## Women and Babies: Management and Investigation of Sudden Unexpected Death or Collapse in Apparently Healthy Term Neonates

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<table>
<thead>
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Management and Investigation of Sudden Unexpected Death or Collapse in Apparently Healthy Term infants

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SLHD - RPA Management and Investigation of Sudden Unexpected Death or Collapse in Apparently Healthy Term Neonates

1. Introduction
   • Management and investigation of Sudden Unexpected Death or Collapse in healthy babies is essential to ensure adequate treatment and to provide answers to families.

2. The Aims / Expected Outcome of this Guideline
   • The Aims of this guideline are to guide clinicians on the management and investigation of neonates who have had a sudden unexpected death or collapse.

3. Risk Statement
   SLHD Enterprise Risk Management System (ERMS) Risk # 105 - Minimise adverse events
   • The risks associated with not following this guideline include the inadequate investigation and management of cases of SUDI.

4. Scope
   • Neonatal medical and nursing staff.

5. Key Performance Indicators and Service Measures
   • Audit.

6. Guidelines
   Definition
   The Sudden Unexpected Postnatal Collapse of apparently healthy term neonates includes any baby at or near term (>35 weeks gestation) who:
   • Is well at birth – deemed well enough to have routine postnatal care.
   • Collapses unexpectedly – is in a state of cardiorespiratory extremis such that resuscitation with intermittent positive pressure ventilation is required.
   • Either dies or goes on to require intensive care.

   Incidence
   The incidence of sudden unexpected and unexplained death or neonatal collapse is reported as between 0.035/1000 to 0.4/1000 live births. Although rare, greater than half of these infants die and the majority of survivors have significant long term neurodevelopmental morbidities. 1,2,3,4,5,6,7

   Background
   It is clear from the retrospective examination of neonatal sudden unexplained death in infants (SUDI) in NSW, that the history, examination and investigation of these cases are not always completely adequate. Of the 123 neonatal sudden unexplained infant deaths reported (1996-2008), 37 (30%) occurred in the first 7 days of life.

Compliance with this Guideline is Recommended
The British Paediatric Surveillance Unit performed a study looking at the sudden unexplained collapse or death of apparently healthy term infants in the first 12 hours of life. In this study, 30 out of 45 cases had no identifiable underlying disease/abnormality but in 24 there was clinical or pathological evidence of airway obstruction\textsuperscript{10}. Ten out of the twelve infants who died had a post-mortem and a cause of death was identified in 50 \% of cases. Underlying conditions including infection, congenital cardiac defects, metabolic defects, intracranial haemorrhage/infarction, meconium aspiration syndrome, severe chronic anaemia (related to parvovirus infection), congenital diaphragmatic hernia, central hypoventilation syndrome and adrenal hypoplasia were all identified as causative in infants.\textsuperscript{11}

In an Australian national surveillance study, the incidence in NSW and Queensland was 0.1 and 0.08/1000 live births respectively. The cause of death was identified in 42 out of the 48 infants reported. The three common causes were accidental asphyxia during breastfeeding or skin to skin, cardiac disease or PPHN.\textsuperscript{2} This study highlighted the need for the development and implementation of guidelines to ensure safe sleeping in hospital to ensure the safety of the newborn.

In infants who die in the first week of life, more than 50\% are explained after post-mortem examination. The information obtained from investigations and from post-mortem examination is extremely important for the management and prognosis of infants who survive such an event, for counselling of families and for potential future pregnancies.

Neonatal unexplained death is a rare condition with the above important implications for the baby and family. For these reasons a protocol with checklists for history, examination and investigations has been developed.

A reminder that such cases by law must be referred to the Coroner; however, a discussion with the forensic pathologist can enable a paediatric perinatal post mortem. The pathological investigation of infants dying in the first week of life has a higher diagnostic yield compared with later SUDI.\textsuperscript{12}

**Risk Factors**

In the reported literature, many of these infants are found face down on the mother’s breast suggesting that airway compromise may be a contributing factor. The association of skin-to-skin, breast feeding and prone position have been well documented.\textsuperscript{2,9} Other risk factors include primaparous women, recent maternal analgesia, bed-sharing and unattended mothers.\textsuperscript{11} In the study by Polberger \textit{et al} all deaths or collapse occurred between 11pm and 6am while six out of ten infants in the study by Burchfield \textit{et al} collapsed in the early morning hours.\textsuperscript{1} The history of the event occurring in the early hours of the morning was not consistent in all the reported literature.

**Approach to Sudden Unexpected Death or Collapse**

- **History**

  All infants who present with sudden unexpected collapse or death in the neonatal period need a thorough history and clinical examination to in an attempt to establish the cause for the event. If at all possible, this history and examination should be performed by a neonatologist/ paediatrician or the most senior neonatal/paediatric clinician.

