Policy Title | Management of Sudden Unexpected Death in Neonates and Children (0-18yrs)
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Policy Number | OP98
Version Number | 2.0
Ratified By | Designated Doctor and Designated Nurse Safeguarding in absence of Safeguarding Committee due to Covid-19
Date Ratified | 01/03/2020
Effective From | 13/05/2020
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Expiry Date | 01/02/2023
Withdrawn Date | 

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<td>1.0</td>
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<td>Dr Carmen Howey</td>
<td>Safeguarding Committee</td>
<td>08/02/2019</td>
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<td>2.0</td>
<td>13/05/2020</td>
<td>Dr Carmen Howey, Dr Maryam Rehan</td>
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Management of Sudden Unexpected Death in Neonates and Children (0-18yrs)

1.0 Introduction

This policy is intended to provide guidance to health care professionals working for Gateshead NHS Foundation Trust who may encounter the unexpected death of a child in their clinical work.

The policy is based upon the following documents and resources:

- The Bristol Royal Infirmary Enquiry 2001 (Kennedy Report)
- Working together to safeguard children (HM GOV 2018) Chapter 5
- Child Death Review: Statutory and operational guidance (HM GOV 2018)
- Discussion with Mr Carney, Coroner for Gateshead
- Stillbirth and Neo Natal Death Society (SANDS) www.uk-sands.org
- Lullaby Trust www.lullabytrust.org.uk
- Gateshead Safeguarding Children Partnership
- North and South of Tyne Safeguarding Children Partnership Procedures Manual

2.0 Policy Scope

These guidelines are to be used in the management of cases where a child aged 0-18 years dies unexpectedly in Gateshead with specific guidance in the following circumstances:

- When a child is brought to the Emergency Care Centre and is pronounced dead in the department.
- When a child is pronounced dead outside of hospital and is brought to the Queen Elizabeth Hospital Gateshead after death.
- When a neonate dies in the maternity department/SCBU of the Queen Elizabeth Hospital
- When a child from Gateshead dies either in another hospital or outside of hospital and is taken to a hospital other than the Queen Elizabeth Hospital Gateshead after death.

Professionals should note that stillbirth is not covered by the scope of this policy.

3.0 Aim of Policy

The main objectives of management are:

- To collect the evidence needed to determine the cause of death.
- To provide support for the bereaved family.
- To ensure that the law is complied with, and that forensic requirements are met.
- To support the Child Death Review (CDR) Process

It is acknowledged that a difficult balance needs to be achieved between supporting parents and families and enabling the police to thoroughly investigate the death.

- Parents should be able to feel in control, and should be supported in making their own decisions about what happens to them and where possible to their child.
- The care given to bereaved parents should be responsive to their individual feelings and needs, allow them the opportunity to talk about their child, the death and their feelings.

- Parents need the right information to help them make informed choices and to guide them through their child’s death, the immediate aftermath and the child death review process. There is a new CDR leaflet available to share with families following their child’s death to ensure they are informed of the process. A copy of the leaflet is inserted as follows. A paper copy will be available on each ward.

![WHEN A CHILD DIES](parent-leaflet-child-death-review-v2.pdf)

- Communication with parents should be clear, sensitive and honest. Do not use technical terms or jargon and check that it has been understood. The bereaved parents/carers should be given the contact details of their key worker (can be any person known to the family i.e. GP, health visitor 0 – 19 service or Paediatrician) and their medical lead. The family should be informed who will contacting them and when they will be contacted after discharge from hospital or hospice (and what to do should they have any question in the meantime). Where appropriate Gateshead Safeguarding Children Partnership (GSCP) Multi-agency Child Protection Procedures should be followed:

http://www.proceduresonline.com/nesubregion/Gateshead_SCB/p_cdop.html

Guidance relevant to the Child Death Review process should also be followed (Appendix 2 and Chapter 5 Working Together 2018).


4.0 Duties (Roles and Responsibilities)

Chief Executive
- Ensure that Gateshead NHS Foundation Trust has policies and procedures in place which are in line with the GSCP multi-agency procedures for safeguarding children and the Child Death Review Process as outlined in Working Together 2018.

Director of Nursing, Midwifery and Quality
- To be the Link Director for Safeguarding Children
- To represent the Trust on the Local Safeguarding Children Partnership
- To ensure the Trust is represented at Child Death Review meetings
- To chair the Trust integrated Safeguarding Committee and ensure that Child Death updates are discussed within that committee

Head of Corporate Risk
- To ensure that external reports are made as appropriate
• **Designated Paediatrician Child Death** To be the operational and strategic lead within the Trust and fulfil this role as described in Chapter 5 Working Together to safeguard children.

• To act on behalf of the Commissioners (Newcastle Gateshead CCG) to facilitate an independent review of all deaths of Gateshead children and to feedback the outcome of the review to the local Child Death Overview Panel

• To represent the Trust at Child Death Review meetings

• To provide expert advice, scrutiny and identify learning as a member of the local Child Death Overview Panel.

**Associate Directors, Service Line Managers, Head of Midwifery, Senior Nurses, Ward and Departmental Managers**

• To adhere to and implement the policy for Sudden Unexpected Deaths in Neonates and Children.

• To ensure support and access to training for members of staff who are involved in the deaths of children.

**All staff**

• To familiarise themselves with the policy and ensure the guidance is applied in their practice.

• To participate in/attend multiagency joint agency response (JAR) discussions and meetings as appropriate.

