

Sudden and Unexpected Postnatal Collapse:
A BAPM Framework for Reducing Risk, Investigation
and Management

May 2022

# Sudden Unexpected Postnatal Collapse A BAPM Framework for Practice

# Contents

Summary of recommendations	3
Introduction	4
Purpose	4
Definition	5
Target users	5
Background	5
Framework for practice: process and review	7
Funding	7
1. The SUPC Risk Reduction Pathway	8
1.1 Principles of safe care	8
1.2 Specific staff education, including parental education and empowermen	t11
1.3 Audit and Evaluation	11
2. Assessment, Investigation and Management	12
2.1 Care pathway - Immediate action	12
2.2 Care pathway - Detailed assessment	12
2.3 Care pathway - Monitoring	12
2.4 Care pathway - Investigation	13
2.5 Care Pathway - Reporting and Review	17
2.6 Care pathway - Ongoing management	18
2.7 Care pathway - Discharge and follow up	21
References	23
Appendix 1. Sample staff education programme	26
Appendix 2. Resources	29
Appendix 3. Recommended dataset	31
Appendix 4. Aetiologies of SUPC	33
Appendix 5. The radiological investigation of suspected physical abuse in child	ren 35
Appendix 6. Protocol for MRI examination of brain	36
Appendix 7. Post mortem procedure	37
Appendix 8. Perinatal Mortality Review Tool: Parent Engagement Flowchart	39
Appendix 9. Signposting and support organisations for parents	40
Appendix 10. Members of working group	41
Annendix 11 Stakeholder Consultation	42

## **Summary of recommendations**

- There should be ongoing effective surveillance of all mothers and infants in the hours and days after birth, in order to help prevent sudden and unexpected postnatal collapse (SUPC) in otherwise healthy babies
- A risk reduction pathway should be implemented, including specific staff and parental education programmes which are audited and evaluated
- Skin-to-skin contact has numerous benefits for parents and infants, and should be offered and supported as part of ongoing care for all babies who are well at birth (irrespective of feeding method), ensuring staff are available to support and that information is shared with parents about keeping baby safe and well
- Care providers should have guidelines and processes which ensure safety during skin-to-skin practices, breastfeeding, bottle-feeding and infant sleep.
- Infants who suffer a SUPC within the first week of life should be recognised as having an
  increased risk of infection, congenital anomaly or metabolic disease as an underlying cause for
  their collapse and undergo comprehensive investigation to determine this
  - A detailed history of the family and of situational events is essential and should be obtained by a senior member of medical staff
  - This investigatory process should involve interdisciplinary liaison to maximise diagnostic yield whilst minimising unnecessary tests for the baby
- Therapeutic hypothermia may be considered after effort is taken to determine any underlying reason for collapse, and after discussion with parents about potential benefit and risk
- All infants who die following a sudden and unexpected collapse where the <u>cause of the</u>
   <u>collapse</u> has not been established before death (and includes those where death is secondary
   to hypoxic-ischaemic sequelae) should be notified to the Coroner/Procurator Fiscal. These
   infants should undergo a post mortem examination performed by a perinatal pathologist.
- A detailed multiprofessional case review should follow the investigation of any unexpected infant death as per national standards

Heidi had a SUPC during skin-to-skin within the first hour of life. She needed resuscitation and was transferred to our level 3 unit for cooling. We stayed in hospital for 8 weeks before transferring home. Heidi is now nearly 7 — cerebral palsy, fully tube fed, tracheostomy, and a list of extras, but is a very happy and much-loved little girl who enjoys school (and watching Strictly Come Dancing!).

I wish I had known about SUPC before I had Heidi. I was naïve in the sense that I thought we were out of danger when we got to term. If I had known that SUPC was a thing then maybe I would have known more about what to look out for, had more confidence to question things. I also wish I had known that life after HIE would be ok, even if our 'ok' isn't as we originally planned.

Sarah Land, mother of Heidi.

© BAPM, 2022



#### Introduction

#### **Purpose**

This Framework for Practice (FfP) provides guidance for care providers and all perinatal professionals to help prevent the occurrence of Sudden Unexpected Postnatal Collapse (SUPC) in the first week after birth through careful surveillance and risk assessment with effective observation of all mothers and babies in the immediate postpartum period. This guidance aims to support safety whilst promoting skin-to-skin contact, supporting parents to get breastfeeding off to a good start and encouraging parents to start building a close and loving relationship in the early postnatal period.

This FfP also provides guidance for the management of infants who survive SUPC, and aims to standardise the investigation of both survivors and those who die in order to:

- Establish the most likely cause of collapse.
- Determine any underlying disease whether or not it is considered a direct cause for collapse.
- Provide information relevant to the future reproductive health of parents and the future. health of siblings of the case infant.
- Collect and secure evidence where required by the Coroner/Procurator Fiscal.
- Clarify prognosis and plan ongoing management in those who survive.

It takes account of recommendations from the Healthcare Safety Investigation Branch (HSIB) National Learning Report on Neonatal Collapse alongside Skin-to-skin Contact<sup>1</sup>, guidance for the investigation of Sudden Unexpected Death in Infancy (SUDI)<sup>2</sup> and the expert consensus of a group of UK perinatal professionals.



We are grateful for the HSIB for working in collaboration with BAPM on this document.

This document is not intended to replace or duplicate the existing guidance for the investigation of Sudden Unexpected Death in Infancy<sup>2</sup> but aims to improve the likelihood of diagnosis in this group of infants who collapse soon after birth. The 2018 Statutory and Operational Guidance in England applies in full to all child deaths from birth to the age of 18years in England, and must be followed for all child deaths, including those in the perinatal period. Specifically, unexpected collapse in the perinatal period that leads to the death of the infant must trigger a Joint Agency Response as defined in the guidance, and the precise arrangements for multi-agency involvement will be determined by the circumstances and place of the sudden collapse.

#### **Definition**

For the purpose of this FfP, an infant who suffers a 'Sudden Unexpected Postnatal Collapse' includes any term or near term (≥35 weeks' gestation\*) infant who:

- is well at birth (with a normal 5-minute Apgar score\*\* and deemed well enough to have routine postnatal care) and,
- collapses unexpectedly (i.e. discovered in a state of cardiorespiratory compromise such that resuscitation with intermittent positive pressure ventilation is required) and,
- collapses within the first seven days from delivery and,
- either dies or goes on to require intensive care with or without developing an encephalopathy.

It is recognised that some other infants may experience a lesser degree of collapse, for example they may respond to IPPV without need for intensive care. Clinicians should seek to understand the reasons for such collapse in all babies and may find the investigatory approach outlined in this document useful for all such babies.

- \* Note the gestational lower limit in this document has been extended to infants from 35+0 weeks, the majority of whom are nursed alongside their mothers after birth in the UK. Where a hospital facilitates even less mature infants to remain with their mothers while receiving enhanced postnatal care, the general principles of prevention, management and investigation still apply.
- \*\* A normal 5 minute Apgar score is defined as 7 or above<sup>3</sup>. In infants with dark skin tones it is more difficult to assess the 'appearance' element from the skin alone. Instead, the colour of the nail beds, tongue and oral mucosa should be examined.

#### **Target users**

- All maternity staff caring for the mother during labour, and for the mother and her baby in the hours and days after birth
- All paediatric and neonatal staff involved in the care of the newborn
- Radiologists undertaking antenatal and/or ante mortem and/or post mortem imaging of the newborn
- Pathologists undertaking perinatal post mortem examinations.

### Background

Sudden unexpected postnatal collapse (SUPC) in the days and hours after birth occurs in 2.6-19 per 100,000 livebirths<sup>4</sup> with an incidence in the first twelve hours of 1 in 20,000 live births within the United Kingdom<sup>15</sup>. Whilst rare in any individual centre (for example, it may occur on average around once every 4 years in a unit with 5000 births per annum), it has potentially catastrophic consequences including death or severe disability in 33-56% of cases and a post-asphyxial encephalopathy in three quarters of those who do not have an identified underlying cause<sup>56</sup>.

The timing of SUPC is close to birth with a third occurring in the first 2 hours, a further third between 2 and 24 hours, and the remaining occurring largely by 72 hours. The pathoaetiology is complex with newborn infants generally falling into two categories with a remaining small number of infants where the cause of collapse remains undetermined despite comprehensive investigation<sup>5</sup>. These categories are:

- Infants with an underlying condition where signs are not recognised.
- Infants where the circumstances suggest accidental asphyxiation secondary to airway obstruction.

# Sudden Unexpected Postnatal Collapse A BAPM Framework for Practice

As such SUPC may be the most preventable tragedy to befall well newborn infants in contemporary times and indeed key situational risk factors are consistently identified<sup>67 48</sup> including:

- Position of the mother and baby during skin-to-skin contact (SSC).
- Position of the mother and baby during breastfeeding.
- Prone position of baby.
- First-time parents.
- Parents left unsupported while caring for their baby.
- Reduced maternal awareness through sedation from analgesia, position, fatigue or distraction through mobile phone use.
- Dim lighting.

Close monitoring of all mothers and babies has significant potential either to fully prevent or to substantially modify the severity of deterioration and collapse. As such national learning reports<sup>1</sup>; international organisations<sup>9</sup>; resuscitation councils<sup>10</sup> and professional paediatric and nursing organisations<sup>9</sup> 11 12 13 recommend that services providing routine newborn care develop policies and processes for risk assessment of mothers and babies from birth, including:

- Effective observation of the mother and baby in the first hours after birth.
- Education of parents and listening and responding to parents' concerns.
- Development of a clear pathway to improve safety for postnatal care practices.

This FfP proposes a pathway for reducing the risk of SUPC, starting before birth and continuing to discharge and beyond.

Underlying congenital anomalies and conditions arising through pregnancy and birth are over-represented in this group of infants compared to older infants who suffer sudden unexpected death<sup>14</sup> <sup>15</sup>, and include antenatal brain injury, infection, metabolic defects, congenital central hypoventilation syndrome, congenital adrenal hypoplasia and cardiac abnormalities such as structural anomalies, cardiomyopathy, infarction and conduction abnormalities (Appendix 4). When babies die, determining the cause has important implications for the parents, not only in explaining their baby's catastrophic deterioration but also in aiding the grieving process and providing information for future pregnancies. In those infants who survive, a detailed set of investigations will optimise the chance of finding an explanation for the collapse which will have implications for management and prognosis of the infant.

The proximity to birth and the frequency with which SUPC is associated with postnatal care practices such as ineffective observation of the baby's wellbeing, positioning during skin-to-skin contact or during breastfeeding, parents being left alone and their concerns not being heard means a thorough examination of perinatal and situational factors is essential. Although the guidance for Sudden Unexpected Death in Infancy (SUDI) should inform the investigation of all infant deaths, the emphasis is on those dying outside hospital after the first month of life, where parental lifestyle factors and physical abuse have more contribution. Moreover, for babies who suffer a SUPC in hospital and who subsequently die, there is an opportunity to carry out investigations during the period of intensive care. This FfP provides a comprehensive dataset and investigatory schedule both for babies who die and for those who survive.

Management of the infant who survives a SUPC is largely supportive with treatment of the underlying cause where determined. However, around three quarters of infants where there is no identified cause for collapse, go on to develop a typical post-asphyxial encephalopathy<sup>7</sup>. Many of

# Sudden Unexpected Postnatal Collapse A BAPM Framework for Practice

these infants appear to have had a short severe hypoxic-ischaemic insult resulting from acute airway obstruction. This FfP provides basic neuroprotective principles of management as well as providing key information and resources for communicating with and supporting parents.

