Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

A Clinical Guideline

For Use in: All emergency departments, children’s assessment units, children’s inpatient wards and neonatal units at Norfolk and Norwich, James Paget and Queen Elizabeth, Kings Lynn, hospitals.

By: All medical and nursing staff

For: Children and young people dying suddenly and unexpectedly, prior to their 18th birthday. (The same guidance should be used for children resuscitated after cardiac arrest, or admitted moribund, and who are likely to die.)

Division responsible for document: Women and Children’s Division

Key words: Sudden unexpected death in infancy (SUDI) Sudden unexpected death in infancy and childhood (SUDIC), Sudden infant death syndrome (SIDS), Cot death

Name and job title of document author: Dr. Ravi Alanoor – Consultant Paediatrician, SUDIC Lead for the NNUH Trust

Name and job title of document author’s Line Manager: Dr. Bina Mukhtyar - Clinical Governance Lead, Paediatrics, NNUH

Supported by: Dr. Stephen Nirmal - Consultant paediatrician, JPUH. Dr. Abigail Reeve - Consultant paediatrician, QEHKL.

Assessed and approved by the: Clinical Guidelines Assessment Panel (CGAP)

Date of approval: 08/04/2020

Ratified by or reported as approved to (if applicable): Clinical Safety and Effectiveness Sub-Board

To be reviewed before: 08/04/2023

To be reviewed by: Responsible doctor for child deaths in the Trust

Reference and / or Trust Docs ID No: 1228

Version No: 6

Description of changes: Addition of COVID information on page -8

Compliance links: No

If Yes - does the strategy/policy deviate from the recommendations of NICE? If so why?: N/A

The guideline is divided into the following colour coded sections for ease of use. It is intended to be used in conjunction with the SUDIC paperwork.
<table>
<thead>
<tr>
<th>Section</th>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Introduction</td>
<td>3, 4</td>
</tr>
<tr>
<td></td>
<td>Definition, objectives &amp; General principles</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Algorithm</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>Declaration of Death</td>
<td>5, 6</td>
</tr>
<tr>
<td></td>
<td>Discontinuing resuscitation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Informing the family of death</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>History</td>
<td>7-8</td>
</tr>
<tr>
<td></td>
<td>Circumstances of death and recent events</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Past Medical History</td>
<td>5-6</td>
</tr>
<tr>
<td></td>
<td>Household composition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family History</td>
<td>6</td>
</tr>
<tr>
<td>Four</td>
<td>Examination</td>
<td>6-7</td>
</tr>
<tr>
<td>Five</td>
<td>Investigations</td>
<td>7-10</td>
</tr>
<tr>
<td></td>
<td>Obtaining samples &amp; Chain of Evidence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Samples Required</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>Checklists</td>
<td>11-12</td>
</tr>
<tr>
<td></td>
<td>Medical &amp; Nursing Checklists</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other professionals to be notified</td>
<td>12</td>
</tr>
<tr>
<td>Seven</td>
<td>Guideline Development</td>
<td>12-13</td>
</tr>
<tr>
<td></td>
<td>Guideline development process</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Audit standards</td>
<td></td>
</tr>
<tr>
<td></td>
<td>References</td>
<td></td>
</tr>
</tbody>
</table>
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

Definition of an unexpected child death

Unexpected child death is death of a child **prior to their 18th birthday** that was not anticipated as a significant possibility 24 hours prior or where there was a similarly unexpected collapse leading to or precipitating the events that led to subsequent death.

To facilitate appropriate recording of information, use the SUDIC paperwork.

Objectives of this guideline

- To ensure a thorough systematic and sensitive approach is undertaken to establish, as far as it is possible, the cause or causes of the child’s death with emphasis on history, examination and investigations, and to identify any potential contributory or modifiable causes
- To ensure that bereaved families are offered optimal support during a traumatic time, and that sensitivity is maintained alongside thorough objectivity towards the cause/s of death.
- To ensure that the wellbeing and welfare of siblings, any other children, and subsequent children, whatever the cause of death.
- To work within the guidance of the Norfolk Safeguarding Children’s Board (NSCB) and the current national guidance regarding management of sudden unexpected death in childhood and to ensure that all statutory obligations are met.

