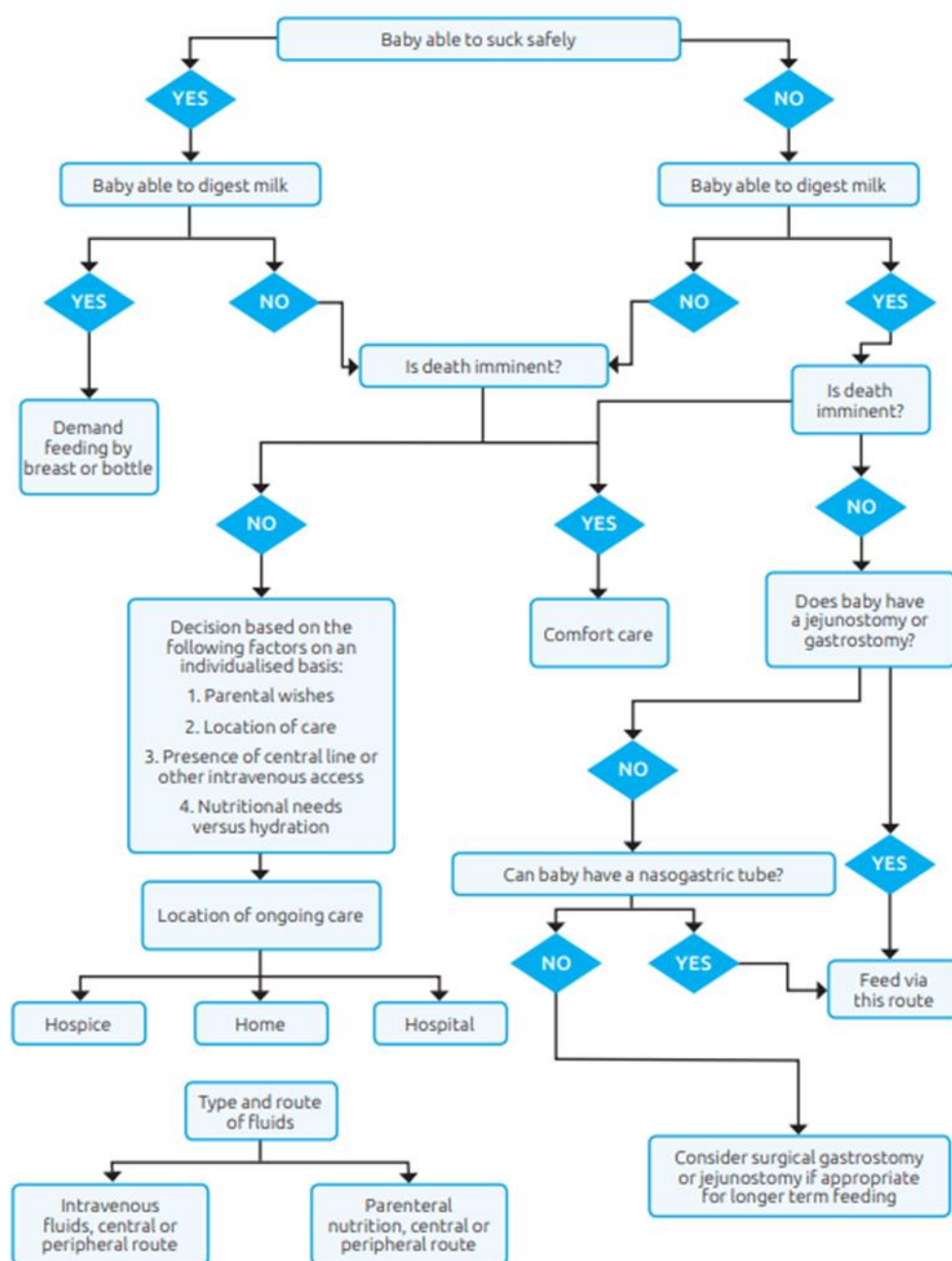
Morphine	Acute pain/post operative	<p>50–100microgram/kg infused over 5min, then by continuous infusion 5-20micrograms/kg/hr adjusted according to response up to max 30micrograms/kg/hr.</p> <p>80microgram/kg every 6 hours adjusted according to response</p> <p>160microgram/kg/ 24hr</p>	<p>Intravenous bolus then continuous infusion</p> <p>Oral/rectal</p> <p>Continuous Subcutaneous infusion</p>
Omeprazole	Gastro-oesophageal reflux	700microgram/kg once daily increased if necessary, after 7–14 days to 1.4mg/kg. Some neonates may require up to 2.8mg/kg once a day	Oral
Paracetamol As per BNFC	Pain Pyrexia	<p>Neonate 28–32 weeks corrected gestational age: 20mg/kg single dose, then 10–15 mg/kg every 8–12 hours as necessary. Maximum 30mg/kg/day</p> <p>Neonate ≥32 weeks corrected gestational age: 20 mg/kg single dose, then 10–15 mg/kg every 6–8 hours as necessary. Maximum 60mg/kg/day</p> <p>Neonate 28–32 weeks corrected gestational age: 20mg/kg single dose, then 10-15mg/kg every 12 hours as necessary. Maximum 30mg/kg/day</p> <p>Neonate ≥ 32 weeks corrected gestational age: 30mg/kg single dose, then 15-20mg/kg every 8 hours as necessary. Maximum 60mg/kg/day</p> <p>Neonate <32 weeks 7.5mg/kg 12 hourly (15mg/kg/day)</p>	<p>Oral</p> <p>Rectal</p> <p>Intravenous over 15mins</p>