#### Framework for practice: process and review

The first edition of this FfP was the 'Guideline for the Investigation of Infants suffering a Sudden and Unexpected Postnatal Collapse'<sup>16</sup>. This document solely focussed on investigation of this group of infants and was endorsed by the BAPM in 2011. Following the 2019 HSIB National Learning Report there was appreciated a need to revise this document to provide preventative guidance for Trusts. Past members of the original group, self-selected BAPM members and representatives from key organisations were assembled as an expert group.

This new document provides a framework with which Trusts can develop a local risk reduction pathway including strategies for risk assessment and enhanced observation in the neonatal period. The previous schedule of investigations has been updated in line with current evidence and practice. Management includes a key focus on the needs and support of parents and consideration of therapeutic hypothermia.

The information provided in this FfP will be reviewed by BAPM and where appropriate updated in line with new evidence and opinion in December 2027.

#### **Funding**

The charity WellChild (www.wellchild.org.uk) funded development of the original guidance in 2011 following their funding of the British Paediatric Surveillance Unit Study of the Incidence of Sudden Unexpected Postnatal Collapse<sup>16</sup>. The views or interests of the funding body have not influenced the final recommendations of this guideline.

# 1. The SUPC Risk Reduction Pathway

SUPC may be preventable or at least modifiable through early identification of underlying conditions or processes which may lead to impaired cardiorespiratory function during transition to extrauterine life and/or the identification of a potentially asphyxiating position during routine postnatal care practices. Whilst it is recognised that some babies may be at greater risk of SUPC, all babies are at risk due to the sudden and unexpected nature of the event. This risk reduction pathway is therefore applicable to **ALL** babies and includes those born in hospital and at home.

Some of the known risk factors of SUPC overlap with those associated with baby falls. Therefore, the BAPM Framework for Practice for Baby Falls should be considered alongside guidance for SUPC in order to inform an overarching prevention policy<sup>17</sup>. This should continue in addition to active promotion of skin-to-skin contact (SSC), effective early infant feeding and healthy parent-baby relationships.

In preventing both SUPC and baby falls, there are common key recommendations:

- 1. Principles of safe care, including effective observation and assessment of the mother and baby during routine postnatal care practices.
- 2. Specific staff education.
- 3. Parental education and empowerment.

The following section outlines these recommendations in relation to SUPC and provides ideas for change, sample training programmes, resources, and a prevention pathway.

#### 1.1 Principles of safe care

It is essential that parents, birth partners and carers understand the importance of effective observation of their baby. Preparation for this starts in the antenatal period; families need to be empowered to share their concerns and call for help if needed, knowing that they will be listened to. Staff need to undertake effective monitoring processes, be supported to listen to families and know how to take prompt action when required.

Modifiable risks should be identified and addressed, for example by:

- Supporting parents to remain engaged with their baby.
- Keeping the baby close.
- Enabling parents to raise concerns.
- Ensuring optimal positioning of the mother/partner/carer and baby when in SSC or when in the cot.
- Ensuring staffing levels are sufficient to support effective observation and assessment of the mother/parent/carer and baby.

Staff need to maintain situation awareness, particularly when undertaking tasks immediately following birth. Staff should delegate the responsibility for effective observation and assessment of the mother/parent/carer and baby to a colleague if unable to undertake that task themselves (http://bit.ly/rcog\_video)<sup>18</sup>.

#### Principles of safe care to reduce the risk of SUPC

#### 1) Effective antenatal conversations, to include a discussion on:

- a) The value and safe facilitation of skin-to-skin contact (SSC), irrespective of feeding method
- b) Supporting parents to observe and recognise that their baby is well and to feel confident to call for help at any time.

#### 2) Care immediately after birth

- a) Offer to lay the baby in SSC with the mother or parent in conjunction with an assessment of Apgar score of the baby at 1, 5 and 10 minutes
- b) Position the mother in a semi-recumbent position (45°) so the baby is not lying fully prone
- c) When in SSC, ensure that:
  - i) the baby's head is turned to the side and that their chin is not on their chest
  - ii) the mother can see the baby's face
  - iii) the baby's nose is not pressed against any maternal body parts
  - iv) the baby's legs are flexed.
- d) Encourage parents to observe their baby and empower them to raise any concerns with staff
- e) Ensure that ongoing, effective observations of mother and baby continue under adequate lighting.

#### 3) Ongoing care of the:

#### Mother

- a) Continue observations of the mother's vital signs and level of consciousness throughout the period of SSC, with particular attention to any sedation, fatigue, limited mobility, procedures or pain. Ongoing support and supervision of the mother should be provided in order to observe changes in the baby's condition. Support should be given to reposition the baby when needed
- b) Many mothers can continue to hold their baby in SSC during perineal suturing or caesarean section, provided they have adequate pain relief. However, a mother who is in pain may not be able to hold her baby safely. Mothers should not be in SSC with their baby when they are receiving Entonox or if consciousness is affected as a result of other analgesics or medicines. If mother is undergoing such a procedure, the baby should be observed by an additional person such as family/staff member.

#### **Baby**

- c) All babies should continue to be observed both when held by the mother/parent/carer or when placed in the cot. Observe the following under adequate lighting:
  - i) Position: check that the baby's position is such that a clear airway is maintained. Observe respiratory rates and chest movement and listen for unusual or absent breathing sounds
  - ii) Perfusion: assess perfusion of the baby by looking at their entire body. Limbs can often appear discoloured, and even subtle changes to colour can indicate a change in the baby's condition.
  - iii) Tone: the baby should have a solid, flexed tone and should not be limp or unresponsive.
  - iv) Temperature: ensure the baby is kept warm from birth onwards.
- d) Utilise appropriate pathways for babies at risk, such as NEWTT. Perform Routine Newborn Examination +/- pulse oximetry for detection of critical cardiac conditions

#### **Environment**

- e) Staff should maintain a high level of situation awareness in relation to care provision and their environment. Ensure the mother is continually supported and assisted with the care of the baby during the first 2 hours after birth, with the help of partners/family or staff members, or until her and her baby's condition exhibit no cause for concern. Ensure that if staff are not able to easily and adequately monitor baby's condition that additional staff members are involved
- f) Parents should be encouraged to continually observe and respond to their baby's needs during SSC avoiding distractions (such as using a mobile phone) which may distract them from observing and changes in their baby and raising concerns.

### 4) Support and information for parents

- a) Parental education should include information:
  - i) on how to recognise when the baby is well and when the baby shows signs of illness
  - ii) that includes verbal/written/visual formats appropriate to individual language needs/context.
- b) Parents should be enabled to raise concerns, ask questions and to know that they will always be listened to and that actions will be taken to respond immediately to any concerns raised.

# The SUPC Risk Reduction Pathway

Effective perinatal team knowledge and skills to help reduce the risk of SUPC

**Antenatal** 

Labour

At birth- 2 hours

Subsequent hours and days Transfer home/ ongoing care

#### **PREPARE**

#### Antenatal conversations

- Parents should be encouraged to connect with their baby in pregnancy
- Remind parents of the value of skin-to-skin contact (SSC) for all babies
- Explain how to get breastfeeding off to a good start and the value of human milk
- Position baby safely in SSC
- Advise parents on how to recognise that their baby is well and when baby is showing signs of illness
- Remember to share information on safe sleep practices
- Enable parents to recognise when help is needed and how to call for assistance

#### **SUPPORT**

#### Mother

- Skin-to-skin: offer to lay baby in skin-to-skin, with mother in semi-recumbent position so baby is not lying fully prone
- Understanding: ensure parents understand how to raise concerns; always listen and respond immediately to any concerns. Discourage mobile phone use during SSC.
- Position: offer help for breastfeeding and to change baby's position if required
- Practice continued effective observation of mother and act if any changes in mother (e.g. sedated, fatigued, limited mobility, undergoing procedures, pain)

#### Baby

- Ongoing observation: assess Apgar scores and ensure ongoing effective observations, including positioning, clear airway, flexed legs
- React: take action if baby shows any changes in respiration, breathing sounds, perfusion. tone, temperature.

#### **Environment**

Timely observation/assessment of mother and baby, ensure family are not alone in first hour

#### **OBSERVE**

#### Mother

- Ongoing observation and assessment of SSC
- Breastfeeding and bottle-feeding support for responsive feeding
- Safe sleep guidance both in hospital and on discharge to home
- Ensure mother knows how to recognise a well baby and raise concerns, in hospital and at home.

Regular assessment of wellbeing in SSC and in the cot, including observations for any signs of illness e.g. reluctant feeder, hypoglycaemia, poor thermal control. Perform Routine Newborn Examination +/- pulse oximetry for detection of critical cardiac conditions

#### Environment

- Vigilant awareness by staff of environment, mother and baby
- Ensure parents are always listened to and staff respond

**Apgar** score

•1min

•5min

•10min

Ongoing effective observation and mother and baby

- Positioning in SSC
- Mother's wellbeing
- Vital signs
- Mobility
- Pain management

#### Baby's wellbeing

- Feeding
- Activity
- Respiration, Perfusion Tone & Temperature

Relevant pathways if required

- NEWTT
- •Reluctant feeder
- Hypoglycaemia
- Falls

10 © BAPM, 2022

#### 1.2 Specific staff education, including parental education and empowerment

A rolling education programme should adequately train relevant staff in all settings to be able to reduce the risks, recognise and respond to SUPC and should ensure that staff are familiar with the relevant policies. See (Appendix 1) for a sample education programme.

All hospitals should have standardised guidelines/policies (see Appendix 2 for resources) for assessing and monitoring the wellbeing of:

- The mother and baby at birth, including during promotion of safe SSC, irrespective of feeding method.
- Babies when in SSC with a partner or carer
- Mothers and babies whilst breastfeeding
- Babies being bottle fed by their parent or carer
- Babies when asleep.

Units who are working to achieve Baby Friendly Accreditation will have a training programme in place to support safe skin-to-skin care with regular training updates and practical skills assessment.

#### 1.3 Audit and Evaluation

Units must consider how they implement, audit and evaluate the recommendations, including:

- Provision of antenatal education and resources for parents to raise awareness of SUPC.
- Delivery of an ongoing specific staff education training programme.
- Orientation and updating of staff to relevant guidelines/policies.
- Evaluation/audit of impact of all areas of the prevention pathway.

Many hospitals now supplement face-to-face education with virtual learning. The SUPC risk reduction pathway (above) and readily visible posters and crib cards also serve as a further reminder to parents/carers and staff (Appendix 2).



Cillian was born by caesarean section two days after his due date when I stopped feeling him move in the womb. He was only 6 lb 1 oz at birth. He started to breastfeed well but after around 36 hours he vomited. When I told staff I was concerned I felt my concerns were dismissed so I didn't feel confident to speak up again when he stopped feeding in the hours afterwards. The staff were attentive to me, but I felt they never really checked in on Cillian. In the morning I was encouraged to do skin to skin but I found him floppy and not breathing. He needed resuscitation but had a pulmonary haemorrhage and was transferred for oscillation. He is now nine years old and thankfully is doing well. The whole event was terrifying and I have blanked many details out. We both wish we had been offered more support afterwards and directed towards organisations that could have helped us understand it all better.

Niamh O'Neill, mother of Cillian.

## 2. Assessment, Investigation and Management

This guidance aims to support units to develop an approach to assessing and managing babies safely following a sudden unexpected postnatal collapse specifically in the clinical setting.

#### 2.1 Care pathway - Immediate action

The UK Resuscitation Council NLS algorithm outlines the approach to newborn resuscitation and should be followed in the case of a SUPC even if the baby is several hours or days old<sup>19</sup>. The priority should be ensuring a patent airway and establishing or re-establishing cardiorespiratory stability. In a baby who is several days old, the umbilical cord may not be suitable for access in an emergency and intravenous (IV) or intraosseous (IO) access should be considered in a baby where cardiopulmonary resuscitation does not quickly result in improvement in the heart rate.