• To participate in a de-brief for all staff involved in the care of the deceased child in Gateshead Health NHS Foundation Trust

### 5.0 Definitions

• An unexpected death is one in which the death was not anticipated as a significant possibility 24 hours prior to the death.

• A child is an individual from live birth at any gestation to 17 years and 364 days old and so covers anyone who has not yet reached their 18th birthday. “Child” therefore means child or young person throughout.

### 6.0 Guidance for staff in Managing Sudden and Unexpected Death in Neonates and Children (0-18 years).

#### 6.1 When a child is brought to the Emergency Care Centre and is pronounced dead in the department

##### 6.1.1 General guidance for Paediatric and ECC staff

The on duty Paediatric team should be called immediately through the hospital switchboard. This should include the on-call Paediatric Consultant. Resuscitation will usually be attempted and carried out by a team of staff including Paediatric and Emergency Medicine medical and nursing staff. Anaesthetic staff is also likely to attend.

Whilst resuscitation is underway, it is important that the following occur:-

• A history is obtained from the ambulance service staff that brought the child to hospital. This should include details of the circumstances in which the child was found as well as the resuscitation efforts that have already been made.
• The names of the people who have come with the child and their relationship to him/her is determined accurately.
• If the parents don’t speak English well an interpreter must be organised urgently.
• Determine the child’s first name or the name the child is known by and use this at all times.
• An experienced nurse should look after the parents in the resuscitation room or in a suitable quiet waiting room. If the parents choose to be present during the resuscitation then the nurse needs to explain to the parents what is happening, particularly for events which may look alarming eg IO access, intubation. Every effort should be made to provide privacy for distressed parents. Someone should remain with them until they leave
• Keep the family informed about what is happening.
• Ensure that someone is looking after any other young children/dependants in the family and offer to contact other family members or close friends.

The doctor leading the resuscitation, usually the Consultant Paediatrician or Consultant in Emergency Medicine, should decide when it is appropriate to discontinue resuscitation and then inform the parents. (It is usual to discontinue resuscitation if there is no detectable cardiac output after 30 minutes including prior resuscitation by paramedics). If the parents are in the room they should be informed that resuscitation is going to stop prior to it doing so; to prevent them surmising this through everyone “walking away”.

6.1.2 Guidance for the Paediatric Consultant on-call

Attend the Emergency Care Centre as soon as possible to lead resuscitation attempts and decide on when resuscitation should be discontinued through discussion with colleagues from Emergency Medicine and Anaesthetics.

Introduce yourself to the parents and explain to them what is happening or has happened.

• Be sensitive and sympathetic throughout.
• The family should be treated with respect and honesty.
• The family should be invited to ask questions at any stage.

Complete the workbook for the Investigation and Management of Sudden Unexpected Death in Infancy and Childhood a paper copy of which should be available in the ECC. Everything should be extensively, accurately and legibly documented.

Inform the parents of the statutory processes that will follow and ensure that the relevant services are informed of the child’s death:
• Further investigations will be undertaken in order to try and establish a cause for death.
• The Coroner whose duty it is to investigate all sudden and unexpected deaths must be informed. The Coroner’s Officer, acting for the Coroner, will arrange for the post mortem examination to take place, and he or colleagues in the police will also ask the parents for information.
- The Police will need to be informed of the child’s death. They will visit the family and will also need to look at the scene of death.
- Childrens Social Care are routinely informed of unexpected deaths in childhood.
- The death will be reviewed through the Child Death Review Process and the Designated Paediatrician will contact them to fully explain this.
- Explain to the parents that the various processes can take many months and in particular the final post-mortem report may not be available for over 6 months.

If the death is suspicious it is important to consider if there are any other children or vulnerable adults who may be at risk.

There is local agreement with the Coroner and Police that a Paediatrician does not need to visit the scene of the child’s last illness or place of death.

If a twin baby, offer the opportunity to admit the surviving baby for observation and discuss offering the CONI programme.

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.

Discuss the follow up arrangements with the parents and establish whether they would like an appointment in the next 48 hours as well as one in approximately 6 weeks. Ask whether they would like these appointments to take place at home, possibly with someone who will be the lead practitioner for the family e.g. Health Visitor.

Secure all health records held within the Trust about the dead child and read them thoroughly to see if they contain anything of relevance.

Complete a report outlining the events relating the child’s final illness and resuscitation.

Arrange a joint de-brief for Paediatric and Emergency Medicine medical and nursing staff who were involved in caring for the child. Sometimes a “hot” de-brief at the end of the shift can be a good way of gathering everyone’s thoughts and feelings quickly. This should then be followed by a “cold de-brief” which should take place within the next few days. Any staff unable to attend should be directly contacted by the Consultant Paediatrician to ensure their well-being.

Notify the local Child Death Overview Panel of the Child Death. This should be done by completing a Child Death Notification Form. This can be accessed via the following link at any time of the day.

https://www.ecdop.co.uk/NorthandSouthTyne/Live/public

There may be a need to attend a Joint Agency Response meeting (see Appendix 5). and at a later date to attend a Child Death Review Meeting

You should also complete a Child Death Reporting Form (see Appendix 4) as soon as possible. The link to access this form would be sent to the relevant
6.2 When a child is pronounced dead outside of hospital and is brought to the Queen Elizabeth Hospital Gateshead after death.