General considerations

- This guideline and documentation should be used when children and young people die unexpectedly **prior to their 18th birthday**.
- In some circumstances, a child is revived by resuscitation efforts, but subsequently dies. In these cases, it is still appropriate to use this procedure.
- Where there is uncertainty about whether the death should be regarded as sudden and unexpected, seek advice from the consultant paediatrician on call, or the Trust’s lead paediatrician for unexpected deaths.
- For deaths occurring in the community, the child’s body will **in almost all circumstances** be brought to A&E, unless the circumstances of death indicate an obvious criminal cause, or it is otherwise inappropriate to do so.
- All family members should be dealt with in a sensitive manner with early involvement of Senior Medical Staff:
  - Children under 16y – Acute General Paediatrician on-call.
  - Children 16 & 17y of age – SUDIC Consultant.
- Careful documentation of the resuscitation, history and examination is vital.
- Every sudden unexpected death in childhood requires a multi-agency investigation including the Coroner, Police and Children’s Services, and other agencies as relevant. Every such child should be referred to the coroner and no measures taken without the coroner’s permission. This guideline should be considered as prior permission from the coroner for those steps – including invasive investigations – that are outlined in this guideline. A Medical Certificate
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

for Cause of Death should not be issued except in those rare cases where the cause may be apparent, but even then only after discussion with the coroner.

- All unexpected deaths – including those occurring in hospital – are covered by this guideline.

Declaration of Death

Usually, though not invariably, a child would have had attempts at resuscitation. The decision to discontinue resuscitation is a difficult one and should be made by the most senior doctor present. If there is no detectable cardiac output or any sign of cerebral activity for 20 minutes (including pre-hospital), it is reasonable to stop resuscitation efforts.

In many cases of sudden unexpected death there are clear signs that death occurred some time before the child was discovered, eg rigor mortis, post-mortem livedo. In the absence of clear signs of death the child/young person should be observed by the person responsible for confirming death for a minimum of five minutes to establish that irreversible cardio-respiratory arrest has occurred.

Any spontaneous return of cardiac or respiratory activity during this period of observation should prompt a further five minutes observation from the next point of cardio-respiratory arrest. After five minutes of continued cardio-respiratory arrest, the absence of the pupillary responses to light, of the corneal re-flexes, and of any motor response to supra-orbital pressure should be confirmed. The time of death is recorded as the time at which these criteria are fulfilled.

Parents may wish to remain with the child in the resuscitation room. If this is the case an experienced nurse or doctor should be allocated to remain with them explaining procedures throughout. Alternatively they may be taken to a private room nearby and kept informed of events. A team member should obtain a brief history at this stage.

Informing the family of the death

- When the child has been pronounced dead, an experienced paediatrician - preferably a consultant - should break the news to the parents, after having reviewed all the available information. If possible, this should be done with the Police, in order to avoid duplication and reduce distress.
- The interview should be in the privacy of an appropriate room. A nurse should also be present to support the family.
- The family should be treated with respect and honesty. They should be allowed to ask questions at any stage.
- Unless there is an obvious cause of death, it is usually best to say that an opinion cannot be given until after the post-mortem examination.
- Explain that any sudden death of unknown cause must be reported to the police and the coroner. The police have a duty to investigate any sudden unexpected death at any age. The coroner will arrange a post-mortem examination.
- The Rapid Response Team (RRT), comprising a health professional and a senior police officer will normally visit the family home and/or scene of death, within 24 to 48 hours. The rapid response team or the hospital team will also liaise with
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

other professionals to best understand the cause of death.

- Explain the need to take blood, urine and CSF samples to help with the evaluation of cause of death.
- The relevant consultant, Coroner’s officer and/or RRT will keep the family updated with information from investigations and the post mortem examination.
- Parents should be encouraged to hold the child and spend as much time as they wish with them, but may not be left unaccompanied.