The majority of SUPC occur in hospitals but they can also occur in the homebirth setting. In this instance, immediate assistance should be requested via 999. First responders and ambulance staff are to follow their protocols and guidance towards initial resuscitation and stabilisation before arranging timely transfer to a suitable nearby hospital.

Parents should be facilitated to be with their baby during resuscitation if they wish and supported by nursing, medical or midwifery staff throughout.

#### 2.2 Care pathway - Detailed assessment

Following resuscitation and stabilisation of the infant, a detailed assessment of the event, the background history and current circumstances should be undertaken. This is fundamental in understanding the mechanism of collapse and in formulating a differential diagnosis in the case of an underlying condition. Situational factors at the time of collapse such as the position of the mother and of the baby, the awareness state of the mother and baby, lighting, the names, roles and activities of attendant staff and family, and last known record of baby appearing well, are essential pieces of information.

#### Assessment should include:

- Obtaining a detailed history from parents, family and caregivers about the collapse and the
  preceding hours (See Appendix 3 for a recommended dataset). Many parents will have made
  a video recording or taken photos of the baby prior to collapse— seeing these may be
  extremely helpful in identifying any predisposing factors.
- Completing a thorough examination including neurological assessment.

#### Then:

- Consider the place of further care and observation.
- Undertake relevant investigations with blood sugar and blood gas taken as soon as possible after resuscitation as a minimum.
- Instigate initial treatment for likely causes e.g. hypoglycaemia, infection.

#### 2.3 Care pathway - Monitoring

The location and extent of monitoring after a postnatal collapse should be carefully considered by a senior decision maker. This will be a clinical decision based on the circumstances of the collapse and extent of resuscitation (if any) that was required. The likelihood of secondary complications as well as recurrence of the event should be taken into consideration. Those born in the community should be transferred to a hospital with appropriate neonatal expertise and facilities for ongoing

monitoring, investigation and management. The safest place of care may be influenced by staffing levels and parental factors.

The following suggestions indicate the level of monitoring dependent on location. The duration of observations and monitoring will depend on the baby's condition:

Ongoing care beside mother (Labour ward, Birth Centre and Postnatal ward)

- Regular intermittent observations (Newborn Early Warning Trigger and Track (NEWTT) or equivalent) for at least 12 hours.
- Regular blood sugar monitoring until a stable glucose profile has been ascertained.
- Healthcare professional observation and assessment.
  - when the baby is in skin-to-skin contact with the parent/carer irrespective of feeding method
  - o of mother and baby whilst breastfeeding
  - when the baby is being bottle fed by their parent or carer
  - o when the baby is asleep.

#### SCBU/LNU/NICU

- Regular intermittent observations (Newborn Early Warning Trigger and Track (NEWTT) or equivalent).
- Regular blood sugar monitoring until a stable glucose profile has been ascertained.
- Continuous oxygen saturation and/or ECG monitoring.
- Non-invasive blood pressure or invasive blood pressure monitoring where signs of cardiovascular compromise.
- Assessment of acid-base and respiratory status with blood gas measurement.
- Assessment of neurological status at least 1-2 hourly for the first 6 hours after collapse.
- Cerebral function monitoring (CFM) if signs of encephalopathy develop.
- Healthcare professional observation and assessment
  - when the baby is in skin-to-skin contact with the parent/carer irrespective of feeding method
  - o of mother and baby whilst breastfeeding
  - o when the baby is being bottle fed by their parent or carer
  - when the baby is asleep.
- Consider assessment of end-organ hypoxic injury: renal and liver function tests, echocardiogram, brain MRI.

#### 2.4 Care pathway- Investigation

#### 2.4.1. SUPC outside hospital

These cases should be investigated as per the guidance for the investigation of Sudden Unexpected Death in Infancy<sup>2</sup> and according to any local procedures. The following additional investigations are recommended in this early neonatal group due to the temporal proximity to birth as well as the contribution of congenital anomalies or infection to aetiology. The investigations should also be carried out for survivors.

#### 2.4.2. Investigations to be performed whilst infant is alive

Maternity units should consider the value of routine 'bagging and labelling' of the placenta after birth with temporary storage if space allows, to allow examination of the placenta for any baby who requires admission to the neonatal unit in the first 6 hours of life.

Liaison with local and regional laboratories is essential to ensure optimal collection and timing of samples. Priority should be given to early collection of dried blood spot samples for some specific metabolic and genetic assays (see below). In addition, in some centres, dried blood spot samples can now be analysed using targeted metabolomic assays for simultaneous detection of inherited metabolic disorders, infection, and major organ function and damage. Where this is not available, clinicians should use judgement in individual cases as to which tests should be given priority to ensure optimal diagnostic yield with least intervention (Appendix 4). Transfer to a specialist unit for imaging should be considered if the baby is stable.

- 1. Placenta- where it is available after the time of collapse, placenta and cord should be sent for pathology and microbiology.
- 2. Maternal specimens:
  - blood: early Kleihauer regardless of maternal blood group, viral titres (frozen serum for acute phase titres, including SARS COV 2 sample for PCR), HbA1c
  - urine for toxicology
  - high and low vaginal swabs including Enriched Culture Medium for Group B Streptococcus.
- 3. Neonatal specimens:
  - o Blood:
    - Dried blood spots
    - Full blood count, coagulation, blood gas, renal and liver biochemistry, glucose, lactate, calcium, magnesium, ammonia, beta-hydroxybutyrate, amino acids, insulin, free fatty acids, acyl carnitine profile, urate, uric acid, cortisol (3 samples at different time points), culture, viral titres, blood spot for cardiolipin analysis
    - Specific genetics- DNA and chromosomes, retained blood spot.
      - a. Array-based comparative genomic hybridisation is a useful investigation that will replace conventional karyotyping in the near future as a method for detecting causative chromosomal deletions and duplications. Where available this should be the investigation of choice.
      - b. If there is any suspicion that the collapse or death may have been as a consequence of unrecognised hypoventilation/apnoea, then a sample of DNA should be sent specifically to look for abnormalities of the PHOX2B gene which is commonly implicated in congenital central hypoventilation syndrome.
      - c. Testing for mutations and copy number variation in MECP2 should be considered as may present as newborn encephalopathy and/or apnoeas and respiratory collapse.
      - d. Consider testing for genetic anomalies of cardiac conduction.
      - e. Consider trio exome testing if multiple malformations with or without growth anomalies (including overgrowth)
  - Cerebrospinal fluid: biochemistry, glucose (paired with plasma glucose), culture, virology, lactate, amino acids including glycine, storage
  - Surface swabs: bacteriology
  - Nasopharyngeal aspirate: bacteriology and virology, including SARS COV 2 sample for PCR
  - Urine: bacteriology, virology, toxicology, organic acids including orotic acid, amino acids including urinary sulphocysteine and urine to be retained for storage
  - Meconium toxicology if appropriate for longer term antenatal exposures
  - o 12 lead ECG
  - Skin biopsy for fibroblast culture
  - o Muscle biopsy if unable to exclude neuromuscular or mitochondrial disorder.

- 4. Imaging: skeletal survey (Appendix 5) cranial ultrasound scan (CrUSS) day 1, MRI brain as soon as safe and practical with timing guided by BAPM Framework for Practice<sup>20</sup> (Appendix 6 for recommended sequences), renal/adrenal USS, electrocardiogram (at presentation and after 3 weeks of age), echocardiogram.
- 5. Ophthalmoscopy/Retcam.
- 6. Electroencephalogram.
- 7. Genetics assessment and clinical photographs.

#### 2.4.3 Investigations performed after death

A dedicated staff member such as a member of the bereavement of family support team can be valuable in supporting the family whilst facilitating investigations and reporting following death. The Lullaby Trust has produced information for parents and families after the sudden and unexpected death of a baby and the booklet can be downloaded here. In addition if a baby dies, local guidance for ongoing parental support and review processes should be followed. It is recommended that in all neonatal services the standards of the National Bereavement Care Pathway (in England and in Scotland) should be adopted<sup>21</sup>.

Where death has occurred after discharge from hospital:

These cases should be investigated as per the guidance for the investigation of Sudden Unexpected Death in Infancy<sup>2</sup> and according to any local procedures. The following additional investigations are recommended in this early neonatal group due to the temporal proximity to birth as well as the contribution of congenital anomalies or infection to aetiology.

Where death has occurred on hospital premises:

#### a) Before post mortem examination

It is recommended that if it has not been possible to take samples during life then, where feasible, certain samples should be taken immediately following death whilst awaiting post mortem examination. This will prevent significant degradation of material which will occur after death such that important diagnostic information will be lost.

The taking of post mortem samples must be performed on licensed premises (Human Tissue Act 2004) requiring the infant to be taken to the pathology department or where the local Pathology Licence permits, on the neonatal unit or in the emergency department. Each area must establish a local agreement with their Coroner/PF regarding the taking of such samples. Consent should be sought from parents (or the Coroner/PF) and documented using the appropriate sections of the standard neonatal post mortem consent form following full explanation of what samples are required and why there is a need. The baseline samples should, where possible (and always where death occurs in Scotland), be discussed with and agreed by a pathologist and where indicated a biochemist. Those usually recommended are:

- Throat and nose swabs for bacterial and viral culture, including SARS COV 2 sample for PCR
- Blood culture
- Blood and urine for metabolic studies including glucose, acyl carnitine, organic and amino acids including orotic acid and sulphocysteine, freeze urine for storage
- Blood for DNA, chromosomes
- Dried blood spots on several cards
- CSF obtained by lumbar puncture or ventricular tap- biochemistry, glucose, culture, virology, lactate, amino acids including glycine, freeze and storage
- Skin biopsy for culture and storage of fibroblasts- 3x 2mm full thickness collected under sterile

- conditions into culture or viral transport medium or saline soaked gauze. Send promptly to cytogenetics laboratory.
- Muscle biopsy for electron microscopy, histopathology and enzymology- wrap in aluminium foil, snap freeze and store at –70C. Contact metabolic physician or pathologist before collection of sample.

#### b) Post mortem procedure

Every death resulting from SUPC where the *cause of collapse* is not known must be notified by law to the Coroner/Procurator Fiscal. **This includes babies who die of the hypoxic-ischaemic sequelae of a collapse for which the cause is undetermined before birth.** In this situation, the doctor caring for the infant must not issue a Medical Certificate of the Cause of Death (MCCD). A MCCD (usually issued by a doctor who attended the deceased) enables the deceased's family to register the death. This is not the same as a death certificate, which is issued after the death has been officially registered and is never issued by a doctor.

It is important to recognise the additional distress that referral to a Coroner/Procurator Fiscal may cause parents. The routine nature of this process should be emphasised, with an explanation as to why the referral is being made. It is also important that parents do not feel they are under suspicion for their child's death, and that instead, answers are being sought which may influence future decision-making<sup>22</sup>. Where the Coroner/Procurator Fiscal does not order a post mortem (PM) examination, it remains important to discuss with parents the value that a full or even limited PM examination has in confirming the clinical cause of death and identifying other associated anomalies or conditions. It is highly recommended that such consent be obtained by a consultant paediatrician and/or where locally available a dedicated nurse specialist in PM consent. If despite all efforts both the Coroner/Procurator Fiscal and parents decline either a full or limited PM, consideration should be given to requesting a post mortem MRI.