Children who are pronounced dead outside of hospital can be taken directly to the mortuary in specific circumstances:

- If the death of the child was expected and anticipated by healthcare professionals as part of end of life care and therefore does not need to be treated as an unexpected death in childhood.
- If the overarching cause of death of the child is immediately obvious and not suspicious eg road traffic collision
- If the child has clearly been dead for some time and it is not felt appropriate to initiate resuscitation attempts.

It may be more appropriate to take the child to a quiet and appropriate room within the ECC. There should be a discussion with the Paediatric Consultant on-call regarding the best place for the child to be taken prior to the child being brought to the hospital. This discussion should include North East Ambulance Service (NEAS) and the Police.

Sometimes it is not clear to staff, Eg. ambulance staff and Police attending the scene of a road traffic collision, that a deceased individual is under 18 and therefore there have been occasions when a child has been taken directly to the mortuary. In the event of this happening once the individual has been identified as being under 18 the Consultant Paediatrician on-call should be informed.

It is still important that all appropriate history should be taken and relevant investigations should be carried out including the completion of the workbook for the Investigation and Management of Sudden Unexpected Death in Infancy and Childhood a paper copy of which should be available in the ECC. The investigations should be completed as appropriate and if there is any doubt should be discussed with the coroner. Everything should be extensively, accurately and legibly documented.

There is local agreement with the Coroner and Police that a Paediatrician does not need to visit the scene of the child’s last illness or place of death.

Notify the local Child Death Overview Panel of the Child Death. This should be done by completing a Child Death Notification Form (see Appendix 4). This can be accessed via the following link at any time of the day. https://www.ecdop.co.uk/NorthandSouthTyne/Live/public

There may be a need to attend a Joint Agency Response meeting (see Appendix 5) and at a later date to attend a Child Death Review Meeting

You should also complete a Child Death Reporting Form (example shown in Appendix 4) as soon as possible. The reporting form will need to be completed and submitted electronically on e-CDOP system. The link to access this form would be sent to the Consultant Paediatrician via an e mail by the CDOP Coordinator. This will need to be completed on electronic CDOP system.
Paediatrician on-call by CDOP co-ordinator. Please discuss this with the Designated Doctor for child death.

6.3 When a neonate dies in the maternity department/SCBU of the Queen Elizabeth Hospital

6.3.1 Support for the family

Staff on maternity and SCBU may be involved with parents who experience a neonatal death. In some cases it can be anticipated that the infant will not survive for a number of reasons eg extreme prematurity, illness, congenital abnormality and in these situations this can be discussed with the parents and their wishes taken into account. They may wish to take their infant home or to a quiet place for them to die or they may wish to spend time with the baby before treatment is withdrawn.

Support from the hospital chaplain or Minister of other religions should be offered to parents who may request a blessing for the child. An interpreter should be called if required. If the chaplain is unable to attend before death staff may perform a blessing or say a prayer for a child if requested. Baptisms should be recorded in the baptism register and the parents should be given a card.

A private relative’s room is available for the use of bereaved parents in the Maternity department. They should be allocated a named midwife to support them and be enabled to spend time after death with the infant and family. The amount of time will vary from family to family.

The parents should be given a Child Death Review leaflet and should also receive the telephone number for SANDS (stillbirth and neonatal deaths support group). The link to CDR leaflet for families/parents/carers is as follows:

WHEN A CHILD DIES
parent-leaflet-child-death-v2.pdf

Follow up appointments should be offered with the mother’s Obstetrician, and the Paediatrician if involved, to enable the parents to receive results and to discuss the cause of the baby’s death.

6.3.2 Issuing a medical cause of death certificate

Any neonatal death should be reported to the Coroner and his officers may want to attend the unit to interview staff. In this situation the support of staff should be considered.

Paediatric staff should be notified of any delivery where risk factors are identified either prior to or during labour which suggests that the baby will require resuscitation after birth. In cases where a baby is born unexpectedly in poor condition they will be called urgently and the Consultant Paediatrician will also be notified if the baby requires intensive resuscitation. The paediatric team would not attend any delivery of an infant of a gestation less than 22 completed weeks. This is because resuscitation of infants below that gestational age is known to be ineffective and is not current UK practice. If an infant is a live birth below 22 completed week’s gestation then it is still appropriate for both a birth and a death
certificate to be issued following discussion with the Coroner. This should be completed by the Consultant Obstetrician.

If the baby dies in the early neonatal period following resuscitation attempts but before retrieval to a regional intensive care unit the parents should receive advice and support from staff as described in other sections of this guidance. A post-mortem may be required to determine the cause of death or alternatively following discussion with the coroner it may be possible for a medical practitioner to issue a medical cause of death certificate. It is good practice for this to be completed by the Consultant Paediatrician.

Any loose documentation containing clinical information is to be kept within the clinical records.

6.3.3 Reporting and notification of Neonatal deaths

Notify the local Child Death Overview Panel of the Neonatal Death. This should be done by completing a Child Death Notification Form (an example shown in Appendix 4) via the link given below. This can be accessed at any time of the day.

https://www.ecdop.co.uk/NorthandSouthTyne/Live/public

As per statutory guidance the death of any live born baby (showing signs of life at birth) regardless of their gestation will require a child death review. A child death notification form (link given above) and a reporting form will need to be completed by the relevant professional i.e midwife/Obstetrician or a Paediatrics Consultant on-call if involved. Request for completing the reporting form and the link to access this would be sent via an e-mail by the CDOP team. Please discuss this with the Designated doctor for child death.