Documentation

After death has been declared, it is important to thoroughly document all aspects of resuscitation, including invasive procedures, and any investigations performed, in the patient’s Emergency Department record. It is important to capture this information as quickly as possible after death, as it may prove difficult to obtain some of the information later.

Detailed account of events Prior to Death

In particular, note the following:

- Time when last seen alive.
- For infants, note where and how the baby was put down, clothing, bed coverings, position and if co-sleeping, who else was sleeping with the child and their positions relative to the baby.
- Where, when and by whom the child was found, position, appearance of any unusual features.
- Record the subsequent course of events including:
  - When ambulance service contacted.
  - When ambulance arrived.
  - Any CPR given prior to arrival of ambulance crew, and by whom.
- Record a detailed account of all events leading up to death. This will include at least the last 48 hours prior to death.
- Include details of any signs of illness, sleeping and waking, oral intake, including when food/drink was last consumed.
- Note use of any medication (including non-prescribed medication), drugs, and alcohol in the child and / or family members.

Previous Medical History including

- Medical conditions and their current status and treatment: illnesses, operations, accidents, particularly noting outpatient and inpatient Hospital and A&E Attendances. Where a child had been admitted to hospital before, determine where, when and why.
- Where relevant, details of birth history, antenatal problems, and admission to neonatal unit.
- Immunization history.
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

- Development & Behaviour.
- School/Nursery/Child minder attended. Any problems/concerns?
- Medication.
- Allergies.

Household & Family Composition

- A surviving sibling may cause the family concern following the death and urgent arrangements should be made for them to be examined and admitted if necessary. There may be other children who may be affected, such as half-siblings and step-siblings. It is important to obtain and document details of such children.
- If non-accidental injury is suspected, urgent arrangements must be made to examine all vulnerable siblings, especially those <2 years of age. The on call paediatrician should discuss arrangements for this examination with the community paediatrician on-call for safeguarding.
- Note first name, surname, date of birth, and relationship to the child, of all individuals living in the household.
- Note names and details of other individuals who had close contact with the child.
- Record any significant family history:
  - Medical conditions.
  - Mental health problems in parents or immediate family members.
  - History of easy bruising or fractures in family members (if relevant).
  - Any infectious contacts/foreign travel.
  - Any previous infant or other sudden deaths (child or adult) in the family.
  - A family tree is a helpful way of documenting the information (social and medical). Note the school the child attended, and, if known, the class teacher.

Resuscitation

- Ensure that the resuscitation efforts are appropriately, and where possible contemporaneously, documented in the medical record and make a photocopy to attach to the SUDIC paperwork.

Examination

A detailed physical examination of the body is required after death. The examination should normally be performed by a senior paediatrician. The following should specifically be noted:

- Rectal temperature (and time taken).
- Weight, length and head circumference.
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

- Any canulation or venepuncture sites, or other marks arising from resuscitation efforts.
- Presence or absence of rigor mortis, and its extent.
- Post-mortem livedo.
- Hygiene.
- Nutritional State.
- Any rashes, marks, bruises, abrasions, cuts, bite marks, etc. These should be documented on the body maps in the SUDIC paperwork. Include measurements and detailed description whenever possible. Particularly in infants, note any dysmorphic features.
- Deformities, masses and swelling.
- If it is clear that not much time has elapsed since the death occurred (i.e. witnessed death, other history suggestive of very recent signs of life, and absent post-mortem changes), discuss with the ophthalmologists regarding the feasibility of meaningful retinal examination for haemorrhages, when there is a suspicion of non-accidental injuries.

Note that any medical equipment sited in resuscitation should remain in situ, after death has been declared. Tubes may be cut short, so as not to be obtrusive. If any equipment has been removed - after obtaining the coroner’s permission – this should be documented clearly. The ETT tube should only be removed after the position has been checked directly and confirmed by a doctor different from the one who intubated. The child’s clothing and nappy should be placed in a labelled plastic property bag, closed with tape and remain with the child.