The PM examination should be carried out by a perinatal or paediatric pathologist<sup>2 23</sup> soon as possible. It is essential that all relevant information is available to the pathologist at the time of PM, including details of the mother, her pregnancy and labour as well as those of the infant, the birth, the events surrounding collapse and care until death. It is recommended that pathologists undertaking such examinations liaise with local radiology and laboratory colleagues with respect to the range of ancillary investigations as there may be some variation in local practice. Although post mortem imaging may be helpful in identifying underlying structural abnormalities, local availability of equipment and trained personnel is limited. Histological investigation of macroscopically normal organs provides reasonable diagnostic yield in this clinical context, and remains an essential component of the examination<sup>24</sup>. Suggested PM procedure is provided in Appendix 7.

Whole organs are not routinely retained beyond release of the body for funeral. Occasionally, it may be of benefit to retain the heart or brain for an extended period of time for further specialist examination if the pathologist suspects the presence of an abnormality related to death. The decision whether to retain the brain for an extended period of fixation and the extent of examination (i.e. examination and sampling within several days of the PM by a paediatric pathologist, or referral for formal neuropathological examination, requiring weeks of fixation) should be determined by the reporting pathologist on a case-by-case basis, according to the clinical history and context<sup>25</sup>. If consent for whole organ retention is withheld, the organ in question may be fixed for a shorter period of time (24-72 hours) before comprehensive sampling and then release for the funeral.

It is recommended that as in standard PM procedures, consent be sought for use of residual material in tissue blocks and frozen samples for potential future diagnostic investigation or research purposes. Although requesting such consent may be regarded as too sensitive an issue at the time of death, as new diagnostic techniques become available, it may be possible to retrospectively test retained samples from previous cases for diagnostic purposes. The Lullaby Trust and SUDC UK have produced a video for parents explaining how important it is for tissues to be retained-many parents will find this helpful (https://vimeo.com/617024160) In England and Wales, tissues taken at a Coroner's PM must be destroyed within 12 weeks of the end of the inquest (if held) or the Coroner's involvement, unless permission has been given for retention. This does not apply in Scotland. The fibroblast culture from skin biopsy is not included in the requirements of the English Human Tissue Act, and such samples may legally be retained without the need for specific parental consent.

Specific consent will also be required for genetic testing. In the event of non-consent or lack of suitable genetic material from the infant, it is important to inform parents that it might be possible to offer them limited genetic investigations. This includes carrier testing for common mutations for some inborn errors of metabolism. Specific advice should be sought from the clinical geneticist.

Reports should be made available as quickly as possible without compromising quality. A provisional report recording all investigations initiated should be made within one week of PM to the Coroner/Procurator Fiscal who should thereafter report findings to the clinician. From the date of PM, issuing a final report should normally take no longer than two months; if a specialist examination on a retained organ has been requested, the examination may take longer.

The lead paediatrician must meet with the parents at the earliest opportunity to explain the findings of all investigations. Where the Coroner/Procurator Fiscal is involved, this meeting should be with their consent.

#### 2.5 Care Pathway- Reporting and Review

#### 2.5.1 Reporting

- a. The approach to reporting on the Medical Certificate of the Cause of Death will be governed by national reporting classification systems but the following is proposed:
  - if there is a definite diagnosis then this should be given as the cause of death
  - in all other cases a 'holding' diagnosis should be given e.g. 'unexplained pending further examination'
  - a final cause of death i.e. a specific diagnosis or 'sudden unexpected early neonatal death' should be submitted after all investigations are completed.

The use of the term 'hypoxic-ischaemic encephalopathy' as a primary cause of death is discouraged. In England and Wales this will almost always be rejected by the Registrar, who will usually refer the case to the Coroner.

b. In England there is a statutory requirement to notify the local child death review team and via this team the National Child Mortality Database (NCMD) within 48 hours of the death. The clinical team at the NCMD may be able to assist and advise on which specific investigations are advised, and how to obtain access to these investigations. There may be other reporting requirements, for example to the Healthcare Safety Investigation Branch.

#### 2.5.1 Review

In England it is a statutory requirement that every child death is subject to a child death review by

the local child death review team which must be a multi-agency investigation involving all agencies potentially involved i.e. it will always involve the primary care team as well as the hospital team, and may involve social care and sometimes the police. This process will be set in motion as soon as the death is reported to the child death review team (which must occur within 48 hours of the death).

There should be a timely multidisciplinary and multispecialty review, following standardised trust risk management procedures, of the perinatal care of any infant who requires neonatal unit admission for SUPC with a particular focus on avoidable factors. This should be discussed with parents in a timely, open and honest way, meeting standards of GMC/NMC duty of candour. There should be peer review of all cases that are assessed for possible TH, including clinical details, aEEG and neuroimaging where available.

The review process should include mechanisms for dissemination of learning and an action plan which addresses any failures in care.

There should be regular audit against standards identified in guidelines created from this Framework for example, all hospitals should have standardised guidelines/policies for assessing and monitoring the wellbeing of:

- The mother and baby at birth, including during promotion of safe SSC, irrespective of feeding method.
- Babies when in SSC with a partner or carer.
- Mothers and babies whilst breastfeeding.
- Babies being bottle fed by their parent or carer.
- Babies when asleep.
- Staff and parent education.

#### 2.6 Care pathway - Ongoing management

In order to guide appropriate ongoing management in babies who survive for at least some hours after SUPC, an underlying diagnosis must be actively sought. Simultaneously, physiological stability should be achieved and maintained.

In addition to the primary cause, infants may sustain a secondary hypoxic injury as a result of their collapse. Stabilising, differentiating and instigating appropriate management is a challenge in which a risk assessment of harm versus benefit should be undertaken. This includes the decision to provide therapeutic cooling.

#### 2.6.1 Initial management recommendations:

Engage with parents: During resuscitation the parents should be supported by a member of
the midwifery, nursing or medical team and should be provided with basic explanations of
what is happening. As soon as stability is achieved, attention should be turned to the parents
and other family members if present. They are critical in establishing an accurate history and
in urgent need of compassion and explanation. Translation services should be used where
appropriate.

#### Provide Information

Parents require a concise discussion explaining what has happened, what has been done so far and what will happen next. Communication should be tailored to each parent or set of parents individually. Some will wish a large amount of detailed explanation while others will not be in a position to receive that immediately. Be guided by parental questions and be sensitive and flexible in the approach.

#### History

When appropriate, it will be necessary to obtain a history from the parents regarding the time preceding and immediately prior to the collapse, as well as a general medical and family history (Appendix 3). Be mindful of the context in which a history is taken- parents are at their most tired and vulnerable and often blame themselves for their baby's collapse.

#### Involvement in care planning

Parents should be involved in the decisions around the care of their baby after a SUPC. This will include discussions about the potential for therapeutic hypothermia and may include anticipatory care planning. Further advice and information about this process can be found in the BAPM Enhanced Shared Decision-making Framework<sup>26</sup> Parents should be encouraged to participate in their baby's cares and actively supported to talk to, touch and hold their baby.

#### Support

Parents must be supported to be with their baby whenever they choose as these may constitute their last hours or days with their baby alive, and missed opportunities to be with their baby may be a source of regret<sup>27</sup>. The environment should be considered to facilitate privacy. Be mindful of the parents' need for support including family members, chaplains, perinatal psychologists, family support teams, established relationships with nursing or midwifery staff, as well as later involvement from family support charities.

#### Infection

- o Treat empirically for bacterial sepsis
  - Treat as early (≤72hours) or late (>72hours) onset sepsis as per local antimicrobial guidelines.
  - Ensure that all maternal microbiology including swabs and urine cultures taken during the pregnancy have been evaluated
- Consider treating for disseminated viral illness
  - This should be considered if there is any family history of oral or genital herpes simplex virus (HSV), if there are herpetic skin lesions present or if seizures / encephalopathy is suspected.
  - HSV may present as cutaneous, central nervous system related or disseminated and may present as late as day 10-19<sup>28</sup>. However, this should not be ruled out in babies presenting earlier if there is clinical suspicion, as it is often indistinguishable from bacterial sepsis.
- Maintain normoglycaemia as per BAPM recommendations<sup>29</sup>.
- Maintain normothermia at 36.5-37.5C unless a decision is made to institute therapeutic hypothermia (see below).
- Nutrition: consider safety of feeding (consider whether safe airway or a metabolic disorder may be present) and where possible encourage oral/enteral feeding. Where intravenous fluids are required, support mothers who are breastfeeding in establishing lactation.

#### 2.6.2 Consideration of Therapeutic Hypothermia

Therapeutic hypothermia (TH) is a standard of care for infants of 36 weeks' gestation or more who have moderate to severe encephalopathy following birth asphyxia. Evidence supports its benefit when the therapy is instigated within 6 hours of birth<sup>30</sup>.

There is currently no robust evidence to support the use of TH following postnatal collapse. Furthermore, given the relative rarity of SUPC, it is unlikely that robust trial data will become available in the near future.

However, around three quarters of babies with SUPC without an identified underlying cause develop a post-asphyxial encephalopathy and therapeutic hypothermia has been increasingly adopted following collapse<sup>31 6 32 33</sup>. While the potential for favourable outcome has been described in one small case series<sup>6</sup>, other retrospective studies have observed no effect on long term outcomes<sup>31</sup>.

The key difference between birth asphyxia and SUPC is the wide range of potential underlying causes for the latter. There are theoretical risks which may outweigh benefits in the context of bleeding diatheses and haemorrhage, and in particular cranial haemorrhage, cardiac arrhythmias and anomalies, and in pulmonary hypertension<sup>31</sup>. It is therefore recommended that every effort be taken to understand the mechanism and cause of collapse before TH is instigated, to ensure that TH will not cause harm.

In summary, when considering TH following SUPC, the following is recommended:

- TH may be considered on a case by case basis where it can be commenced within 6 hours of collapse.
- Decision to cool should involve a second senior person, ideally a second consultant or senior associate specialist.
- LNU/SCBU consultants should discuss potential cases with their designated specialist centre providing TH at an early stage. If necessary, safe transfer to a facility where CFM monitoring can be instituted should be arranged.
- Undertake reasonable first line investigations to identify possible cause and to reduce adverse events of TH (refer to previous section in guideline).
- Intracranial bleed should be excluded as far as possible by use of bedside ultrasound scan
- Assess for any other signs of haemorrhage (e.g. subgaleal) and consider need for correction
  of any bleeding diathesis prior to starting cooling.
- Involve parents in a shared decision-making process acknowledging the off-protocol use of TH with an explanation of the potential risks and benefits.

#### Documentation:

- Repeated neurological examination, HIE grading assessment and CFM pattern
- Justification for TH and any senior staff involved in decision-making
- Information given to parents

All infants undergoing TH following SUPC should be managed according to the BAPM FfP including MRI at 5-15 days after collapse and standardised neurodevelopmental assessment at 2 years<sup>30</sup>.

#### 2.6.3 Withholding intensive care and redirection to comfort care

Around 25% of babies will die following SUPC either due to unsuccessful resuscitation or redirection to comfort care. Guidance on making decisions to limit treatment can be found in the RCPCH Framework of Practice<sup>34</sup>. The principles of parent care and support detailed in 2.6.1 should apply for all families. In addition if a baby dies, local guidance for ongoing parental support and review processes should be followed. It is recommended that in all neonatal services the standards of the National Bereavement Care Pathway (in England and in Scotland) should be adopted<sup>21</sup>.