Neonatal deaths should be discussed in the next perinatal morbidity and mortality meeting and it would be good practice for the Designated Doctor for Child Death to attend in order to help with understanding the circumstances of the death and considering if there were any modifiable factors.

For the avoidance of doubt, it does not include stillbirths, late foetal loss, or terminations of pregnancy (of any gestation) carried out within the law.

- Stillbirth: baby born without signs of life after 24 weeks gestation
- Late foetal loss: where a pregnancy ends before 24 weeks gestation

Cases where there is a live birth after a planned termination of pregnancy carried out within the law are not subject to a child death review.

The following neonatal deaths require reporting to MBRRACE – UK (Mothers and Babies Reducing Risk through Audits and Confidential Enquiries across the UK):

- Early neonatal deaths – death of a liveborn baby (born at 20th weeks gestation of pregnancy or later or 400g where an accurate estimate of gestation is not available) occurring before 7 completed days after birth
• **Late neonatal deaths** – death of a live born baby (born at 20^{th} weeks gestation of pregnancy or later or 400g where an accurate estimate of gestation is not available) between 7 and 28 completed days after birth.

The Risk Management Midwife is responsible for submitting this information electronically to MBRRACE and will arrange an RCA (Root Cause Analysis) when required. The death may also require reporting via the Perinatal Mortality Review Tool which is linked to the MBRRACE database.

6.4 **When a child from Gateshead dies either in another hospital or outside of hospital and is taken to a hospital other than the Queen Elizabeth Hospital Gateshead after death.**

In this circumstance the child’s death should be managed by the local team at the hospital the child is taken to. The Designated Paediatrician for Child Death in Gateshead should be notified and take part in any Joint Agency Response discussions/meeting which may be indicated.

If the child has had contact with Gateshead NHS Foundation Trust then the health records should be secured and relevant information made available to the Designated Doctor Child Death, Childrens Services and Police as needed.

6.5 **Covid 19 update**

• SUDIC guidelines have been adapted in light of the pandemic and can be found here [https://www.ncmd.info/2020/04/07/jar-covid-19/](https://www.ncmd.info/2020/04/07/jar-covid-19/)
• To complete child death notification forms within 48 hours of death for all cases that are suspected or confirmed COVID-19.
  Where infection is known or suspected COVID 19 (including maternal infection where the baby has died) request airway and rectal COVID-19 swabs with appropriate PPE.

7.0 **Investigations**

7.1 **Medical investigations**

The following investigations should be carried out and documented in the workbook and/or the child’s hospital notes.

<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</td>
<td>Microbiology</td>
<td>Normal</td>
<td>Microscopy, culture and</td>
</tr>
<tr>
<td>Test</td>
<td>Department</td>
<td>Result</td>
<td>Additional Information</td>
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</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>
<tr>
<td>Airway &amp; rectal swabs (for Covid 19)</td>
<td>Virology</td>
<td>Taken with appropriate PPE</td>
<td>Nucleic acid amplification techniques</td>
</tr>
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### 7.2 Forensic specimens (liaise with the Police regarding these)

Plain forensic swabs should be taken as follows (and handed to a police officer under chain of evidence or placed in a locked fridge if no police officer present):

- Clean all around the mouth with one gauze swab lightly dampened with sterile water
- Clean all around the teeth with one dry swab
- Clean around the nostrils with one gauze swab lightly dampened with sterile water.
- Any areas of bruising (lightly dampened with sterile water)
- Any gauze swabs used to clean the body should also go individually into chain of evidence bags
- An unopened dry swab and the sterile water vial used to dampen the above swabs.
- All clothing, including the nappy on admission, needs to be put in separate brown forensic bags with appropriate chain of evidence labels

The chain of evidence label must be marked with the site of the swab, signed, dated and the bag sealed.

### 7.3 Skeletal survey

A skeletal survey needs to be performed as soon as possible after unexpected deaths in infants under the age of 1 year. This does not apply to deaths on the neonatal unit. This should also be considered in any case where abuse or neglect is a possible contributing factor to the death. If there is any doubt then there should be discussion between the Consultant Paediatrician, the Police and Coroner as the results of this may inform future action. This should be reported on by a consultant radiologist as soon as possible.

The discussion about how and when a skeletal survey will take place should be held by the Consultant Paediatrician and the Consultant Radiologist. There is currently an agreement that skeletal surveys will be performed between 9am-5pm Monday-Friday excluding Bank Holidays and will be reported as soon as possible. This means ensuring
secure electronic transfer of the images to an appropriate clinician working at another hospital site as per agreement with the Trust. Currently an SLA (Service Line Agreement) is in place with Alder Hey to facilitate this.

If abuse or neglect is felt to be the cause of death of a child then consider arranging a skeletal survey for any child aged under 2 living in the same household at the JAR as per https://www.rcr.ac.uk/audit/skeletal-surveys-suspected-physical-abuse

8.0 The post-mortem examination

Copies of any accident and emergency / hospital records must accompany the child to the post mortem. If required the skeletal survey must have been performed prior to the post-mortem.