  **Maternal history**

  - Maternal antenatal care
  - Maternal gravidity
  - Maternal infection - GBS status, urinary tract infections, fever during labour

Compliance with this Guideline is Recommended
- Previous pregnancy resulting in stillbirth, neonatal death or collapse
- Maternal complications during pregnancy
- Maternal medications or substance use during pregnancy
- Analgesia during labour
- Post-delivery analgesia including timing
- Family history – cardiac disease, genetic conditions, consanguinity, metabolic disease
- Parents’ occupations

The delivery
- Mode of delivery
- Onset of labour
- Presence of meconium stained liquor
- Resuscitation required at birth including Apgar scores
- Arterial cord gas if available

The presentation
- Who found the baby?
- Who was in the room at the time of event?
- Time of the event
- Position the baby was last placed
- Position and place the baby was found
- Any items near the face – toys, bumper pads, positional supports
- Was the baby using a dummy at the time of the collapse
- When last reviewed was the baby feeding, awake but not feeding or asleep
- Date and time of last observation/check before being found
- Feeding – breast, formula or both. Timing of last feed.
- Infant medications
- In the 24 hours prior to the collapse did the neonate have an acute illness
- In the 24 hours prior to the collapse was there a history of trauma/fall

If the collapse occurs in the delivery suite, it may be helpful to obtain photos’ of the baby, with or without the mother, from the family in the time leading up to the collapse. This may be especially useful if the collapse is thought to be due to positioning of the baby.

- Examination

The examination should be thorough and systematic as detailed in the PSANZ perinatal audit guidelines. Anthropometric data should be documented (weight, length and head circumference) and percentiles charted on the WHO growth charts. Any obvious dysmorphic
features should be highlighted. Clinical photographs (with consent) should be considered if it is unlikely that the baby will be reviewed by a geneticist.

**Suggested Investigations on infants presenting with sudden unexpected collapse**

### Neonatal collapse

- **History and Clinical examination**

### Primary investigations

#### SEPSIS
- **Blood** – FBC, coagulation studies, CRP, blood cultures, parvovirus PCR
- **Urine** – MC&S, CMV PCR
- **CSF** – bacterial culture, HSV and enterovirus PCR
- **Stool** – enterovirus
- **NPA** – viruses
- **CXR**

#### CARDIAC DISEASE
- **ECG** – conduction defects
- **CXR**
- **Cardiac ultrasound**

#### METABOLIC DISEASE
- **Blood** – venous gas, electrolytes, CMP, ammonia, LFT, glucose, amino acids, organic acids, lactate, uric acid, acyl carnitine, sulphocysteine
- **Urine** – metabolic screen
- **CSF** – lactate and pyruvate
### Suggested Investigations on babies presenting with sudden unexpected death

<table>
<thead>
<tr>
<th>Investigation</th>
<th>Blood investigations</th>
<th>Skin and muscle</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical photographs</strong>&lt;sup&gt;12,13&lt;/sup&gt;</td>
<td>Blood culture (cardiac tap)</td>
<td>Skin Surface Swabs (MC and S)</td>
</tr>
<tr>
<td></td>
<td>AP view – whole body including limbs</td>
<td>Skin and muscle biopsy</td>
</tr>
<tr>
<td></td>
<td>PA view</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lateral view of the body</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lateral view of the face</td>
<td></td>
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<tr>
<td></td>
<td>Frontal view of face</td>
<td></td>
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<tr>
<td></td>
<td>Photograph of any detected abnormality</td>
<td></td>
</tr>
<tr>
<td><strong>Blood investigations</strong></td>
<td>Dried Blood spot (NBST)</td>
<td>Sepsis</td>
</tr>
<tr>
<td></td>
<td>Sepsis</td>
<td>Mitochondrial disorder</td>
</tr>
<tr>
<td></td>
<td>Metabolic Disease and DNA storage</td>
<td>Skin biopsy for fibroblast line as a source of DNA (storage)</td>
</tr>
<tr>
<td>Imaging</td>
<td>CXR, Skeletal survey</td>
<td>Congenital anomalies</td>
</tr>
<tr>
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<tr>
<td>Post mortem</td>
<td>Including anthropometric measurements (weight, length, head and abdominal circumferences). Preferably performed by a paediatric or perinatal pathologist.</td>
<td></td>
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</tbody>
</table>

**Suggested maternal investigations**

The following investigations are recommended for mothers whose newborn baby presents with unexpected collapse or death