		Neonate \geq 32 weeks 7.5mg/kg 8 hourly (22.5mg/kg/day) Neonate post term 10mg/kg 6 hourly (30mg/kg/day)	
--	--	---	--

***Chloral Hydrate** – MHRA alert 2021 position statement is to use for maximum of 2 weeks due to carcinogenic properties. Consider but may choose to continue use if symptoms are managed. [NPPG-Position-Statement-Chloral-Dystonia-V2.pdf](#). Oral solution contains propylene glycol which can accumulate in the neonate after repeated doses which can be potentially harmful (neurotoxicity). Must be given at the smallest dose for shortest time frame with regular review.

Appendix D: Fluid therapy

Suggested algorithm for the management of fluid and nutritional intakes



Appendix E: Taking my baby home

APPENDIX 8:

Consent letters (if child died from natural causes and a death certificate can be issued):
 Consent Letter to take a Child's Body Home from Worcestershire Acute Hospital
 Consent Letter to take a Child's Body from Worcestershire Acute Hospital to Acorns
 Consent Letter to take a Child's Body from Home to Acorns Hospice

Worcestershire Health and Care **NHS**
 NHS Trust

ORCHARD SERVICE
 (Community Children's Nursing & Palliative Care Team)

Non-emergency Health/OOH GP - 111

Non-emergency Police - 101

Consent Letter to take a Child's Body Home from Worcestershire Acute Hospital

Letter of Consent to take a Child's Body Home by Car.

Date & Time :

To whom it may concern.

Re : name : _____

NHS no : _____

D.O.B : _____ Date and time of death _____

Address : _____

G.P : _____

The family of the above named child is taking their child home from hospital.

The child died at Worcestershire Acute Hospital on Riverbank/..... and their family wish to have their child at home.

The child died of natural causes and the doctor/s is /are happy to issue the Death Certificate.

Name of doctor/s :

If you need confirmation of these details please contact the Hospital on:

....., but additional information cannot be given without the permission of the parents.