Explain to the parents that a post mortem examination is important to find any medical condition that could have led to the death of their child. A post mortem can also rule out diseases or abnormalities which parents suspected or feared. But even the most rigorous investigation may leave some questions unanswered. This is distressing, but it can help to know that at least a treatable illness was not missed. Explain that a pathologist, with the same care that would be used if a child were having an operation, does the post mortem examination. It includes an examination of the child’s body and internal organs. The body is carefully restored after the post mortem so that the parents and their family may see and hold the baby again. Parents who wish to see their child again after the post-mortem should be told about the incisions that are made: they must not discover the stitching by accident.

Parents will be anxious to receive the post-mortem / investigation results as soon as possible. A provisional report may be available quickly but the full report often takes several months. The full report will be sent to the Paediatrician and the child’s GP, and parents should know that this would be done. Parents can ask the Coroner for a copy of the Pathologist’s report but they may be charged a small fee. They will be told whom they can contact if they have any further questions.

There should be the minimum of delay in providing parents not only with the results but also the opportunity to discuss them fully. However in the minority of cases where there is an ongoing criminal investigation into the death, the timing and content of information sharing will need to be discussed with the Police. The professional who is talking with the parents should be prepared for a wide discussion.

If the child’s death is found to be the result of a heredity disorder, parents should be offered the opportunity to see a genetic specialist. They may want to take up this offer at a later date when they feel ready for it, so they should know whom to contact and how.

If there are indications that further investigations or treatment would be necessary in a future pregnancy, parents must be told how this can be organised. The Coroners Officer will discuss with the family how to ultimately dispose of any tissue taken at the post mortem.

9.0 The Coroner

9.1. Role of the Coroner
Explain that by law the Coroner whose duty it is to investigate all sudden and unexpected deaths must be informed. The Coroner’s Officer, acting for the Coroner, will arrange for the post mortem examination to take place, and he or colleagues in the police will also ask the parents for information.

9.2 Registration of the death including in Coroner’s cases
Following the provisional post-mortem report the Coroners Officer will contact the family and explain:
- The cause of death
- How to register the death

Then either of the parents can go to the Registrar to register the death. Once the death is registered, a death certificate can be issued and a funeral can then take place.

If there is to be an inquest, the Coroner often opens it and adjourns it as soon as possible (usually within a few days) so that a Burial Order or Cremation Form can be issued. This enables the parents to go ahead with the burial or cremation. Once the inquest is over, the Coroner usually sends a certificate to the Registrar who then registers the death.

All deaths must be registered in the registration district in which they occur.
In Gateshead this is the Registry Office, Civic Centre, Gateshead Tel No. 4333000
Both the birth and death must be registered. If the birth has not already been registered, it can be registered at the same time as the death

10.0 The mortuary

Staff should explain that parents need to make an appointment first. This can be done by contacting mortuary staff on 01914452309. If they just arrive at the Chapel of Rest they may well be refused entry much to their distress and the distress of the mortuary staff. Explain where the child’s body will now be taken, and when and how they can see their child again if they wish. If the child is to have a Post Mortem their body will be transferred to the RVI but can be returned if the family would like to visit again in the QEH.

Parents may wish to provide clothes for their child to be dressed in after the post-mortem. Alternatively, if there is to be a privately arranged funeral, parents can ask their funeral director to prepare their child for them.

11.0 Spiritual Needs of the Family

For every religion there are the rites and rituals that are particular to that faith and so it is important to ask the family about these and to accommodate them if at all possible. It cannot be stressed strongly enough the pain inflicted on families if these are ignored or considered unimportant.

In some religions the handling of the body by anyone not of their faith is to defile that body. It is therefore advisable that staff wear gloves at all times when handling these children.

In some faiths notably Judaism and Muslim there is a requirement that the body be buried as quickly as possible, preferably within 24 hours. This need may conflict with the requirements of the law and the involvement of the coroner and will cause distress to both staff and family.
• The following faiths prefer cremation: Hindu, Sikhism and Buddhism.
• The following prefer burial: Judaism and Muslim.
• Those of any Christian tradition will opt for either burial or cremation out of personal choice. They will have no religious objections to post-mortems and the body will not be defiled if touched.
• The following faiths will resist post-mortems: Muslim, Judaism and Hindu.

Hospital chaplains can be helpful and supportive to bereaved parents of all religious beliefs and of none. The hospital chaplains can hold simple services for parents of any faith, and also for parents who have no formal religious belief but whom want a funeral service or other ceremony for their baby. However, some parents, for a variety of reasons, will not want contact with a hospital chaplain. It is important never to assume or pressurise.

The chaplains can help parents to think through what they want for the funeral of their child and can advise as how to go about organising it.

The Chaplaincy Team
Rev Peter Jones
Gareth Rowlands (from Dec 2015)

How to Contact:-
During Office hours:- 0191 445 2072
Out of hours, please contact via switchboard 0191 482 0000
Roman Catholic Priest:- 0191 445 2121

12.0 Information about Funeral / Burial / Cremation

For many parents the loss of their child is their first experience of bereavement. They may have no knowledge of the arrangements that have to be made, or of the wide range of choices open to them. They need information, support and time so that they have positive memories of what they did, or what was done, for their child.