**Clinical photography:**

Where the death is considered suspicious, clinical photographs should be considered in liaison with the police, using a right-angled measurement scale.

**Investigations**

- Note any laboratory and other results from specimens that have been taken during resuscitation or prior to death. Inform the laboratory that these samples should not be discarded.

**Post-mortem sampling**

- All investigations need to be ordered on the web ICE requesting system: See Laboratory Investigations/Profiles/SUDIC.
- In order to help ascertain the cause of death, it may be important to obtain specific blood, urine and CSF samples after death. The time of sample should be recorded. Samples should be taken as soon as possible after death.
- Ensure that blood gas results are copied into the notes as the printout fades with time.
- Blood samples may be taken by a femoral puncture or from the heart (insert syringe and needle at 90° in the 4th intercostal space at the left sternal edge).
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

Repeated attempts should be avoided and cardiac puncture should be avoided in forensic cases.

- Urine samples can be taken by using a catheter/feeding tube, or by suprapubic aspirate. Avoid repeated attempts.
- CSF is obtained by lumbar puncture in the usual way. Avoid repeated attempts.

### Chain-of-Evidence Procedure for SUDIC Samples

1. Order appropriate tests from SUDIC profile on webICE.
2. Take samples, label correctly and attach request forms
3. Complete the chain of evidence form (see SUDIC paperwork) Complete the check boxes for all tests requested. Not all tests are mandatory. Discuss with consultant and/or laboratory staff if unsure of appropriateness of samples.
4. Specimens with the signed chain of evidence form handed over to the person taking the sample to the laboratory.
5. Retain a photocopy of the chain of evidence form so that it can be filed in the notes.
6. All specimens (pathology and microbiology and Neonatal Screening (“Guthrie”) card) must be taken by hand to the main pathology lab, and physically handed over to the laboratory staff, who should also sign the form to document receipt.
7. A photocopy of the form with signatures of microbiology and pathology lab personnel will be returned to the responsible consultant for filing in the hospital notes.

All investigations need to be ordered on the WebICE requesting system:
See Laboratory Investigations/Profiles/SUDIC. *Covid-19 T/N swabs to be requested*.

### Post-mortem Samples Required

<table>
<thead>
<tr>
<th>Sample</th>
<th>Send to</th>
<th>Handling</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood (serum) 1–2 ml</td>
<td>Clinical chemistry</td>
<td>Spin, store serum at –20°C</td>
<td>Toxicology if indicated*</td>
</tr>
<tr>
<td>Blood cultures – aerobic and anaerobic 1 ml</td>
<td>Microbiology**</td>
<td>If insufficient blood, aerobic only</td>
<td>Culture and sensitivity</td>
</tr>
<tr>
<td>Blood from Guthrie card</td>
<td>Clinical chemistry</td>
<td>Normal (fill in card; do not put into plastic bag)</td>
<td>Inherited metabolic diseases</td>
</tr>
<tr>
<td>Blood (lithium heparin) 1–2 ml</td>
<td>Cytogenetics</td>
<td>Normal – keep unseparated</td>
<td>Genetic testing (if indicated)</td>
</tr>
<tr>
<td>Cerebrospinal fluid (CSF)</td>
<td>Microbiology***</td>
<td>Normal</td>
<td>Microscopy, culture and sensitivity</td>
</tr>
<tr>
<td>Nasopharyngeal aspirate</td>
<td>Virology#</td>
<td>Normal</td>
<td>Nucleic acid amplification techniques**</td>
</tr>
<tr>
<td>Nasopharyngeal aspirate</td>
<td>Microbiology</td>
<td>Normal</td>
<td>Culture and sensitivity</td>
</tr>
<tr>
<td>Swabs from any identifiable lesions</td>
<td>Microbiology</td>
<td>Normal</td>
<td>Culture and sensitivity</td>
</tr>
<tr>
<td>Urine (if available)</td>
<td>Clinical chemistry</td>
<td>Spin, store supernatant at –20°C</td>
<td>Toxicology if indicated, inherited metabolic diseases</td>
</tr>
</tbody>
</table>
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

**Blood Tests**

i. Blood Glucose & ketones.

ii. U&Es, LFTs, Ca, phosphate, Mg, CRP.

iii. FBC.

iv. Post-mortem blood alcohol.

v. Tryptase (if unexplained shock).

vi. Neonatal Screening Card (for Acylcarnitines)*.


viii. Viral serology (only in children over 6 months).

ix. Low resolution micro-array*.

x. EDTA sample for storage.

xi. Plasma sample for storage.

xii. Serum sample for storage.