Yours faithfully,

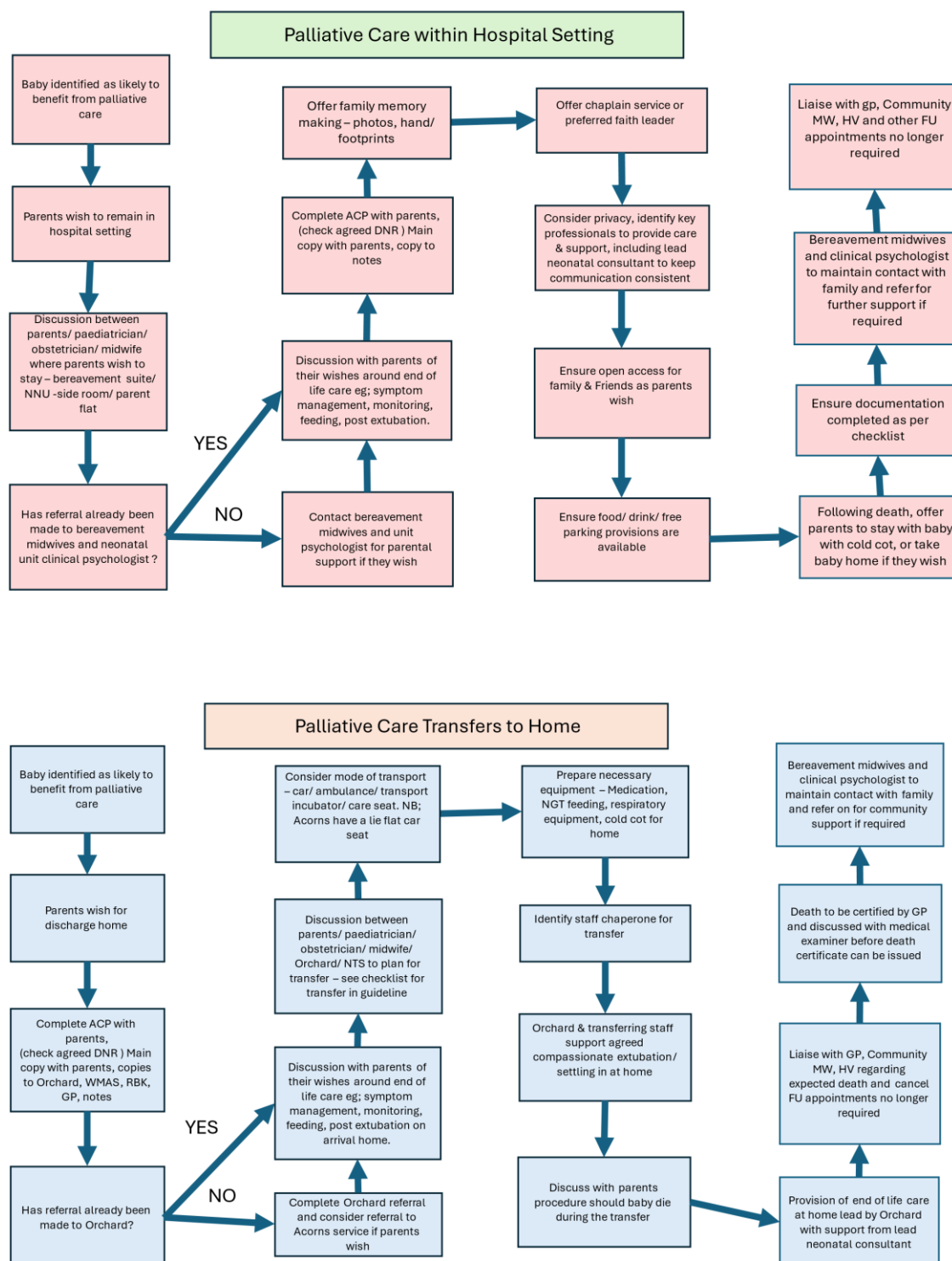
Nurse in charge :