Funerals:
• A funeral holds different meanings and values for different parents and families. A funeral may be important to parents for religious and spiritual reasons, but it can also be non-religious, and a religious ceremony can take many different forms.
• For some parents, arranging or participating in a funeral or some other kind of ceremony for their child, no matter how simple or private, helps give reality and expression to their loss and can affirm the significance it holds for them. It can be an important way of honouring their child and creating memories for the future.
• A funeral is not obligatory and some parents may want their child’s body or remains to be respectfully buried or cremated without any kind of ceremony of their own.
• Sometimes parents’ options may be restricted by religious or cultural factors. For example, the parents’ religion may not provide any formal ceremony for babies who die during pregnancy or shortly after birth. Parents may be expected to suppress their grief and accept their loss as God’s will. This can sometimes cause conflict and additional
distress and some parents may need sympathy and support to help them live with these restrictions.

**Cremation:**
- Parents need to be aware there may be no cremated remains (ashes).
- All crematoria have books of remembrance in which parents can enter their child’s name and an inscription. There is a book of remembrance in the hospital chapel.

**Burial**
- If parents are considering burial, they may find it helpful to visit the cemetery to see where their child would be buried.
- Some parents may prefer to have their child buried in a nearby or familiar churchyard. Whether this is possible will depend on the church regulations. Other parents (Muslim and Jewish parents, for example) may wish their child to be buried in a cemetery reserved for members of their faith.
- Burial can involve extra costs such as the purchase of the grave and a headstone. These will need to be met by the family. If the family does not purchase the plot then there is always the possibility that some years in the future the plot may be reused for another child. While this is unlikely it could happen.

**Costs**
- For a private funeral for a child, most funeral directors charge only a nominal fee and some do not charge at all. Parents have to pay the crematorium or cemetery authorities’ charges (if any), and any other costs, such as fees for a religious service, if wanted.
- For a cremation, costs include the crematorium fees (if any) and if the parents wish, the cost of a plaque or some other form of memorial. Medical staff should waive fees for cremation forms.
Appendix 1

Neonatal Unit Last Offices (to be carried out following certification of death by medical staff)

Parents should be allowed to spend as much time with the baby as they need. Photographs should be taken for parents or to go into notes for later date. Hand and foot prints taken, lock of hair may also be kept. The baby should be washed and dried, then dressed in clothes of parents’ choice – parents may or may not want to do this or be present while this is carried out. Check name bracelets x 2 are in position and are correct; these may be replaced with new ones if parents wish to keep originals.

<table>
<thead>
<tr>
<th>CHECKLIST FOR LAST OFFICES NEONATAL DEATH</th>
<th>COMPLETED BY</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure any investigations are completed as required by Consultant Paediatrician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Label baby using identification procedure: 2 identification bracelets in position 1 mortuary card to be completed and tied loosely round wrist or ankle Baby should be wrapped in baby sheet, 2nd mortuary card is taped onto outside of sheet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand and foot prints, lock of hair. Placed in memory box.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photographs for parents or notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inform chaplain or equivalent at parent’s request</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LEAFLETS (as appropriate) Saying goodbye to your baby When a child dies (parent support and information leaflet) attached After the death or stillbirth of your baby Family and friends how you can help The loss of your grandchild Fathers Support for you when your baby dies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrangements for the funeral discussed Chaplaincy – remembrance book entry request</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NOTICE OF DEATH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- White copy central admission in envelope provided - Pink copy baby notes - Blue copy leave in book</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ensure MBRACE data is completed by risk management midwife</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete cancellation of Antenatal appointment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete suppression of mail from Bounty form</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Porter to be informed that the baby is to be taken to mortuary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baby taken to mortuary in Moses basket via hospital ambulance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Notify the local Child Death Overview Panel of the Child Death as soon as possible through the</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
following link. [https://www.ecdop.co.uk/NorthandSouthTyne/Live/public](https://www.ecdop.co.uk/NorthandSouthTyne/Live/public) (can be accessed at any time of the day.

<table>
<thead>
<tr>
<th>In the event of a post-mortem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give all post mortem leaflets to parents as per pack</td>
</tr>
<tr>
<td>Placenta to be sent with baby if available</td>
</tr>
<tr>
<td>Summary of maternal history, previous pregnancy current illness prepared by medical staff</td>
</tr>
<tr>
<td>Post mortem request to Forensic Medicine RVI 0191 2820982</td>
</tr>
<tr>
<td>Photocopy baby notes</td>
</tr>
<tr>
<td>Post mortem consent form to be delivered by hand to Mortuary QE</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Follow up arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow up appointment for parents. Consultant to decide</td>
</tr>
<tr>
<td>General Practitioner informed of death by phone</td>
</tr>
<tr>
<td>Community Midwife informed of death</td>
</tr>
<tr>
<td>Health Visitor informed of death</td>
</tr>
</tbody>
</table>
Appendix 2

Notification Checklist following a Child’s Death

The following people (where applicable) should be informed as soon as possible about the child’s death:

<table>
<thead>
<tr>
<th>Time</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Police – Central Referral unit Tel: 2957170</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Please note the Police inform the Coroner)</td>
<td></td>
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</tr>
<tr>
<td>Chaplain or other religious representative (with the consent of family)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP informed of death by phone</td>
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</tr>
<tr>
<td>Health Visitor (inform if a health visitor is involved with the family even if the deceased child is older)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School Nurse (inform if a school nurse is involved with the family even if the deceased child is younger)</td>
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<td></td>
</tr>
<tr>
<td>Midwife (if baby under 28 days old)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Consultants who see the child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children’s Social Care – Referral and Assessment Team</td>
<td></td>
<td></td>
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<tr>
<td>0191 433 2653</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Notify the local Child Death Overview Panel of the Child Death. This should be done by completing a Child Death Notification Form through the following link:</td>
<td></td>
<td></td>
</tr>
<tr>
<td><a href="https://www.ecdop.co.uk/NorthandSouthTyne/Live/public">https://www.ecdop.co.uk/NorthandSouthTyne/Live/public</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist Health Visitor / Children’s Community Nurses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tel: 0191 283 4660 check</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Record Depts.:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Queen Elizabeth Hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tel: 0191 445 2166</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gateshead Community Child Health</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It is everybody’s responsibility to check that any outstanding appointments for the child are cancelled.
Appendix 3