**Urine Samples**

- Urinalysis.
- Urine toxicology.
- Urine metabolic screen*.
- Urine MC&S.
- Urine for storage (spin & freeze at -20°C).

*Required in infants, or (unless already performed) in older children with a history of neuro-developmental problems and/or dysmorphic features

**CSF Samples**

- CSF glucose.
- CSF Protein.
- CSF MC&S.
- CSF for storage (spin & freeze at -20°C).

**Note:** It is important to record the appearance of the CSF obtained at LP. If there is significant blood staining, this may indicate intra-cerebral haemorrhage/closed head trauma. Ensure that the Police and the Coroner are aware of this finding.

**Other Microbiology Samples**

- Gastric aspirate (for culture)
- Nasopharyngeal aspirate
- Throat Swab
- Nasal swab
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

- Surface swabs from any skin lesions

Others
- Occasionally a skin biopsy may be required for metabolic tests. These should ideally be taken as soon as possible after death, to increase the likelihood of successful fibroblast culture. Suitable transport medium is kept in cytogenetics. Out-of-hours, samples may be kept in sterile normal saline, and refrigerated.
- Muscle biopsy: when a mitochondrial disorder is suspected.

Stored samples

Note that stored samples are discarded after 6 months.

Skeletal survey

Most deaths under two years of age warrant a full skeletal survey. At the NNUH (including referrals from QEH and JPH), this will be arranged by the paediatric pathologists.

The Child Death Review Process

The parents should be counselled about the child death review processes and that they will receive further information regarding this. This is usually sent to the home address by post.

Multiagency reviews and planning

1.1. Initial information sharing and planning (within first 2 hours)
An initial information sharing and planning discussion should be co-ordinated by the most senior paediatrician present, within 2 hours and before the family leaves. At a minimum this should include the senior paediatrician, lead police investigator, rapid response nurse and the hospital safeguarding team in working hours. The lead police investigator should ensure that background information is sought from Children’s Social Care prior to this discussion. Information should also be promptly obtained from the ambulance crew – ideally before they leave ED.

1.2. Initial strategy meeting (on the day)
A section-47 strategy meeting should be held on the day in the case of all sudden or unexpected deaths in children. This should be chaired by the Head of Social Work in Children’s Social Care.

1.3. Initial child death review meeting (within 2 days)
The hospital safeguarding team will arrange a child death review meeting within two days of the initial strategy meeting. The meeting will be chaired by the consultant paediatrician or the designated doctor for deaths. This is to review all information obtained since the child’s death and any information that may be available from initial post-mortem findings. The outcomes of this meeting should be captured in Form B.

1.4. Final child death review meeting (within 6-8 weeks)
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

The hospital safeguarding children team will convene a further multi-agency meeting 6 – 8 weeks after the death to review any further information and report to the CDOP. The meeting will be chaired by the designated doctor for child deaths supported by the lead paediatrician and the hospital safeguarding team and the health RRT.

Checklists

It is vital to ensure that all correct steps have been followed, and all relevant individuals informed of a child’s death.

Medical Checklist

Notify the following immediately after a death. Note who was spoken to (first name, surname and contact information)

- Coroner’s Officer
  - Telephone 01603 663302 in office hours, via hospital switchboard out-of-hours.

- Rapid Response Team
  - Available via hospital switchboard 8am to 6pm every day.
  - Answerphone message may be left out-of-hours.

