

## JOINT HEALTH SERVICE GUIDELINES

# THE RESPONSE TO SUDDEN UNEXPECTED DEATH IN CHILDREN IN DERBY CITY AND DERBYSHIRE

May 2016

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### Version Control

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## 1. Introduction

This joint health service guidance is intended for emergency departments, paediatric staff and the rapid response paediatrician, to support the response and investigation of sudden unexpected death (i.e. not anticipated 24 hours previously) in children up to 18 years of age for the whole of Derbyshire, including Derby City. If a child who is normally resident outside this area dies in Derbyshire, it is anticipated that the immediate response will take place in Derby City or Derbyshire County and that the case will then be handed over to the relevant area.

According to RCPCH Why children die (May 2014), annually around 6,000 children between 0-19 years die in UK. Around two thirds death happens in first year of life. In children less than one year congenital anomalies and perinatal factors contribute largely to death whereas young children between ages of 1-4 years three most common causes of death are injuries and poisonings, cancer and congenital causes. The sudden infant deaths contribute to a small proportion of about 5%. The office of national statistics (ONS 2015) shows that there were 249 unexplained deaths in England and Wales. The rate of unexplained deaths rose to 0.36 per thousand live births in comparison to 0.32 per thousand in 2012. Almost two thirds were recorded as sudden infant deaths and 35% were unascertained. Unexplained infant deaths accounted for 9% of all deaths occurring in 2013. Over the years there has been a gradual decline in sudden infant death in Derbyshire although there may be some unexpected fluctuations. The Derbyshire CDOP report published in 2015 show that there were about 15 unexplained deaths in total across all ages in children and accounted for about 13% of total deaths. There were about 40% cases where modifiable factors were identified. Some cases which initially appear to be sudden death, after investigation may have an underlying medical cause or may have an injury.

In addition to this, older children will occasionally die in sudden and unexpected circumstances. For a number of these, e.g. road traffic accidents, systems are in place to investigate the circumstances led by other agencies such as the police. For others, a multi-agency approach, similar to that for SUDI, will be beneficial.

The aims of the process are to:

- identify a cause of death where possible;
- support parents and reassure them that the child's death has been fully investigated;
- ensure that future children are protected and satisfy any wider public interest concerns.

A working definition of SUDI includes children who die unexpectedly: unexpected death is defined as the death of an infant or child which was not anticipated as a significant possibility for example, 24 hours before the death; or where there was an unexpected collapse or incident leading to or precipitating the events which lead to the death (Working Together, 2015). This may include children:

- found dead
- brought in dead to the emergency department (ED)
- brought in to the ED in a state of cardio-respiratory arrest – but where resuscitation is successful in restoring cardio-pulmonary output for a period of time before death
- Die in the ED following unsuccessful resuscitation.

This guidance recognises that implementation within North Derbyshire & South Derbyshire/Derby City may have small variances. Therefore separate appendices should also be consulted depending on where the child died.

## 2. Admission to hospital and confirmation of death

- The first professional on the scene, whether ambulance personnel, police or GP should initiate or continue resuscitation attempts. Special note must be made of the position of the child, clothing worn and the circumstances of how the child was found. Those remaining at the scene must be asked not to disturb or move items around where the child was found until the police have viewed the scene. Any comments made by parents, background history, possible substance misuse and the living conditions should be noted and reported to the receiving medical and nursing staff in the ED. The police should be notified if not already aware.
- Ambulance staff will transfer children who have collapsed at home to a hospital ED. Resuscitation will follow national protocols. If unsuccessful, death must be confirmed by the resuscitation team leader.
- If the child has presented in cardio-respiratory arrest and resuscitation restores cardio-pulmonary output initially, but the child subsequently dies, the same process for investigation will need to be followed. The timing and sequence should be discussed between the police and the rapid response paediatrician on call after discussion with the medical team caring for the baby.
- On very rare occasions, when the child is recognised to be life extinct due to unequivocal death, the ambulance staff will have contacted the police who may arrange for the death to be confirmed at the scene by a police surgeon or other suitably qualified professional. The body must **NOT** be touched until the police have arrived and given permission (any religious process that may involve touching the child must wait until the police have given permission). In cases where infanticide is suspected the body should be left undisturbed at the scene of death pending police intervention. If the ambulance is still present when the body is due for removal in these circumstances, then the crew should transport the body to hospital as above. If the ambulance has left, then a further crew should be requested once the police have given permission for the body to be moved. The senior investigating officer will discuss with the coroner's office as to where body should be transported to if not taking to the Emergency Department.
- It is the responsibility of the doctor confirming the dead to clarify with the police whether the rapid response process is to be activated to ensure that relevant interagency communication takes place. The police usually contact the on call rapid response paediatrician to arrange the joint home visit.
- If the child dies suddenly or unexpectedly at home or in the community, the child should normally be taken to an Emergency Department rather than a mortuary. In some cases when a child dies at home or in the community, the police may decide that it is not appropriate to move the child's body immediately, for example, because forensic examinations are needed
- In the rare event that the body is to be taken directly to the mortuary, the person bringing the body must inform the mortuary (or switchboard if out of hours) at either the Royal Derby Hospital or Chesterfield Royal Hospital, to advise them of the estimated time of arrival, so that mortuary staff are available to receive the body. The person bringing the body is responsible for completing and attaching a printed label with as much information as possible.