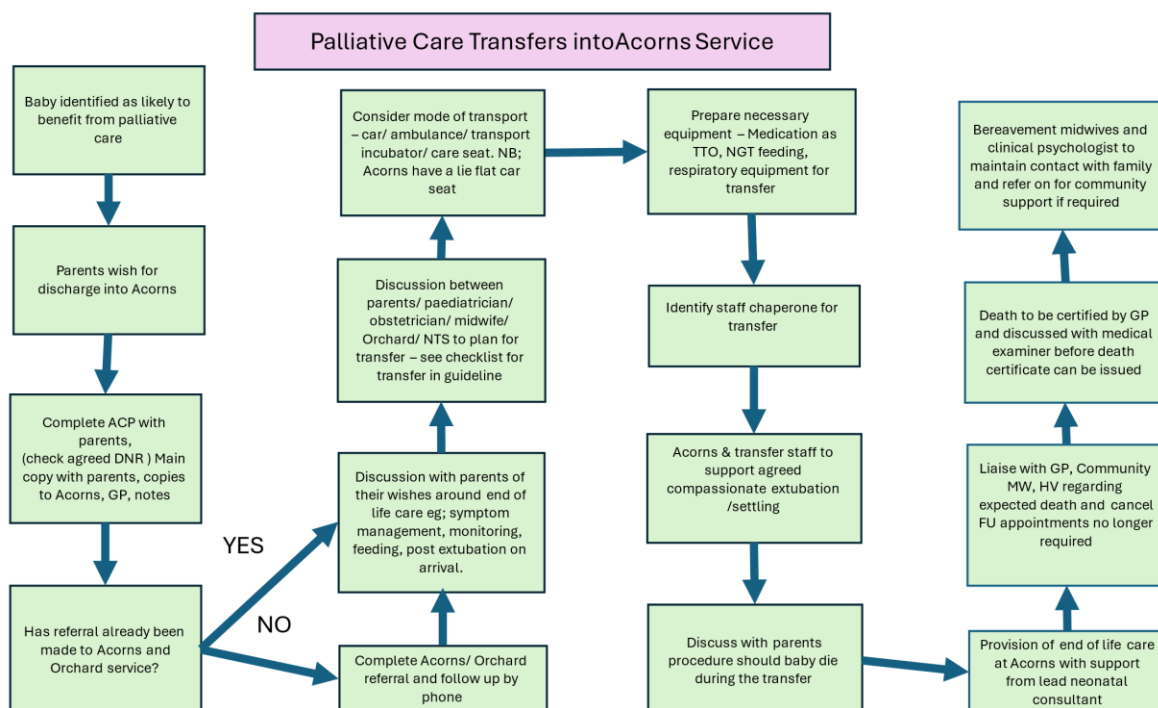
Print name

Investigation of Sudden and Unexpected Deaths in Children Under 18 Years		
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Appendix F: Flowcharts for place of care

NB: Families can move between pathways if they change their mind around place of care of the clinical situation changes.





Appendix G: Checklist



Checklist Following a Neonatal Death

Checklist to be completed following the death of a baby on the Neonatal Intensive Care Unit and Transitional Care. All sections to be completed prior to filing in the baby's notes.

Mother's name:	Baby's name:	
Mother's hospital number:	Baby's hospital number:	
Mother's NHS number:	Baby's NHS number:	
Contact telephone number:	Date of birth:	Time of birth:
Gravida: Parity:	Gestation:	
Previous NND/Stillbirth/Miscarriage		
Father's name:	Date of death:	
Names of siblings:	Time of death:	

Parent flat on the neonatal unit: If parents are at home, offer use of the parents flat situated next to the neonatal unit. Cuddle Cot or Techni ice can be used should they wish to spend time with their baby.

Snowdrop or forget me not Suites: If a mother is an in-patient on delivery suite/postnatal wards/transitional care it may be appropriate to transfer her to one of the bereavement suites with the baby. Liaise with Delivery suite shift leader, NICU shift leader and postnatal ward shift leader in this instance.