#### 2.6.4 Staff Support

If appropriate, work with any staff present as soon as possible after an event to establish keys facts about the situation. The history taking tool in Appendix 3 may be used in this process. The staff involved in a SUPC are key in providing information as well as support to the family. However, it should be remembered that they have also experienced a traumatic event and may need support themselves. It is recognised that adverse events in maternity settings are more likely to be regarded as personal errors<sup>35 36</sup>. The HSIB National Learning Report explores the negative impact of safety incidents on staff<sup>1</sup>. Fear, self-doubt, anxiety, increased sick leave, burnout, defensive practice and loss to the profession are all described in staff groups after adverse incidents<sup>37</sup>. An early focus on resilience and understanding may allow this response to be modulated.

A team debrief immediately after or in the days after a SUPC is recommended and is a key starting point in allowing staff to explore this traumatic experience safely. 1:1 mental health "first aid" can also be offered and longer-term counselling and support through trust wellbeing services. Organisations such as HSIB and NHS Resolution work to identify shared learning from adverse events/claims and staff should be supported to engage with investigations where appropriate.

Resources for UK healthcare professionals, managers and organisations to support staff involved in SUPC are found in Appendix 2.

### 2.7 Care pathway- Discharge and follow up

- Follow up: To a large degree this will be determined by any underlying pathology and the
  impact of collapse. All infants undergoing therapeutic hypothermia must be offered a
  standardised neurodevelopmental assessment at two years of age. Babies in high and
  medium risk groups for brain injury should have early and sequential assessments with
  experienced medical and/or Paediatric Allied Health Practitioners. This should be aimed at
  early detection of developmental problems with early intervention to optimise outcomes.
- Communication:

#### Parents in all cases:

- Parents should receive a copy of the discharge letter which has been explained to them by a member of the healthcare team
- Where appropriate, parents should be signposted to local and national support groups (Appendix 9).
- Specifically if the baby has died or an adverse event investigation has been triggered, parents should be informed of the local adverse event (and if relevant, Perinatal Mortality Review Tool (PMRT) and HSIB and NHS Resolution) process, who their key contact is and made aware that any questions or concerns they have will be addressed by the review/investigation process. Refer to the Perinatal Mortality Review Tool (PMRT) Parental Engagement Flowchart and resources <sup>21</sup> (Appendix 8). Currently the PMRT and the Child death review systems are not fully integrated —

- the arrangements for how they work together will vary between areas.
- Where parents don't speak English as a first language translation services to support them in understanding what happens next should be used.

#### Parents where their baby has survived:

- The principles of parent care and support detailed in 2.6.1 should apply for all families
- Where appropriate, parents should receive contact details for specialist or outreach teams involved in the care of their child.
- Parents should be provided with verbal and written information on safety around skin-to-skin contact, infant feeding, infant sleeping and co-sleeping, and this should be documented in the patient record.
- Offer parents the opportunity to learn basic newborn life support skills.
- Parents can be signposted to the Baby Check Scoring System App to supplement the clinical assessment of their baby for possible illness in the community.<sup>38 39</sup>

#### Healthcare professionals:

- Community teams including the GP, health visitor +/- community midwife should receive a written handover of care which includes information about prognosis, parental understanding and expectations.
- In areas where the Care of Next Infant (CONI) programme is available then the local CONI coordinator should be contacted to ascertain if they may be able to provide support to the family as per the procedure following an Apparent Life-Threatening Event (ALTE)/ Brief Resolved Unexplained Event (BRUE).

#### References

- 1. Neonatal collapse alongside skin-to-skin contact. National Learning Report: Healthcare Safety Investigation Branch, 2020.
- Sudden unexpected death in infancy and childhood. Multi-agency guidelines for care and investigation: The Royal College of Pathologists and the Royal College of Paediatrics and Child Health, 2016.
- 3. The Apgar score. *Pediatrics* 2006;117(4):1444-7. doi: 10.1542/peds.2006-0325 [published Online First: 2006/04/06]
- 4. Herlenius E, Kuhn P. Sudden unexpected postnatal collapse of newborn infants: a review of cases, definitions, risks, and preventive measures. *Transl Stroke Res* 2013;4(2):236-47. doi: 10.1007/s12975-013-0255-4 [published Online First: 2013/03/23]
- 5. Becher JC, Bhushan SS, Lyon AJ. Unexpected collapse in apparently healthy newborns--a prospective national study of a missing cohort of neonatal deaths and near-death events. *Arch Dis Child Fetal Neonatal Ed* 2012;97(1):F30-4. doi: 10.1136/adc.2010.208736 [published Online First: 2011/07/01]
- 6. Pejovic NJ, Herlenius E. Unexpected collapse of healthy newborn infants: risk factors, supervision and hypothermia treatment. *Acta Paediatr* 2013;102(7):680-8. doi: 10.1111/apa.12244 [published Online First: 2013/04/05]
- 7. Monnelly V, Becher JC. Sudden unexpected postnatal collapse. *Early Hum Dev* 2018;126:28-31. doi: 10.1016/j.earlhumdev.2018.09.001 [published Online First: 2018/09/30]
- 8. Rodriguez NA, Hageman JR, Pellerite M. Maternal distraction from smartphone use: a potential risk factor for sudden unexpected postnatal collapse of the newborn. *The Journal of Pediatrics* 2018;200:298-99. doi: 10.1016/j.jpeds.2018.04.031
- 9. Skin to skin contact. Implementing Baby Friendly Standards resources: UNICEF UK.
- 10. Fawke J, Wyllie J, Madar J, et al. Newborn resuscitation and support of transition of infants at birth Guidelines. 2021
- 11. Piumelli R, Davanzo R, Nassi N, et al. Apparent Life-Threatening Events (ALTE): Italian guidelines. *Ital J Pediatr* 2017;43(1):111. doi: 10.1186/s13052-017-0429-x [published Online First: 2017/12/14]
- 12. Optimizing support for breastfeeding as part of obstetric practice. ACOG committee opinion number 756.: American College of Obstetricians and Gynecologists Breastfeeding Expert Work Group & Committee on Obstetric Practice, 2018.
- 13. Sudden Unexpected Postnatal Collapse in Healthy Term Newborns: AWHONN Practice Brief Number 8. *Journal of Obstetric, Gynecologic & Neonatal Nursing* 2020;49(4):388-90. doi: 10.1016/j.jogn.2020.05.002
- 14. Reyes JA, Somers GR, Chiasson DA. Sudden Unexpected Death in Neonates: A Clinico-pathological Study. *Pediatric and Developmental Pathology* 2018;21(6):528-36. doi: 10.1177/1093526618764054
- 15. Weber MA, Ashworth MT, Risdon RA, et al. Sudden unexpected neonatal death in the first week of life: autopsy findings from a specialist centre. *J Matern Fetal Neonatal Med* 2009;22(5):398-404. doi: 10.1080/14767050802406677 [published Online First: 2009/06/17]
- 16. Guidelines for the Investigation of Newborn Infants Who Suffer a Sudden and Unexpected Postnatal Collapse in the First Week of Life: Recommendations from a Professional Group on Sudden Unexpected Postnatal Collapse. London: WellChild, 2011.
- 17. BAPM. The Prevention, Assessment and Management of in-Hospital Newborn Falls and Drops.
- 18. RCOG. Each Baby Counts: Situational Awareness., 2015.
- 19. Draft 2020 European Resuscitation Council Guidelines for Newborn Resuscitation and Support of Transition of Infants at Birth. https://api.resuscitation2020.eu/asset-document/35-Draft%20NLS%20Guidelines%20for%20Public%20Comment%2019Oct20.pdf.

- 20. Fetal & Neonatal Brain Magnetic Resonance Imaging: Clinical Indications, Acquisitions and Reporting. A BAPM Framework for Practice: BAPM, 2016.
- 21. Sands. National Bereavement Care Pathway: Department of Health and Social Care, 2017.
- 22. Garstang J, Griffiths F, Sidebotham P. Parental understanding and self-blame following sudden infant death: a mixed-methods study of bereaved parents' and professionals' experiences. *BMJ Open* 2016;6(5):e011323. doi: 10.1136/bmjopen-2016-011323 [published Online First: 2016/05/21]
- 23. Ernst LM. A pathologist's perspective on the perinatal autopsy. *Semin Perinatol* 2015;39(1):55-63. doi: 10.1053/j.semperi.2014.10.008 [published Online First: 2014/12/17]
- 24. Lewis C, Hutchinson JC, Riddington M, et al. Minimally invasive autopsy for fetuses and children based on a combination of post-mortem MRI and endoscopic examination: a feasibility study. *Health Technol Assess* 2019;23(46):1-104. doi: 10.3310/hta23460 [published Online First: 2019/08/29]
- 25. Pryce JW, Paine SM, Weber MA, et al. Role of routine neuropathological examination for determining cause of death in sudden unexpected deaths in infancy (SUDI). *J Clin Pathol* 2012;65(3):257-61. doi: 10.1136/jclinpath-2011-200264 [published Online First: 2011/12/03]
- 26. Enhancing Shared Decision Making in Neonatal Care: A BAPM Framework for Practice: British Association of Perinatal Medicine, 2019.
- 27. Redshaw M, Henderson J, Bevan C. 'This is time we'll never get back': a qualitative study of mothers' experiences of care associated with neonatal death. *BMJ Open* 2021;11(9):e050832. doi: 10.1136/bmjopen-2021-050832
- 28. Kimberlin DW, Baley J. Guidance on management of asymptomatic neonates born to women with active genital herpes lesions. *Pediatrics* 2013;131(2):e635-46. doi: 10.1542/peds.2012-3216 [published Online First: 2013/01/30]
- 29. Identification and Management of Neonatal Hypoglycaemia in the Full Term Infant: A BAPM Framework for Practice: British Association of Perinatal Medicine, 2017.
- 30. Therapeutic Hypothermia for Neonatal Encephalopathy: A BAPM Framework for Practice: British Association of Perinatal Medicine, 2020.
- 31. Brito S, Sampaio I, Dinis A, et al. Use of Therapeutic Hypothermia in Sudden Unexpected Postnatal Collapse: A Retrospective Study. *Acta Med Port* 2020 doi: 10.20344/amp.13767 [published Online First: 2021/04/24]
- 32. Filippi L, Laudani E, Tubili F, et al. Incidence of Sudden Unexpected Postnatal Collapse in the Therapeutic Hypothermia Era. *Am J Perinatol* 2017;34(13):1362-67. doi: 10.1055/s-0037-1603678 [published Online First: 2017/06/02]
- 33. Smit E, Liu X, Jary S, et al. Cooling neonates who do not fulfil the standard cooling criteria short-and long-term outcomes. *Acta Paediatr* 2015;104(2):138-45. doi: 10.1111/apa.12784 [published Online First: 2014/08/29]
- 34. Larcher V, Craig F, Bhogal K, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Arch Dis Child* 2015;100 Suppl 2:s3-23. doi: 10.1136/archdischild-2014-306666 [published Online First: 2015/03/25]
- 35. Coughlan B, Powell D, Higgins MF. The Second Victim: a Review. *Eur J Obstet Gynecol Reprod Biol* 2017;213:11-16. doi: 10.1016/j.ejogrb.2017.04.002 [published Online First: 2017/05/21]
- 36. Scott SD, Hirschinger LE, Cox KR, et al. The natural history of recovery for the healthcare provider "second victim" after adverse patient events. *Qual Saf Health Care* 2009;18(5):325-30. doi: 10.1136/qshc.2009.032870 [published Online First: 2009/10/09]
- 37. Busch IM, Moretti F, Purgato M, et al. Psychological and Psychosomatic Symptoms of Second Victims of Adverse Events: a Systematic Review and Meta-Analysis. *J Patient Saf* 2020;16(2):e61-e74. doi: 10.1097/pts.00000000000000589 [published Online First: 2019/03/29]
- 38. Postnatal Care National Institute for Health and Care Excellence; 2021 [Available from: https://www.nice.org.uk/guidance/ng194.