- Once death is confirmed, 3 processes will be activated; support for the parents; notification of death and multi-agency involvement and medical investigations. It is important to recognise that this will require sufficient staff to be allocated to the case for them to proceed simultaneously.

### **3. Medical Investigation**

- In most cases, the initial history and examination will take place in hospital.
- The police are likely to need to interview the parents also at this stage to collect some initial information.
- Any initial concerns about child abuse must be raised immediately and a referral made to children's social care in line with DSCB procedures.
- It is recognised that parents may be too distraught to provide all information at this early stage. A senior police officer, together with the rapid response paediatrician, will then arrange a joint home visit within 24 hours to re-interview the parents and view the circumstances of death.

#### **3.1. History**

- The fact that the child has died should be gently broken to the parents (see section 5 for guidance in this area).
- The history should be taken by the registrar/paediatric ED consultant/consultant paediatrician on call or possibly the ED team if 17 years of age (a brief history may already have been taken by the resuscitation team).
- Remember that you are dealing with people who are in the first stage of grief. They may be shocked, numb, withdrawn, or hysterical.
- Always consider the need for communication support, e.g. interpreters for families where English is not the first language, or signers for deaf individuals. Please remember it may not be appropriate to use friends or family members to support the communication process, particularly if there are any concerns about child abuse.
- Ask the child's name and then use it at all times.
- Take a full paediatric history in the same detail as would be the case for a child presenting with any serious illness. The history should include pregnancy, birth, neonatal period, feeding history, immunisations, drug history, development, family/social history, detailed history of last few days (and in particular the last 24 hours), including precise timings of events, when the child was last seen alive, actions and circumstances of parents when the child was found dead/died, social history, whether the child is christened and any religious needs. For children aged 17 years, this should be as appropriate.

#### **3.2. Documentation**

- Record all details accurately (your records may become a legal document in any future investigation) and according to record keeping standards.

- Record the name of the person(s) giving the history.
- Record any discrepancies between accounts given by different people.
- Note all resuscitation procedures and interventions.

### 3.3. Examination

- Once recognised deceased, the body should be disturbed as little as possible, until permission is given by the senior investigating officer.
- Always handle the child with respect as though s/he were alive.
- A full paediatric examination of children less than 2 years of age should be carried out as soon as possible by the senior paediatrician on call. For older children, this will depend on the circumstances of the death.
- It may be appropriate for another doctor to examine the child whilst the senior doctor talks to parents.
- Keep all clothing in labelled bags and keep with the child initially. Retain any nappy in a separate bag.
- Gently clean the child's face noting any substance that is wiped off, unless suspicious. This should be discussed with the police senior investigating officer.
- Note particularly:
  - Physical state of child
  - Post death changes such as dependant lividity, position and rigidity
  - General hygiene
  - Weight, length & head circumference
  - Ear temperature and time recorded
  - Rashes
  - Bruises, petechiae and other marks (plot on body map – remember to look in hidden areas such as gums, lips, neck, ears, scalp, fundi, genitalia and anus)
  - State of the frenulum
  - Fundoscopy to document any visible retinal haemorrhages
  - Evidence of bleeding
- Note sites of invasive resuscitation procedures on body map.
- ETT tubes may be removed once position has been confirmed by the senior doctor.

### 3.4. Specimens

NB. After death has been pronounced, the coroner has jurisdiction over the body. The coroner has given prior permission for investigative samples as stated in this protocol and mementoes (e.g. footprint, hairlock) to be taken. It is important to record the time that death was certified so that jurisdiction over the body by the coroner is clear.

- The paediatric pathologists in Sheffield, who undertake the coroner's post mortems on children who die in Derby and Derbyshire, have protocols in place for taking

appropriate samples and most samples are satisfactory if taken at post mortem. Therefore samples should not be taken by paediatricians or ED staff after the child has been pronounced dead, except for those children dying at times when a post mortem will not take place within 24 hours – i.e. weekends and bank holidays – **when guidance in Appendix 1 should be followed.**

- If specimens are taken, record the time they are taken, site from which taken, person taking specimen, time of informing the lab and who informed, time specimen arrived in lab and who received it, is carefully recorded. Ensure that the pathologist is aware of all specimens taken, preferably by telephone conversation or faxed report.
- It is important to ensure that procedures are followed promptly, so that the post mortem can take place as soon as possible – preferably within 24 hours.