Taking baby home from the neonatal unit: If they wish, parents can take their baby home prior to registering the death. A copy of 'Taking Baby Home from NICU/Delivery Suite' must be given to the parents on discharge. Parents are then responsible for making private arrangements and must be aware they have to register the death.

A baby that has been referred to the Coroner cannot be taken home by the parents



To be completed by the nurse:

(Yes, No or N/A into Completed box)

	Completed	Signature	Date
Offer memory box, explain contents to parents			
Blessing/chaplaincy support/religious leader offered			
Discuss photographs and use of 'Remember my Baby'			
Consent for hand and foot prints			
Consent for lock of hair (if able to take any)			
Discuss washing and dressing baby			
Offer neonatal flat or bereavement suites (if applicable)			
Cot card given to parents			
Name labels given to parents			
2 new labels onto baby. Addressograph label or an ID band placed on the Gamgee roll which the baby is completely covered in.			
Complete the parental choices form			
Complete Mortuary Transfer Checklist (to be taken with baby to the mortuary and remain with them until discharge to the funeral director)			
Inform Bereavement Midwives 01905 763333 Ext 30583			
Complete Datix (to be completed for all pregnancy loss and neonatal deaths >22 weeks)			



To be completed by medics:

(Yes, No or N/A into Completed box)

	Completed	Signature	Date
Neonatal Death to be discussed with Medical Examiner & Certificate completed by medical team.			
Organ/tissue donation considered if >32/40			
Documentation completed on Badger with letter copied to GP & Community Midwife			
Family need to register the death. The Medical certificate of death will be forwarded to the registrar by the ME team after discussion with the family and countersigning by an ME.			
Ensure death notified to MBRRACE-UK by bereavement midwives within 2 working days.			
Complete Coroners referral form if required. Available online at: (www.worcestershire.gov.uk/council-services/births-deaths-marriages-civil-partnerships-and-citizenship/death-registration-services/coroners-service) or via coroners portal on intranet Or contact 01905 766066.			
Post mortem examination discussed			
Post mortem examination consent: Full Limited External Declined (Please circle)			
Post mortem consent form completed			
Follow up appointment with consultant discussed			
Consultant to inform GP of death (ensure information is disseminated within the GP surgery)			



To be completed by Ward Clerks:

(Yes, No, N/A in Completed box)

	Completed	Signature	Date
Community midwife, Health visitor and GP informed by telephone			
Inform Hearing screening team			
Send copies of badger letter to: <ul style="list-style-type: none"> GP Midwife Health visitor Neonatal screening team 			
Ensure baby is marked as deceased on PAS			

Funeral arrangements:

Families are supported with making funeral arrangements for either burial or cremation. They will be contacted by the Bereavement Team to offer advice and support.

For any advice/information please contact the Bereavement Team:

Team email: wah-tr.bereavementmidwives@nhs.net

Office: 01905 763333 Ext 30583

Steph Beddall: stephanie.beddall@nhs.net (Lead Bereavement Midwife)

Beth Saunders: pauline.saunders-smith@nhs.net (Bereavement midwife)

Clare Phillips: Clare.phillips2@nhs.net

Hours of work vary between the 3 team members, but cover a 7 day service.

Appendix H: Perinatal post-mortem consent form – available on NNU (in drawers) and from bereavement midwives office

WEST MIDLANDS PERINATAL PATHOLOGY **NHS** **Birmingham Women's and Children's**

CLINICAL INFORMATION FOR FETAL / PERINATAL POST MORTEM

Mother (sticker if available)

Family Name:.....
 First Name:.....
 D.o.B.: / /
 Reg No.....

Fetus/ Infant (sticker if available)

Family Name:.....
 First Name:.....
 D.o.B.: / / D.o.D: / /
 Reg No.....

Please carefully complete this form. Any missing information could potentially delay or alter the findings.