- Norfolk Police
  - Ring Norfolk Police Control Room: 0845 456 4567, and speak to a detective inspector from the Vulnerable Person’s Unit, regarding a child death.

- Children’s Services
  - Contact the Emergency Duty Team: 0344 800 8014 (24 hours), and notify the duty Social Worker. Ascertain whether the child is known to Children’s Services, and whether there have been previous safeguarding concerns.

Nursing checklist

Record the following:

- Were the parents present when the child died?
- Has the family had time with their child, if they so wish?
- Have all key friends or relatives been informed?

Cultural & Religious Needs

- Is an interpreter required?
- Does the family have particular cultural or religious wishes?
- For unbaptised children, would the family like a Blessing or other service appropriate to the family’s beliefs? This may be arranged through the hospital chaplaincy, or through the family’s church/faith leader.
Joint Guideline for Management of Sudden Unexpected Death in Infancy and Childhood

- Note any particular wishes, including arrangements (e.g., date/time of funeral).

**Keepsakes**

The parents should be asked if they wish to have keepsakes, such as photographs, hand or footprints, or a lock of hair.

**Patient Administration System**

- Ensure patient has been recorded as having died on PAS. This will ensure that any future appointments are cancelled.

**Other individuals who require notification (next working day)**

- General Practitioner.
- Norfolk Safeguarding Team 01603 257164.
- Trust Safeguarding Team:
  - Dr Richard Reading 01603 287625 or email.
  - Kim Goodby 01603 286300 or email.
- Liaison Health Visitor.
- Community Child Health.
- Child Death Overview Panel Administrator 01603 223380.
- Any other relevant professionals that had involvement with the child/family.

**Guideline Development**

**Audit Standards**

1. All children dying suddenly and unexpectedly should have complete documentation of the resuscitation, history and examination.
2. All should have appropriate investigations undertaken at the time of death, or as soon as possible thereafter.
3. All specimens should have a chain of evidence.
4. All sudden unexpected deaths in children and infants should have a multi-agency assessment.

**Summary of development and consultation process undertaken before registration and dissemination**

The authors listed above wrote the guideline, which was discussed at the Paediatric Directorate Guideline meeting.
During its development it was circulated for comment to:
Ms. Jacqueline Lake - Coroner for Norwich.
All Acute and Community Consultant Paediatricians at NNUH, JPUH and QEHKL.
Drs. Virginia Sams & Xenia Tyler in Paediatric Pathology.
Consultants in Accident and Emergency.
Dr. Duncan Maciver in Paediatric Radiology.
Dr. Hamish Lyall in Haematology.
Dr. Garry John - Consultant in biochemistry.
Dr. Samir Dervisevic - Consultant virologist.
Paul Brookes - Chief biomedical scientist.
Ms. Emily Leach - Senior clinical scientist.
Mr. Paul Dexter - Medical Laboratory Science Officer.
Mr. Peter Coe - Microbiology Laboratory Manager.
Dr. Sarah Steel - Designated Doctor for Safeguarding Children.
Catherine Knox - Designated Nurse for Safeguarding Children.
Dr. Richard Reading - Named Doctor for Safeguarding Children.
Dr. Ravi Alanoor - SUDIC lead for the NNUH Trust.
Kim Goodby - Named Nurse for Safeguarding Children.
Emma Dolman - Paediatric Matron.
Paula Mellor - Paediatric Matron.
Jane Bennett - NICU Matron.
Child Death Overview Panel, Norfolk LSCB.

Comments received have been incorporated into the guideline wherever possible.

Distribution list/dissemination method

Trust Intranet, Accident & Emergency, Buxton ward, CAU, NICU

References

1. Department of Health. Working Together to Safeguard Children. A guide to inter-agency working and promote the welfare of children. DH 2018

2. Sudden Unexpected Death in Infancy and Childhood -Multi-agency guidelines for care and investigation: The report of a working group convened by the Royal College of Pathologists and endorsed by the Royal College of Paediatrics and Child Health; chaired by Baroness H Kennedy. 2016