# Sudden Unexpected Postnatal Collapse A BAPM Framework for Practice

- 39. Baby Check App: The Lullaby Trust; [Available from: https://www.lullabytrust.org.uk/safer-sleep-advice/baby-check-app/.
- 40. The radiological investigation of suspected physical abuse in children: The Royal College of Radiologists and The Society and College of Radiographers, 2018.
- 41. Martin A, Paddock M, Johns CS, et al. Avoiding skull radiographs in infants with suspected inflicted injury who also undergo head CT: "a no-brainer?". *European Radiology* 2020;30(3):1480-87. doi: 10.1007/s00330-019-06579-w

## Appendix 1. Sample staff education programme

#### Aim of the programme

This specific training programme aims to support staff to implement:

- The principles of safe care to reduce SUPC.
- Effective observation and assessment of the mother and baby during routine postnatal care practices.
- Relevant policies associated with assessment and monitoring of the mother and baby
- Effective antenatal and postnatal care to help reduce SUPC.

#### Introduction and background

Working together we can ensure that all babies are kept safe, while still enabling babies, their mothers, and families to benefit from skin-to-skin contact (SSC).

The HSIB report, 2019 comes after six cases of SUPC were identified out of a total of 335 (1.8%) in which positioning of the baby during SSC, alongside other causative factors, may have contributed to SUPC. SUPC is a rare but potentially fatal collapse in babies who appear otherwise healthy. The overarching theme from the learning report is that effective monitoring during SSC straight after birth is key, along with continued vigilance and prompt removal of the baby if there are any health concerns.

#### Knowledge, skills and principles of care to reduce SUPC

#### Part 1. Staff education of why SSC is important

There is a growing body of evidence that SSC after birth helps babies and their mothers by:

- Calming and relaxing both mother and baby
- Regulating the baby's heart rate and breathing and helping them to better adapt to life outside the womb
- Stimulating digestion and an interest in feeding
- Regulating temperature
- Enabling colonisation of the baby's skin with the mother's microbiome, thus providing protection against infection
- Stimulating the release of hormones to support breastfeeding and mothering.

#### Part 2. Facilitating SSC in practice:

- After birth, offer to lay the baby SSC with the mother or parent in conjunction with assessment and Appar scoring of the baby
- Encourage parents to observe their baby and empower them to highlight any concerns
- Position the mother in a semi-recumbent position (45°) so the baby is not lying fully prone
- Position the baby so the face can be seen by mother and ensure baby's nose is free from maternal body parts and that the baby's legs are flexed
- When in SSC, the baby's head should be turned to the side, ensuring that their chin is not on their chest and observations should continue to ensure the baby is breathing normally
- Parents should be encouraged to continually observe and respond to their baby's needs during SSC avoiding distractions (such as using a mobile phone) which may distract them from observing and changes in their baby and raising concerns.

#### Part 3. Ongoing effective observation and assessment of the mother:

- Observations of the mother's vital signs and level of consciousness should be continued throughout the period of SSC
- Ongoing support and supervision of the mother should be provided in order to observe changes in the baby's condition. Parents should be supported to reposition their baby when needed
- Many mothers can continue to hold their baby in SSC during perineal suturing, provided they have adequate pain relief
- A mother who is in pain may not be able to hold her baby safely
- Mothers should not be in SSC with their baby when they are receiving Entonox or if consciousness is affected as a result of other analgesics or medicines.
- If mother is undergoing such a procedure, the baby should be observed by an additional person such as family/staff member.

#### Part 4. Ongoing effective observation and assessment of the baby:

- Ensure Appar scores are assessed and calculated accurately at 1, 5 and 10 minutes for all births.
- All babies should continue to be monitored both when being held and when placed in a cot. The following observations should be included:

•

- I. Position: check that the baby's position is such that a clear airway is maintained. Observe respiratory rates and chest movement and listen for unusual breathing sounds or absence of noise from the baby
- II. Perfusion: assess perfusion of the baby by looking at their entire body. Limbs can often appear discoloured, and even subtle changes to colour can indicate a change in the baby's condition
- III. Tone: the baby should have a solid, flexed tone and should not be limp or unresponsive
- IV. Temperature: ensure the baby is kept warm.
- Utilise appropriate pathways for babies at risk e.g. NEWTT

#### Part 5. Ongoing effective assessment of the environment:

- Staff should maintain a high level of situation awareness in relation to care provision and their environment. Ensure mother is continually supported and assisted with the care of the baby with the help of partners/family or staff members during the first 2 hours after birth, or until her and her baby exhibit no concerns.
- Listen and respond to parents if any questions or concerns are raised
- Never leave the mother alone without the presence of family, friends or staff after the birth. Always ensure that the mother's and baby's condition exhibit no concerns and that she can call for assistance if required (usually 1-2 hours)
- All babies should continue to be monitored whether being held by the mother/parent/carer or having been placed in the cot.
- Always listen to parents/carers and respond immediately to any concerns raised

#### Part 6. Support and information for families: antenatal

All parents should be offered a conversation in pregnancy to help reduce SUPC. This could be part of an antenatal assessment or within antenatal education sessions.

Key points include:

• The value of skin-to-skin contact (SSC) and what this means for mother and baby

- How to position baby safely for SSC at birth and ongoing, including how to maintain a safe airway
- How to recognise when baby is well and when baby shows signs of illness, e.g. changes in the baby's perfusion (colour), tone, temperature and breathing (change in breathing pattern and sounds)
- The importance of recognising when help is needed and how to alert staff and to call for help
- Information on safe sleep

Parental education should include verbal, written and visual formats appropriate to individual language needs and context. Information sharing should be recorded in the maternal records.

#### Part 7. Support and information for families: postnatal

All parents should be offered ongoing conversations to help reduce SUPC Key points include:

- The value of SSC and what this means for mother and baby
- How to position baby safely for SSC at birth and in the postnatal period, including how to maintain a safe airway
- When to offer SSC with the partner or primary care giver if the mother is not available
- How to recognise when the baby is well and when the baby shows signs of illness, e.g. changes in the baby's perfusion (colour), tone, temperature and breathing (change in breathing pattern and sounds)
- The importance of recognising when help is needed, how to alert staff and how to call for help in hospital and at home
- Information on safe sleep in SSC or in the cot
- Information on safe carrier/sling use.

#### Staff should continue to:

- Carry out ongoing effective observation and assessment of the mother/parent/carer in SSC with the baby and/or when the baby is in the cot
- Document care in the maternal and infant records.

## Appendix 2. Resources

#### Skin-to-Skin Care

- UNICEF UK Baby Friendly Initiative https://www.unicef.org.uk/babyfriendly/baby-friendly-resources/implementing-standards-resources/skin-to-skin-contact/
- https://www.unicef.org.uk/babyfriendly/new-hsib-report-confirms-importance-of-close-monitoring-of-babies-in-immediate-postnatal-period/
- https://www.hsib.org.uk/investigations-and-reports/neonatal-collapse-alongside-skin-to-skin-contact/national-learning-report-neonatal-collapse-alongside-skin-to-skin-contact/
- Research on skin-to-skin contact https://www.unicef.org.uk/babyfriendly/news-and-research/baby-friendly-research/research-supporting-breastfeeding/skin-to-skin-contact/
- Video on safe SSC and positioning https://www.youtube.com/watch?v=cXjJVHeNBzg

#### Infant feeding policies and guidance

- https://www.unicef.org.uk/babyfriendly/baby-friendly-resources/implementing-standards-resources/sample-infant-feeding-policies/ https://www.unicef.org.uk/babyfriendly/baby-friendly-resources/breastfeeding-resources/
- https://www.unicef.org.uk/babyfriendly/baby-friendly-resources/bottle-feeding-resources/
- NICE (2014) Public Health Guidance 11: Maternal and Child Nutrition (http://guidance.nice.org.uk/PH11), Issued March 2008 (updated November, 2014)
- NICE (2021) Postnatal care NICE guideline [NG194] Published: 20 April 2021

#### Infant sleep

- UNICEF UK Baby Friendly Initiative resources https://www.unicef.org.uk/babyfriendly/babyfriendly-resources/sleep-and-night-time-resources/
- Baby Sleep Information Source https://www.basisonline.org.uk/
- Lullaby Trust https://www.lullabytrust.org.uk/professionals/publications/

#### Parent information on observing your baby

- Safer Sleep for Babies: A guide for parents and Carers https://www.lullabytrust.org.uk/wp-content/uploads/Safer-sleep-for-babies-a-guide-for-parents-web.pdf
- The T.I.C.K.S. Rule for Safe Babywearing http://babyslingsafety.co.uk/ticks.pdf

#### **APGAR Scoring**

- Apgar V. A proposal for a new method of evaluation of the newborn infant. Curr Res Anesth Analg 1953;32:260-7. doi:10.1213/00000539-195301000-00041 pmid:13083014
- NICE (2014) Intrapartum care for healthy women and babies. Clinical guideline [CG190]Published: 03 December 2014 Last updated: 21 February 2017

#### Improving human factors and situation awareness

- https://www.rcog.org.uk/en/guidelines-research-services/audit-quality-improvement/each-baby-counts/implementation/improving-human-factors/
- https://www.rcog.org.uk/en/guidelines-research-services/audit-quality-improvement/each-baby-counts/implementation/improving-human-factors/further-resources-human-factors/
- https://www.rcog.org.uk/en/guidelines-research-services/audit-quality-improvement/each-baby-counts/implementation/improving-human-factors/video-briefing/

© BAPM, 2022

#### **BAPM Frameworks for Practice**

- Identification and Management of Neonatal Hypoglycaemia in the Full Term Infant (2017) https://www.bapm.org/resources/40-identification-and-management-of-neonatalhypoglycaemia-in-the-full-term-infant-2017
- The Prevention, Assessment and Management of in-Hospital Newborn Falls and Drops (2021) https://www.bapm.org/resources/161-the-prevention-assessment-and-management-of-in-hospital-newborn-falls-and-drops

#### Staff support following SUPC

- Medical Defence Union Second Victim Support https://mdujournal.themdu.com/issuearchive/spring-2019/second-victim-support
- Second Victim Support https://secondvictim.co.uk/
- NHS Resolution Being Fair Report 2019 https://resolution.nhs.uk/resources/being-fair-report/

#### Ideas to support staff education:

- P.S.O (see pathway for details)
   PREPARE the parents
   SUPPORT the mother (parent/carer), baby and environment
   OBSERVE the mother (parent/carer) baby and environment
- M. B. E

MOTHER— information, position, observation, listen and respond BABY — position, observation, respond ENVIROMENT — safe and responsive