<table>
<thead>
<tr>
<th>Placenta</th>
<th>Histopathology</th>
<th>Placental swabs for bacterial and viral culture (bacterial cultures should be taken between the chorion and amnion)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood</td>
<td>Kleihauer Betke Test (QFMH)</td>
<td>Fetal-maternal haemorrhage</td>
</tr>
<tr>
<td></td>
<td>Viral Titres</td>
<td>Sepsis</td>
</tr>
<tr>
<td></td>
<td>Toxicology</td>
<td></td>
</tr>
<tr>
<td>Swabs</td>
<td>High and low vaginal swabs</td>
<td>Sepsis</td>
</tr>
</tbody>
</table>

**Follow-up of families**

These families should be followed up by a neonatologist or paediatrician, a social worker and a geneticist if appropriate at 6-8 weeks after the death. Any outstanding results should be relayed to the family including the preliminary results of the post mortem as soon they become available.
7. **Definitions**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>SUDI</td>
<td>Sudden unexplained death infancy</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
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<tr>
<td>NPA</td>
<td>Nasopharyngeal aspirate</td>
</tr>
<tr>
<td>ECG</td>
<td>Electrocardiography</td>
</tr>
<tr>
<td>CXR</td>
<td>Chest X-ray</td>
</tr>
</tbody>
</table>

8. **Consultation**

- PSANZ Perinatal Audit Guidelines

9. **References**


10. **National Safety and Quality Health Service (NSQHS) Standards, Version 2**

   - Standard 1, Clinical Governance Standard
   - Standard 8, Recognising and Responding to Acute Deterioration Standard
### 1.4 Clinical examination of baby checklist

Please tick appropriate box and complete details as required.

<table>
<thead>
<tr>
<th>Baby measurements</th>
<th></th>
<th></th>
</tr>
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<tbody>
<tr>
<td>1. Crown – heel (stretched)</td>
<td></td>
<td>cms</td>
</tr>
<tr>
<td>2. Head circumference</td>
<td></td>
<td>cms</td>
</tr>
<tr>
<td>3. Weight</td>
<td></td>
<td>gms</td>
</tr>
</tbody>
</table>

If stillborn

Estimated date of IUD:

Maceration degree

Placenta, no skin peeling

Significant maternal skin slippage

Macrosomia, some skin sloughing, moderate skin slippage

Moderate, much skin sloughing but no secondary comprehensive changes or decomposition

Marked, advanced

**HEAD AND FACE**

Head

Relatively normal | Collapsed | Hydrocephalic

Abnormal shape

If abnormally shaped, describe:

Eyes

Normal | Prominent | Sunken

Strabismus | Far apart | Close together

Lid lagging | Downward | Absent

Eyes very small | Very large | Comma opacity

Lens opacity | Other |

Eyelids fused |

Nose

Normal | Abnormally small | Abnormally large |

Asymmetric |

Nasal tip

Apparent, patent | Obstructed | Single nostril | Other |

If other, describe:

Mouth

Nasal size | Large | Small |

Upper lip

Intact | Cleft |

Lips | Bilateral | Right | Midline |

Palate

Intact | Cleft |

Mandible

Normal | Large | Small |

If other, describe:

Ear

Normal | Preauricular tags | Preauricular pits | Posteriorly rotated |

If other, describe:

### Maternal Sticker

Maternal Sticker

(Inc Name, DOB, UR, Address, Telephone Number)

## Singlet | Multiple | Baby number

#### NECK

- Normal
- Mass
- Describe:

#### CHEST

- Normal
- Short & broad
- Other
- If other, describe:

#### ABDOMEN

- Normal
- Distended
- Hernia
- Omphalocele
- Gastrochisis
- Spina bifida
- Other
- If other, describe:

#### BACK

- Normal
- Other
- If other, describe:

#### GENITALIA

- Anus
- Normal | Imperforate | Other
- If other, describe:

#### LIMBS

- Length
- Normal | Short | Long
- If short, what segments seem short
- Other
- If other, describe:

#### HANDS

- Length
- Appearance: Normal | Abnormal
- If abnormal, describe:

#### Fingers

- Number present:
- If not 4 + 4, describe:
- Unusual form of fingers
- Unusual position of fingers
- Normal webbing or syndactyly
- If abnormal, describe:

#### Thumb

- Number present:
- If not 1 + 1, describe:
- Unusual position
- Looks like a finger
- If abnormal, describe:

#### Finger nails

- All present
- If not described:
- Unusual appearance
- If abnormal, describe:

#### FEET

- Appearance: Normal | Abnormal
- If abnormal, describe:

#### Toes

- Number present:
- If not 5 + 5, describe:
- Spacing: Normal | Abnormal
- If abnormal, describe:

#### Toe nails

- All present
- If not described:
- Unusual appearance
- If abnormal, describe:

**Revised gestational age**

Based on

Examined by: (Print name)

Date: ____________

Summary of key findings:

Compliance with this Guideline is Recommended