Follow up Appointments

**NOTE If the death has been suspicious the Consultant Paediatrician needs to discuss with the Police what can be discussed at any follow up appointment.**

The Consultant Paediatrician who was present at the child’s death should offer an appointment to see the parents of the child, at a time appropriate to the circumstances, in order to discuss issues around the death and any questions they might have about the death and subsequent child death review process. (This could be done in conjunction with the Designated Paediatrician for child deaths)

- Parents should be asked where they would like any appointments to take place.
- It is good practice to have another professional present during the interview to document what is said.
- It is unlikely that final post mortem results will be available at the first follow up appointment and parents should be informed of this beforehand. If this is the case a further appointment should be arranged to discuss the results of the post mortem and other investigations.
- The professional(s) involved in the follow-up appointment with the parents should be prepared to answer a wide range of questions as honestly as possible.
- Where there are language difficulties, it is essential that a professional interpreter is available for the entire follow-up appointment. The interpreter should be well informed beforehand about the situation. If an interpreter was used in the resuscitation every effort should be made to use the same interpreter.
- Adequate time should be allowed. There is likely to be a great deal to discuss and much will be difficult and emotional.
- Parents should be reminded of the child death review process.
- At the end of the appointment, parents should be told whom they can contact if they have further questions, problems or worries. A further consultation may be necessary depending on the circumstances.
Appendix 4
The Child Death Review Process

The Child Death Review Process is set out in Working Together to Safeguard Children 2018. Chapter 5. This requires Child Death Review Partners (the Local Authority, CCG and police) to

- Make arrangements for the collation and analysis of information from all deaths in children from birth until the age of 17 years and 364 days
- Make arrangements to ensure that there is a comprehensive and multi-disciplinary review of all deaths of children normally resident in the local area
- Identify any matters relating to the death, or deaths, that are relevant to the welfare of children in the area or to public health and safety, and to consider whether action should be taken in relation to any matters identified. If child death review partners find action should be taken by a person or organisation, they must inform them
- Share the learning from all child death reviews with the National Child Mortality Database, once operational, which may in addition take into account information from other reviews in order to identify any trends or similarities with deaths. Information from the database may be able to inform systematic or local changes to prevent future deaths.
- The local arrangements for the implementation of the updated guidance in Working Together to Safeguard Children 2018. Chapter 5 and Child death Review: Statutory and Operational guidance (England) https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england are such that locally the CCGs have implemented a merge of the North and South of Tyne CDOPs to comply with the new recommendation of the need to review 60 cases per year. For this purpose an electronic CDOP system has been purchased for collating the relevant information for each child death in our area.

All child deaths are reported on new forms which have been in effect since April 2019 and coincide with introduction of the National Child Mortality Database (NCMD). There are three forms which correlate to the old forms; these being the new Notification Form (replacing Form A), the new Reporting Form (replacing Form B) and the new Analysis Form (replacing Form C). Please see below an example of each.

All child death notifications need to be submitted electronically on eCDOP from 1 November 2019. We would recommend submitting the notification form as soon as possible following the child death so that the relevant information can be cascaded. Please use the link below:

https://www.ecdop.co.uk/NorthandSouthTyne/Live/public (can be accessed at any time of the day)

- For additional information we have attached two e-learning presentations on eCDOP which outline the process of notification and completing a reporting form.
Appendix 5

The Joint Agency Response

- When a child dies Police, the Coroner, and Childrens Social Care are notified of the death. The Child Death Overview Panel is notified by sending a completed Notification Form (Appendix 4). The link to access the form is as follows: https://www.ecdop.co.uk/NorthandSouthTyne/Live/public (can be accessed at any time of the day)
- Police/Paediatrician/Childrens Social Care together will consider if there are any immediate safeguarding concerns for another child or vulnerable adult. A Joint Agency Response is required if the death:
  - Is or could be due to external causes;
  - Is sudden and there is no immediately apparent cause (including sudden unexpected death in infancy/childhood);
  - Occurs in custody, or where the child was detained under the Mental Health Act;
  - Occurs where the initial circumstances raise any suspicions that the death may not have been natural;
  - Occurs in the case of a stillbirth where no healthcare professional was in attendance.
- The CDOP administrator will arrange a meeting either face to face or over the telephone with representatives from key agencies particularly Children’s Service’s and the Police. The meeting needs to take place as soon as possible and ideally within 72 hours.

At this meeting there will be a discussion about whether there are safeguarding issues in relation to the death and/or any other children or vulnerable adults and whether any immediate S47 investigation needs to occur alongside a Police investigation. If the results of any investigations suggest evidence of abuse or neglect as a possible cause of death, the relevant safeguarding partners should be informed and this should be discussed with the Child Safeguarding Practice Review Panel as soon as possible. If abuse or neglect is felt to be the cause of death of a child then consider arranging a skeletal survey for any child aged under 2 living in the same household at the JAR as per https://www.rcr.ac.uk/audit/skeletal-surveys-suspected-physical-abuse
Appendix 6
The Designated Paediatrician (DP) for child deaths

- The Designated Paediatrician receives notification of child deaths from a number of sources but will be formally notified by the CDOP administrator.