Parental Background			
Full name of Mother		Full name of Father	
Occupation of Mother		Occupation of Father	
Mother's country of birth		Father's country of birth	
Mother's ethnic origin	Father's ethnic origin		
		<u> </u>	
Mother's language		Father's language	
Social service involvement	(details including dates)		
Social worker name & no. Fertility issues		No of provious missorrioges	
No. of previous pregnancies	No. of previous miscarriages  No. of previous terminations		
No. of previous stillbirths		No. of previous infant deaths	
Details of previous congenital		140. of previous infante deaths	
anomalies/infections/GBS			
Family health conditions			
3 generation family tree	(Please use blank sheet & includ	de consanguinity and assisted reproductive te	chniques)
Pregnancy			
Maternal smoking (amt/day)		Maternal alcohol (units/wk)	
Medications (prescribed &		Tobacco, alcohol or drugs in	
non-prescription) Illnesses/conditions of mother		the 4h before collapse Accidents/falls	
during pregnancy		Accidents/fails	
Any other issues experienced		Particular stresses	
Estimated Dalivary Data		Costation at hooking	
Estimated Delivery Date  Maternal age at booking	Gestation at booking BMI at booking		
Was this ever a multiple		Fetal anomaly concerns	
pregnancy?		Tetal anomal, concerns	
Any concerns including growth,			
Dopplers, liquor, movements			
Results of other microbiology		Swabs taken and results	
	1		-
Labour			
Was labour induced? How?		Maternal pyrexia	
Rupture of membranes	<del></del>	Maternal tachycardia	
spontaneous?			
Duration of ruptured		Maternal antibiotics	
membranes Mode of delivery		Vaginal blooding	
		Vaginal bleeding	
Concerns about fetal		Meconium stained liquor	
movements Concern about CTG/FH			
•		D1416	
Analgesia during labour		Did the mother receive	
including total dose and last timing of opiates		lignocaine for episiotomy?	
timing or opiates		I	1
Birth			
Mode of birth		Estimated blood loss	
Presentation		Placental appearance	+
Order (if multiple birth)		Placenta sent for histology?	
	1min.		10min.
Apgar scores at:-	1min:	5min:	10min:
Cord gases	Arterial: Venous:		

© BAPM, 2022 31

# Sudden Unexpected Postnatal Collapse A BAPM Framework for Practice

Postnatal	
Sex	Any congenital anomaly identified?
Birth weight & centile	Did the baby receive any
Head circumference & centile	medications / immunisations prior to the collapse?
NEWTT/NEWS: Was risk	Stool & urine output adequate?
assessment made appropriately	
and pathway followed?	
Hypoglycaemia: was risk	Feeding mode
assessment made appropriately	(breast/bottle/NG/cup)
and pathway followed?	
Infection: was risk assessment	Were any doses of antibiotics
made appropriately and pathway	missed or given more than 1hour
followed?	after decision to treat
Any concerns raised regarding	
general state of baby between	
birth and collapse?	

Circumstances of collapse	
Age at collapse (hours)	In what position was the baby
	found (prone/supine/side)?
Location within hospital	Location of baby at time of collapse
	(cot/arms/breast/abdomen/bed/
	other)
Who found the baby?	
In whose care was the baby at	Was the baby presumed to be
the time of collapse?	feeding/sleeping or other at the
	time?
List everyone who was in the	Was anyone else helping with care
room at the time of collapse	of the baby? Give details
Consciousness level of mother at	Was the mother undergoing a
time of collapse (alert, tired,	procedure at the time of collapse?
very lethargic, asleep)	
How long prior to the collapse	
did the baby last feed? Give	
details	
How long prior to the collapse	
had the baby last been known to	
be well? By whom and give	
details	
When baby was found, was	
there potential for obstruction	
of the airway observed? Eg face	
against maternal body part or	
pillow	
Had the mother received any	Any other details/information?
medications, prescribed or non-	
prescribed between birth and	
time of collapse?	

Full name of person completing form	Signature
Role/Title of person completing form	Date

# Appendix 4. Aetiologies of SUPC

List of conditions described in the aetiology of Sudden Unexpected Postnatal Collapse or collapse in infancy and relevant investigations.

Condition	Investigations to detect conditions in
	each category
Infection Systemic: Bacterial infection- various Viral infection- Echovirus, Coxsackie, Respiratory Syncytial Virus, Parvovirus, Herpes Meningitis: bacterial, viral	Placenta-histopathology, bacteriology Maternal blood-viral PCR and serology Maternal high and low vaginal swabs- bacteriology Blood- culture, viral PCR and serology, storage, CRP CSF- bacteriology, virology, biochemistry, glucose, dried blood spot targeted metabolomic assay Urine- bacteriology, virology Surface swabs- bacteriology Nasopharyngeal/endotracheal aspirate- bacteriology, virology MRI
Cardiac anomalies	
Cyanotic heart disease: Transposition of the great arteries, Truncus arteriosus, Univentricular heart, Pulmonary stenosis/atresia, Tricuspid atresia Left sided obstructive lesions: Coarctation/interruption of aorta, Hypoplastic Left heart, Aortic stenosis Cardiac conduction problems: Long QT syndrome, Atrial fibrillation Total anomalous pulmonary venous drainage Myocardial infarction Cardiomyopathies Barth syndrome Congenital coronary artery aneurysm Anomalous coronary artery	ECG Chest X-ray Echocardiogram Blood- Troponin, chromosomes and /or aCGH, DNA, storage Genetics for cardiac conduction disorders/cardiomyopathy Blood spot for cardiolipin analysis
Respiratory Conditions	
Airway obstruction: choanal atresia, Pierre Robin, cleft	ENT assessment
palate, accidental smothering Pneumonia +/- aspiration Pulmonary hypertension Pulmonary haemorrhage Congenital diaphragmatic hernia	See investigations for infection Chest X-ray, airway screening imaging ECHO
Maternal drugs and medications	
-Those associated with neonatal hypoglycaemia: beta blockers, carbimazole -Those associated with neonatal sedation, respiratory depression or poor neonatal adaptation: opiates, SSRIs -Those associated with neonatal seizures: Perineal lignocaine for episiotomy injected into fetal scalp, withdrawal from maternal substances such as opioids, cocaine and benzodiazepines	Seek in history and consider all maternal medications that may contribute to neonatal effects listed.  Maternal and baby urine for toxicology
Haematological	Baby full blood count, Group, DAT and film
Anaemia	Maternal Kleihauer Baby and maternal viral PCR and serology Placental pathology

# Sudden Unexpected Postnatal Collapse A BAPM Framework for Practice

Metabolic	Blood- glucose, gas, lactate, ammonia, beta-
Hypoglycaemia	hydroxybutyrate, amino acids, insulin, free fatty
Hypocalcaemia	acids, acyl carnitine profile, uric acid, cortisol (3
Hypomagnesaemia	samples at different time points), VLCFAs, calcium,
Fatty acid oxidation defects- including MCAD	magnesium, renal and liver biochemistry, DNA and
deficiency, VLCAD deficiency, LCHAD deficiency,	chromosomes, blood spot, dried blood spot targeted
carnitine acylcarnitine translocase deficiency, CPT2	metabolomic assay
deficiency, trifunctional protein deficiency	Cerebrospinal fluid- lactate, amino acids including
Urea cycle defects	glycine, storage
Organic acidaemias	
Lysosomal storage disorders- I-cell disease	Urine- organic acids including orotic acid, amino
Peroxisomal disorders- Zellweger syndrome Glycogen	acids including urinary sulphocysteine and urine to
storage disorder types 2 or 4 Heart-specific	be retained for storage
phosphorylase kinase deficiency Mitochondrial	Skeletal survey
disorders- respiratory chain, Leigh's disease	Muscle biopsy
Congenital defects of glycosylation	Skin biopsy- fibroblast culture Ophthalmoscopy/
Congenital defects of glycosylation  Congenital lactic acidoses	Retcam MRI brain Electroencephalogram
Glycine encephalopathy	ECG
Biotinidase deficiency	Echocardiogram
Glucose transporter defect- GLUT1	Lenocardiogram
Molybdenum cofactor deficiency	
Sulphite oxidase deficiency	
Neurological	As above (metabolic)
Any metabolic cause of seizures/apnoea	EEG/aEEG
Drug withdrawal	Maternal and infant urine and blood toxicology
Perinatal infarction	Coagulation screen
Intracranial bleed	Cranial ultrasound scan
	MRI brain
Antenatal injury	
Hypoplasia of brainstem nuclei	Blood, skin biopsy for:
Hyperekplexia: apnoea/tonic	PHOX2B sequencing (congenital hypoventilation
Congenital hypoventilation syndrome	syndrome); MECP2 sequencing and copy estimation (Rett syndrome variants); SMN1/2 sequencing
Rett syndrome variants	, , ,
Joubert syndrome	(Spinal Muscular Atrophy)  Cranial ultrasound scan
Neuromuscular/skeletal	MRI brain
Non accidental injury	
Congenital myasthenia syndromes	Skeletal survey
Nemaline myopathy	Genetics for congenital myasthenic syndromes DNA
X-linked myotubular (centronuclear) myopathy	and chromosomes and/or aCGH
Central core disease	Muscle biopsy - single genes screens for MTM1
	(XLMM), RYR1 (central core disease), NEM1 -5
	(nemaline myopathy), CHRNE & CHRNB1 (subunits of
	the acetylcholine receptor)
	Ophthalmoscopy/ Retcam
Fudestine	(EMG, nerve biopsy)
Endocrine	Blood- glucose, lactate, ammonia, beta-
Hypoglycaemia	hydroxybutyrate, amino acids, insulin, free fatty
Hyperinsulinism	acids, acyl carnitine profile, uric acid, dried blood
Congenital adrenal hypoplasia	spot targeted metabolomic assay
	MRI to assess pituitary
	Cortisol (3 samples at different time points),
	electrolytes
	Renal and adrenal ultrasound scan

# Appendix 5. The radiological investigation of suspected physical abuse in children

Please refer to national guidance<sup>40</sup> here.

A single film ('baby gram') should be avoided as it gives an unsatisfactory exposure and combined views of chest abdomen pelvis and limbs should also be avoided, as limb detail is poor, with oblique projections of most joints.

#### Skull (SXR)

In the post mortem setting, CT head should be performed and as such, SXR is not indicated. 41

#### Body

AP/frontal chest (including clavicles).

Oblique views of the ribs (left and right).

AP Abdomen with pelvis.

#### Spine

Lateral spine - cervical and thoracolumbar.

#### Limbs

AP whole arms (shoulders to wrists), coned lateral elbows and wrists, PA hands and wrists.

AP whole lower limb (hip to ankle), coned lateral knees and ankles, coned AP ankles, DP feet.

#### СТ

CT head is indicated in all cases.

Whole body CT should be performed to investigate skeletal injury or where there is doubt from the skeletal survey.

#### MRI

Whole body MRI should be considered for suspected soft tissue injury.

## Appendix 6. Protocol for MRI examination of brain

1Tesla - 3Tesla

Scan baby when safe and practical. This may be as soon as possible if thinking of redirecting care or if a large intracranial haemorrhage is suspected with possible requirement for neurosurgical intervention. In babies with suspected hypoxic ischaemic encephalopathy ideally scan between 3-14 days with full protocol<sup>20</sup>.

Consider safe individualised sedation as high quality non-motion corrupted images are essential. Monitor baby (heart rate, oxygenation) during the examination and ensure that staff with neonatal resuscitation skills are present throughout.

Use sequences adapted for the higher water content of the neonatal brain and ensure that the neonate's head is in the centre of the coil. The study is best performed by a radiographer with expertise in acquiring neonatal brain images.

#### **Essential**

- T1 and T2 weighted axial images, slice thickness 4mm (use "neonatal" angle- from inferior frontal lobe to torcula)
- T1 weighted sagittal, with thinner slices 1.5-3mm. A volume acquisition sequence is ideal as this
  can then be reformatted into coronal or transverse planes if needed for later comparison with
  histopathology
- T2 weighted coronal
- Diffusion weighted imaging with a generated ADC map

#### **Desirable**

- MR proton spectroscopy in the basal ganglia/thalami; (echo time 135ms and 270 ms) (if white matter appears abnormal and time repeat acquisition in the white matter)
- MR Sinus venogram
- Susceptibility weighted imaging (SWI) or gradient echo sequence, sensitive to the presence of haemorrhage
- MR Angiography
- FLAIR
- If strong suspicion of focal infection or herpes encephalitis and normal renal function, consider using a low risk contrast agent
- Motion resistant acquisitions if baby very unsettled during examination e.g. BLADE, PROPELLER, single shot

#### Post mortem protocol

Consider post mortem cranial ultrasound where there are no antemortem images. If there is easy access to a centre with expertise consider post mortem MRI, if antemortem MRI has not been acquired. Use T1 and T2 weighted sequences from the essential list above. T2 weighted images will have best contrast and quality. Perform each sequence in all three planes. Increase doubling signal averages if time allows to provide a better signal to noise ratio.