Parts 1, 2 and 3 ALL require completion for EVERY referral made.

REFERRING HOSPITAL:..... Ward:.....

HOSPITAL OF BIRTH (if different):.....

(Please include history/ notes from previous hospitals)

CONSULTANT OBSTETRICIAN:.....

CONSULTANT PAEDIATRICIAN:.....

Part 1. MOTHER'S DETAILS

(ALL fields for this section are MANDATORY for ALL requests please)

Ethnic origin:..... Father's ethnic origin (if known).....

Consanguinity between parents? Y/N

Maternal height:..... cm Booking weight:..... kg

Obstetric History:

PREVIOUS PREGNANCIES

	Date	Gestation	Delivery	Sex	Outcome
1.					
2.					
3.					
4.					
5.					
6.					
7.					

Were there any complications with any previous pregnancies (this current pregnancy excluded)?

Further space for writing is provided on p4 of this form.

Please carefully complete this form. Any missing information could potentially delay or alter the findings.

Parts 1, 2 and 3 all require completion.

This form consists of 4 pages. All require your attention.

Consent Form for Post Mortem Examination of a Baby or Child

to be performed at
Birmingham Women's Hospital

Show what you agree to by marking in the relevant boxes. Record any variations, exceptions and special concerns in the space in section 5.

Please be assured that your baby will be treated with respect, care and dignity at all times.

Note for the consent taker

- Anyone seeking consent for hospital PM examinations should have relevant experience and a good understanding of the procedure. They should have been trained in dealing with bereavement and in the purpose and procedures of PM examinations and they should have witnessed a PM examination (Refer to Code of Practice A – Consent and Code of Practice B – Post Mortem Examinations, Human Tissue Authority 2017).



DISTRIBUTION

Yellow - Patient Blue - Hospital Notes Grey - Pathology

Appendix I: Mortuary Transfer Checklist



Transfer to Mortuary Checklist

Maternal addressograph	Babies addressograph If issued or baby's name
Gestation:	
Baby ID band insitu <input type="checkbox"/> Stillbirth/Neonatal death = own ID band on wrist and ankle, plus one maternal ID band with 'baby of' added. Miscarriage = maternal wristband with 'baby of' added and wrapped around waist (smaller babies) (if different surname to be used ie: partners, place an additional red wristband with the same details of baby and alternative surname on one wrist or ankle.	
Baby wrapped and Gamgee labelled with cot card/maternal addressograph <input type="checkbox"/> If baby labelled with own ID numbers include baby addressograph on Gamgee. Complete infection status on page 2.	
Property transferred with baby List any items such as teddies, blankets, clothing and keepsakes. Please update if additions are made/items removed during visits	
If for post-mortem transfer placenta with baby <input type="checkbox"/> N/A <input type="checkbox"/> Place placenta in a placenta bag, zip tie and label with a maternal addressograph. Place the bag in a white pot with the lid secured and label with maternal addressograph on the side and lid. Place white pot in clear plastic bag. NB: if placental histology only, placenta should be transferred to WWH pathology reception for courier to BWH	
Post-mortem consent form, clinical information form and USS copies <input type="checkbox"/> N/A <input type="checkbox"/> Place in a separate brown envelope to midwife certificate and label 'PM paperwork' with a maternal addressograph	
Midwives certificate (none-registrable birth) <input type="checkbox"/> N/A <input type="checkbox"/> Place in a brown envelope and label 'paperwork for funeral directors' with a maternal addressograph. Keep a photocopy in the notes	
Document visits to and from Delivery Suite (date/time, property present/added, return to Mortuary date/time)	
Date/time transferred to Mortuary:	
Midwife signature:	Midwife print:
Porters signature:	Porters print:
Date/time transferred back to <u>maternity unit</u> for parental visit:	
Midwife signature:	Midwife print:
Porters signature:	Porters print:



Date/time transferred back to Mortuary:	
Midwife signature:	Midwife print:
Porters signature:	Porters print:
Date/time transferred back to <u>maternity unit</u> for parental visit:	
Midwife signature:	Midwife print:
Porters signature:	Porters print:
Date/time transferred back to Mortuary:	
Midwife signature:	Midwife print:
Porters signature:	Porters print:

Infection Status (tick where appropriate) Airborne Infection <input type="checkbox"/> Blood-borne Infection <input type="checkbox"/> Gastro-Intestinal Infection <input type="checkbox"/> Neurological Infection <input type="checkbox"/> Contact Infection <input type="checkbox"/> Leakage <input type="checkbox"/> Other <input type="checkbox"/> None <input type="checkbox"/> A Guidance for FD form should be completed on admission if the patient has an infection. Also complete an FD form if they are unsatisfactory and/or when the patient hit their 14-day long-stayer trigger.	
Mortuary use only Winpath Number: Date of admission to Mortuary: Condition on arrival Satisfactory <input type="checkbox"/> Decomposed <input type="checkbox"/> Leaking <input type="checkbox"/> Other <input type="checkbox"/> Comments:	Patient Property checked against "Transfer to Mortuary Checklist" Date/Sign: Date/Sign: Date/Sign: Date/Sign:

Appendix J: Parental choices form

Parental Choices



Maternal addressograph	Partner's name:
Phone number:	Phone number:
<u>Babies</u> addressograph if issued	Gestation:
Baby's name:	Sex:
Date/time of birth:	Miscarriage <input type="checkbox"/>
Date/time of death:	Stillbirth <input type="checkbox"/>
(if applicable)	Neonatal Death <input type="checkbox"/>
Seen by Chaplain: yes/no	Medical Examiner notified <input type="checkbox"/>
Name of Chaplain:	Coroner notified <input type="checkbox"/>
Chaplain to run service: yes/no	Post-mortem being <u>held</u> : yes/no
Funeral Director chosen:	Cytogenetics only: <input type="checkbox"/>
Jacksons Family <input type="checkbox"/>	Placental histology only: <input type="checkbox"/>
Thomas Brothers <input type="checkbox"/>	No examination <input type="checkbox"/>
Edwin Harris <input type="checkbox"/>	Burial <input type="checkbox"/>
Other:	Cremation <input type="checkbox"/>
Attend <input type="checkbox"/>	Ashes to be returned <input type="checkbox"/>
Non-attend <input type="checkbox"/>	Ashes to be scattered <input type="checkbox"/>
Wish to know date/time: yes/no	Witnessed <input type="checkbox"/>
Date/time of funeral:	Unwitnessed <input type="checkbox"/>
Parents informed <input type="checkbox"/>	Location for scattering:
Any other information:	



Appendix K: Resources



8. References

1. Recognising uncertainty: An integrated framework for palliative care in perinatal medicine. A BAPM framework for practice (2024)
2. BAPM Perinatal Management of Extreme Preterm Birth Before 27 weeks of Gestation (2019)
3. Practical guidance for the management of palliative care on neonatal units (2014). A Mancini, S Uthaya, C Beardsley, D Wood and N Modi. Endorsed by RCPCH
4. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (2014). Vic Larcher et al. Archives of Disease in Childhood. Endorsed by RCPCH.
5. ACT valuing short lives. A Neonatal Pathway for Babies with Palliative Care Needs (2009)
6. A Neonatal Pathway for Babies with Palliative Care Needs (TFSL 2024)
http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/neonatal_care_pathway
7. SANDS stillbirth and neonatal death charity – various leaflets and support on website
8. MBRRACE UK (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries)
9. BLISS for babies born premature or sick. Neonatal strand of the National Bereavement Care Pathway
10. Network Neonatal guidelines 2022-2024
11. British National Formulary for Children (BNFc). BMJ Publishing Group Ltd, RPS Publishing, RCPCH Publications Ltd