- In the event of an unexpected death requiring a Joint Agency Response immediate discussions with Police and Childrens Social Care should be led by the Consultant Paediatrician involved in the initial resuscitation and/or examination of the child. This can be delegated to the DP if the death occurs within working hours and the DP is available to take on this role.

- If a Joint Agency Response meeting is required this is convened by the CDOP administrator and chaired by the DP. If possible the DP will attend an RCA meeting in the hospital, or Mortality and Morbidity meetings in other hospitals to collate the relevant information at the initial stages of reviewing a child’s death.

- CDOP Administrator would send out links via an e-mail to access the Reporting Forms. These will be sent to all Medical personnel involved with the child, including the GP, the Paediatrician involved at the time of the child’s death and all other specialists involved in managing any aspects of the child’s care prior to their death (the CDOP administrator sends Reporting forms to Education, Ambulance staff, Social services etc. and the 0-19 service coordinate forms from Health visitors and school nurses). Reporting Forms need to be returned within 3 weeks.

- The parents are written to with a modified standard letter explaining the CDR process. The DP advises that she/he will be in contact to arrange a home visit or collate their views by telephone.

- If a home visit is requested the parents are asked whether they would like a known professional to be in attendance. The home visit is to identify if the parents have any issues arising out of their child’s death which they would like explored during the review. They are also asked how they would like to be informed of the outcome of the review. The DP ensures that family members have the bereavement support they require. Further home visits may be required to give updated/final feedback of the review or this may be done in writing.

- The DP chairs a Child Death Review Meeting and uses the information from that meeting and the Reporting Forms to complete a draft Analysis form. This is then discussed at the local CDOP. The CDOP will oversee any action plans and share information appropriately with the National Child Mortality Database.

- The DP contacts the family to share the outcome of the CD Review.

- During the review the DP may need to challenge organisations on actions taken with respect to the child’s care. If required support can be sought from the Executive Director of Nursing Patient Safety and Quality, Newcastle and Gateshead CCG.

- The DP should feedback the outcome of the CD Review to the relevant department in Safecare sessions.
Appendix 7

All child deaths are reported on new forms which have been in effect since April 2019 and coincide with introduction of the National Child Mortality Database (NCMD). There are three forms which correlate to the old forms; these being the new Notification Form (replacing Form A), the new Reporting Form (replacing Form B) and the new Analysis Form (replacing Form C). Please see below an example of each.

All child death notifications need to be submitted electronically on eCDOP from 1 November 2019. We would recommend submitting the notification form as soon as possible following the child death so that the relevant information can be cascaded. Please use the link below:

https://www.ecdop.co.uk/NorthandSouthTyne/Live/public (can be accessed at any time of day)

A separate link to complete the reporting form would be sent via an e mail by the CDOP Co-ordinator. Please discuss this with DP to ensure access to the reporting form could be given in time.
Appendix 8

Referral to LeDeR for a child with learning disability

- The Learning Disabilities Mortality Review (LeDeR) programme describes a review process for the deaths of people aged 4 years and over with learning disabilities in England. Within the four NHS England regions, a LeDeR Regional Coordinator supports and provides a governance structure to local multi-agency Steering Groups to deliver the LeDeR mortality reviews. The LeDeR programme team aims to support local areas to implement the LeDeR review process and to take forward the lessons learned from individual mortality reviews to make improvements to service provision. The LeDeR programme also collates and shares anonymised information from the review so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

- When notified of the death of a child or young person aged 4-17 years who has learning disabilities, or is very likely to have learning disabilities but not yet had a formal assessment for this, the local CDR Partners should report that death to the LeDeR programme at http://www.bristol.ac.uk/sps/leder/notify-a-death/ or 0300 777 4774.
Appendix 9

Funeral Directors in Gateshead

**Ayton Funeral Directors**
102 Bewick Road
Gateshead
NE8 1RS
0191 477 2398

**E Bush**
Funeral Directors
79 - 83 Old Durham Road
Gateshead
0191 477 1726

**Co-operative Funeral Service**
Elizabeth House
Sheriff Hill
Gateshead
0191 482 2371

13 Durham Rd
Gateshead
01914100162

1 Front Street
High Spen
Rowlands Gill
01207544120

**Derwentside Funeral Services**
4 Front Street
Swalwell
0191 488 2218

**W Lauderdale Funeral Service**
10 Market Lane
Dunston
Gateshead
NE11 9NY
Tel: 0191 460 4698

**M Ovington & Son Funeral Directors**
28 Ravensworth Road
Birtley
Chester-le-Street
0191 410 3863

**E Peart Ltd**
1 Kepier Chare
Crawcrook
Tel: 0191 413 2318
E & J Robinson Funeral Directors
Wrekenton Row
Low Fell Gateshead
0191 487 9693

Rowlands Gill Funeral Services
Unit 1 High Spen Ind Estate
Front Street
High Spen
01207544442

Watsons
282 - 284 Old Durham Road
Gateshead
0191 477 1484

Non-Religious Funerals North East Humanists
4 Jesmond Dene Terrace
Newcastle upon Tyne
Tel: 0191 281 1863