## Appendix 7. Post mortem procedure

The list below is based on previously published protocols; the final decision regarding the extent of sampling should be decided by the pathologist on a case-by-case basis.

- 1. Medical photography, including an overview of the entire body (front and back), face, profile, any dysmorphic features, and any marks or injuries.
- 2. Radiology: full radiological skeletal survey (Appendix 5), reported by a radiologist with paediatric training and experience.
- 3. Anthropometric measurements: body weight, crown-rump, crown-heel, heel-toe and occipitofrontal circumference
- 4. Microbiology: to be taken as early as possible during the autopsy procedure and with stringent efforts to avoid contamination.
  - a. Bacteriology
    - Blood culture
    - Lung tissue/fluid
    - Bronchial swab
    - · Cerebrospinal fluid
    - Spleen
    - Any apparent site of infection.
  - b. Virology (PCR and culture)
    - Postnasal swabs
    - Cerebrospinal fluid
    - Lung tissue
    - Heart muscle
    - Small intestine.
- 5. Organ systems (minimum samples to be taken):
  - Heart (free wall of left and right ventricle, interventricular septum)
  - Each lobe of both lungs
  - Kidneys
  - Liver
  - Thymus
  - Pancreas
  - Spleen
  - Lymph nodes
  - Adrenal glands
  - Costochondral junction of a rib, to include bone marrow sample
  - Muscle
  - Samples of any lesions, including fractured ribs
  - Brain: suggested blocks listed below in section 10
  - Other as specifically indicated.

- 6. Frozen sections- staining with Oil Red O for fat
  - Liver
  - Heart
  - Kidney
  - Lung
  - Skeletal muscle.

#### 7. Biochemistry

- Blood: dried blood spot for acylcarnitine profile.
- Urine- toxicology, amino and organic acids if available
- Bile-bile spot for acylcarnitine
- Skin sample for fibroblast culture.

#### 8. Molecular/ cytogenetic investigations

- Skin-culture medium
- Frozen solid tissue (e.g. spleen, liver, kidney, muscle).

#### 9. Retention of material for further detailed examination

• In some cases, the heart or brain (see below) may be retained for further specialist examination.

#### 10. Central nervous system examination

It may be useful to obtain a post mortem MRI of the brain, or at least a cranial USS, prior to opening the cranium (Appendix 6)<sup>2</sup>. The decision whether to retain the brain for an extended period of fixation and the extent of examination (i.e. examination and sampling within several days of the autopsy by a paediatric pathologist, or referral for formal neuropathological examination, requiring weeks of fixation) should be determined by the reporting pathologist on a case-by-case basis, according to the clinical history and context<sup>25</sup>. If consent for whole organ retention is withheld, the organ in question may be fixed for a shorter period of time (24-72 hours) before comprehensive sampling.

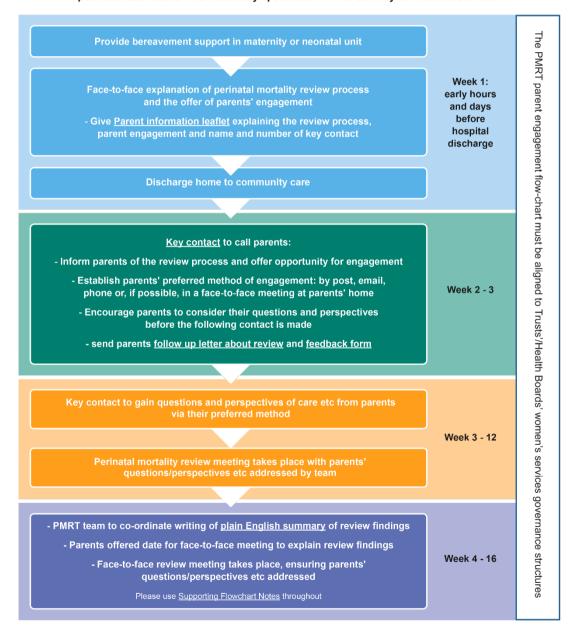
- The fixed brain should be sliced in the coronal plane at 1cm intervals.
- All brain slices should be photographed to provide a permanent record of macroscopic appearances.
- Block selection:
  - a. Cerebrum:
    - Representative sections of frontal, parietal and occipital lobes.
    - Hippocampus including inferior temporal lobe (bilateral)
    - Thalamus (bilateral)
    - Basal ganglia at the level of the mamillary bodies (bilateral). Many of these blocks can be obtained from a coronal section of the cerebral hemisphere taken through the mamillary bodies
  - b. Cerebellum:
    - Each hemisphere including dentate nucleus
    - Vermis
  - c. Brainstem:
    - Midbrain, pons and medulla (all levels of the brainstem if possible)
  - d. Spinal cord:
    - Cervical, thoracic, lumbar and sacral cord if an abnormality is suspected.
    - Dura and venous sinuses, if there is evidence of haemorrhage or thrombosis
    - Other blocks, including lesions, as specifically indicated.

# Appendix 8. Perinatal Mortality Review Tool: Parent Engagement Flowchart

The following flowchart produced by the Perinatal Mortality Review Tool collaboration is designed to assist clinicians in communicating with parents in the PMRT process and complements further resources found here. Training is provided by Sands, the stillbirth and neonatal death charity, here.

# **PMRT Parent Engagement Flow Chart**

for reviewing deaths from 22 weeks gestation (>500grammes) up to 28 days after birth and post neonatal deaths where the baby spent time in NICU but may have died elsewhere









# Appendix 9. Signposting and support organisations for parents

Organisation	Contact Details	Description
Baby Lifeline	www.babylifeline.org.uk	Charity supporting the safe care of pregnant
,	,	women and newborn babies all over the
		UK.
ВеВор	www.bebop.nhs.uk/families	A resource for parents about HIE,
•	,	hypothermia and neuroprotection.
Birth Trauma Association	www.birthtraumaassociation.org.uk	Helping people who are finding it hard to
		cope with their childbirth experience.
Bliss	hello@bliss.org.uk	For babies born too soon, too small, too sick
	www.bliss.org.uk	Provides vital support and advice to families
		of premature and sick babies across the UK.
Child Bereavement Trust	Helpline 0800 02 888 40	Providing specialised support, information
	www.childbereavementuk.org	and training to those affected when a baby
		or child dies, or when a child is bereaved.
The Lullaby Trust	Helpline 0808 802 6869	Charity raising awareness of sudden infant
	www.lullabytrust.org.uk	death syndrome (SIDS), providing expert
		advice on safer sleep for babies and offers
		emotional support for bereaved families
Newlife	Helpline 01543 462 777	Offers practical support for disabled
	www.newlifecharity.co.uk	children throughout the UK, cares for the
		carers, funds medical research, creates
		awareness and campaigns for change.
Peeps	Helpline 0800 987 5422	The only UK charity dedicated to supporting
	www.peeps-hie.org	those affected by HIE
Sands	Helpline 0808 164 3332	Charity supporting anyone affected by the
	www.sands.org.uk	death of a baby, provides training for health
		care professionals, and promotes research
		to reduce the loss of babies' lives.
Scope	Helpline 0808 800 3333	Charity supporting disabled people and
	www.scope.org.uk	their families through practical information
		and support, particularly at the time of
		diagnosis.
SUDC UK	sudc.org.uk	SUDC UK aims to prevent SUDC by raising
		awareness and funding crucial research.
		SUDC connects, families with expert
		professional and peer support.
Together for Short Lives	Helpline 0808 8088 100	Charity working to ensure that all children
	www.togetherforshortlives.org.uk	and young people, unlikely to live or reach
		adulthood, and their families, receive care
		and support whenever and wherever they
		need it.
Tommys	Phone 020 7398 3400	Charity carrying out research into the
	www.tommys.org	causes of miscarriage, stillbirth and
		premature birth. Provides information and
		support to anyone who has experienced
		baby loss.
UNICEF UK Baby Friendly	https://unicef.uk/bf-parents	The UNICEF UK Baby Friendly Initiative
Initiative		provides guidance for health professionals
		and parents on infant feeding, relationship
		building and infant sleep.

## Appendix 10. Members of working group

Chair: Dr Julie-Clare Becher, Neonatologist, Royal Infirmary of Edinburgh

Neil Dalton, Emeritus Professor of Paediatric Biochemistry, Consultant Clinical Scientist, Evelina

London Children's Hospital, London

Francesca Entwistle, Deputy Programme Director, UNICEF UK Baby Friendly Initiative

Nikki Farrington, Specialist Nurse Bereavement & Family Support, Royal Wolverhampton

Peter Fleming, Professor of Infant Health and Developmental Physiology, University of Bristol

Samantha Harrison, Midwife, Chelsea and Westminster NHS Foundation Trust

Marcus Hook, Membership and Finance Coordinator, BAPM

Ciaran Hutchinson, Paediatric Pathologist, Great Ormond Street Hospital for Children

Yogini Jani, Consultant Pharmacist, University College London Hospitals NHS Foundation Trust

Sarah Land, Charity Manager, PEEPS HIE Charity

Janice MacKenzie, Midwifery Clinical Advisor, HSIB

Lisa Marshall, Head of Maternity Investigations, HSIB

Natalie McKie, The Lullaby Trust

Alison Murray, Intrapartum Matron, Liverpool Women's

Niamh O'Neill, Parent member of PEEPS HIE Charity

Louise Page, President of the British Intrapartum Care Society & Deputy Clinical Director, Maternity

Investigations, HSIB

Se-Yeon Park, Neonatologist, Maidstone & Tunbridge Wells Hospital; Clinical Advisor to HSIB

Karen Read, Professional Lead for Neonatal, Unicef UK Baby Friendly Initiative

Mary Rutherford, Professor of Perinatal Imaging & Health, King's College London

Esther Tylee, Infant Feeding Lead Midwife, Bedford Hospital NHS Trust

Rachel Walsh, National Neonatal Clinical Fellow, NHS Resolution

#### With many thanks for review of the document:

Sue Ashmore, Programme Director, Unicef UK Baby Friendly Initiative

Charlotte Bevan, Senior Research and Prevention Advisor, Sands

David Fitzpatrick, Consultant in Clinical Genetics, MRC Human Genetics Unit, Edinburgh

Andy Lyon, Retired Neonatologist, Edinburgh

Amaka Offiah, Chair of Paediatric Musculoskeletal Imaging, Honorary Consultant Paediatric

Radiologist, University of Sheffield and Sheffield Children's Hospital

Stella Parkin, Professional Advisor and Training Lead, The Lullaby Trust

# Appendix 11. Stakeholder Consultation

Bliss

British Association of Perinatal Medicine Executive Committee and membership

**British Neuropathology Society** 

Coroners' Society

Crown Office and Procurator Fiscal Service

Healthcare Safety Investigation Branch

International Stillbirth Alliance

**Lullaby Trust** 

Maternity Voices Partnership

National Childbirth Trust

**National Infant Feeding Network** 

**NHS** Resolution

PEEPS HIE Charity

Royal College of Midwives

Royal College of Obstetrics and Gynaecologists

Royal College of Paediatrics and Child Health

**Royal College of Pathologists** 

**Royal College of Radiologists** 

Sands

Scottish Cot Death Trust

Scottish Pathologists Association

UNICEF UK Baby Friendly Initiative