### **3.5. Further actions**

- It is important that the pathologist receives the child's body as it was received in ED. Cannulae should be left in situ. The child should be wrapped, but not washed or dressed before being given to the parents (if appropriate). The pathology department at Sheffield Children's Hospital will clean and re-dress the child after the post mortem. The family may send the child's own clothes and toy or other item to stay with him/her.
- It is entirely natural for a parent/carer to want to hold or touch the dead child. Providing this is done with a supportive professional (such as a police officer, nurse or social worker) present, it should be allowed in most cases, as it is highly unlikely that forensic evidence will be lost. Where possible, the senior investigating officer should be consulted before a parent/carer is allowed to hold the child - and certainly if the death is by this time considered suspicious.

### **3.6. Factors which may raise concern**

Any information identified by professionals in the course of their involvement that could give rise to concern or provide important information to the investigation must be shared immediately with the police and children's social care. Such factors (not in order of priority) include:

- Previous child deaths in the same family
- Previous child protection concerns in the same family
- Previous unexplained illnesses or injuries
- Inappropriate delays in seeking help
- Inconsistent explanations
- Evidence of drug/alcohol abuse
- Evidence of parental mental health problems
- Unexplained injuries or bleeding
- Neglect issues

### **3.7. Siblings**

The paediatrician carrying out these investigations should consider whether siblings should be examined and/or admitted and make appropriate arrangements. If there are safeguarding concerns discuss with the police and children's social care.

#### 4. Notification & Multi-agency Involvement

- By law, all sudden deaths must be reported to the coroner as soon as possible (even out of hours).
- The coroner will make a decision as to which pathologist will do the post mortem. At present paediatric post mortems are usually carried out at Sheffield Children's Hospital. All original medical notes will go with the child's body to the pathologist and will be retained at least until all elements of the post mortem examination are completed. It is therefore recommended that a photocopied set of notes is kept in the hospital.
- The police should also be informed as soon as possible (they may have been informed by the ambulance service).
- A senior investigating officer (SIO) from the investigative team will attend the ED (he/she may be accompanied by a junior officer but it will always be a senior officer leading the investigation).
- The SIO will decide if further forensic investigations are required. These should be discussed with senior clinicians (medical and nursing) present.
- If there are criminal investigations, the rapid response investigations must proceed under the direct guidance of the police at each stage.
- The police will arrange for an officer from the child protection unit (a detective sergeant) to interview the parents, usually within 24 hours. The rapid response paediatrician will normally be present for that interview and therefore the time and venue should be negotiated between the police officer and the paediatrician.
- The police may appoint a family liaison officer to support the family.
- ED staff will check whether or not the child is known to children's social care and/or is subject to a child protection plan through the relevant contact system.
- Other agencies/individuals should be informed by the ED nursing staff if involved:
  - Child's GP
  - Medical records (to cancel any appointments) – remember, there may be more than one hospital involved
  - Liaison health visitor (if under 17 years)
  - Child Health department (if under 17 years) (who will inform the child's health visitor, school nurse, and the safeguarding children service)
  - Refer to Social Care
- If the child's body has gone straight to the mortuary, the coroner's office will be informed the next working day, and will contact the GP and the hospital mortuary, to inform them and to request records. The mortuary will then inform medical records at the hospital.

## 5. Supporting Parents

### Breaking the news and what to tell parents

NB. This is generic guidance and does not override relevant local protocols, which should always be followed.

- Responsibility for breaking bad news to the parents rests with the most senior member of the team. Nursing staff will have been with the parents giving support during resuscitation and have a key role in providing support to the family. Make sure you make notes of any comments and discussions with the parents.
- Know the name, age and sex of the child. Use the name at all times.
- Check who is present and what their relationship is to the child.
- Make sure there is another relative or friend to support the parent and if possible ensure both parents are present – don't start until everyone has arrived, unless this will cause undue delay.
- Find a quiet room and give your bleep to another doctor. Ensure a nurse is with you.
- Don't take a long time telling them what has happened, they will probably have guessed already and will appreciate you getting to the point.
- Answer questions and give whatever explanations are available, but tell them that the coroner has to be informed and will probably order a post mortem to determine the cause of death.
- Avoid speculating on the cause of death; explain that it will not be possible to give them a diagnosis until all the investigations have been carried out.
- The medical or nursing staff involved in the resuscitation should explain to the parents what will happen next, where their child will be taken and when they will be able to see him/her again. Most post mortems in Derbyshire are undertaken at Sheffield Children's Hospital. Families are always welcome to visit the child in Sheffield, either before or after the examination, by appointment between 8.30 and 15.30 week days and 10.00 to 14.00 during bank holidays and weekends.
- Explain to the parents that all cases of sudden unexpected death must be referred to the coroner for investigation, which will include police involvement and post mortem examination as a matter of routine for all unexpected deaths and must include a multi-agency investigation.
- Parents need a sensitive explanation of post mortem, which will enable them to understand the procedures and give informed consent about the use of tissue for teaching and research. In a coroner's post mortem, the major organs will be removed and examined. The organs are then returned to the body (although they cannot be returned to their original position). The brain may need to be retained for 4 or 5 days to allow appropriate investigation. Samples of tissue and fluids will be taken for later detailed inspection. The samples of tissue taken for testing are kept until after the inquest. After this, they will be disposed of as the family wishes. Written consent,



however, is now a requirement to determine the disposal of any remaining tissue following the post mortem. They can either:

- be kept as part of the child's medical records, in case they are needed to answer further questions about the cause of death, or to help answer questions regarding illnesses of other family members in the future
- be returned to the funeral director after tests are complete and may be buried or cremated
- be returned to the child, prior to the funeral – the funeral may be delayed, so this can happen
- be donated for medical education or research
- be disposed of by the pathology department in a lawful way, usually by cremation.

Nothing is retained without the consent of the family.

NB. It must be remembered the police have the power to seize tissue as part of a criminal investigation.

- The pathologist from Sheffield is very happy to meet the parents either before or after the post mortem, or both. She/he will complete the documentation which records parents' wishes with regard to samples. If the family does not wish to go to Sheffield, then this may be done by the SIO, but in any event will be arranged by the pathologist.
- Take into account any religious and cultural beliefs that may have an impact on procedures and handle discussion of these with sensitivity, but with due regard to the importance of preserving evidence.
- Explain that it is routine for the police to visit the home as soon as possible whenever there has been an unexpected death and that the police officer is likely to want to speak with them. Usually the paediatrician will be present and lead that interview.
- Arrange for photographs to be taken and, if the parent's wish it, for other mementoes to be kept, such as a lock of hair or prints of hands and feet. If this is not done at this time, the pathologist can arrange for it to be done in the mortuary in Sheffield.
- Explain where the child will now be taken and how they can see the child again if they wish.
- Inform family members if parents request this.
- Inform spiritual adviser if parents request this.
- Ask the parents where they are going, document the address and contact number, who will be with them and how they will get there safely (they may need hospital transport).
- Ensure that parents have names and contact numbers for the hospital, the rapid response paediatrician and the hospital bereavement office. The telephone number to arrange to visit the child at Sheffield Children's Hospital is: 0114 2717246

## 6. The Post Mortem and Report

- The rapid response paediatrician and the senior investigating police officer should ensure that both the coroner and the pathologist are provided with all available information at the earliest possible stage.
- The coroner's office will ensure that the parents are aware if the body is to be moved.
- The SIO or a representative and the crime scene investigator may be asked to attend the post mortem, depending on the circumstances and whether their presence is required.
- The interim findings should be forwarded to the SIO who will update professionals via the Child Death Overview Panel (CDOP).
- Communicating the interim findings of the post mortem to the family will be arranged by the pathologist, with the permission of the coroner – this may be in Sheffield, directly to the family by the pathologist, or locally by the senior investigating police officer or the police liaison officer.
- The funeral should not be delayed unless there are good reasons for doing so, and parents should be given the choice as to whether larger samples or whole organs are retained or returned to the body for funeral. Tissue samples or whole organs may only be retained with parental consent once the coroner has concluded the investigation or when retained under Police and Criminal Evidence Act procedures.

## 7. Multi-agency Follow-up

- The 24 hour home visit by the rapid response SUDI paediatrician and child abuse investigation unit police officer will include interviewing the parents and may include visiting the scene of death. If a scene of death visit is not possible, then copies of the police photographs of the scene may be made available.
- The coroner's officer will ensure that the family are kept informed about post mortem processes and that professionals are involved as appropriate.
- Where the circumstances after the death are concerning the LSCB will be notified to enable consideration of the need for a Serious Case Review.
- A preliminary discussion about the case will take place at the Local Safeguarding Children Board's Child Death Overview Panel (CDOP). This group will recommend who should be involved in the enquiry, including health personnel and those from other agencies to be invited to the case discussion. There will be regular follow up discussions at CDOP.
- A provisional date for a case discussion will be agreed, taking into account the likely time frame for gathering information including the final post mortem report; this will normally be between 4-6 months after the child's death.
- Information will be obtained from health organisations involved in the child's care whilst alive and at the time of death and from other agencies if appropriate.

- The SUDI paediatrician will receive the final written post mortem report via the coroner's office as soon as this is available.
- The GP responsible for the family should also receive a copy of the post mortem report from the coroner, unless this is inappropriate for statutory reasons.
- A case discussion will be chaired by the rapid response paediatrician undertaking the initial home visit. It will always involve the family health visitor, the GP and, in the south county/City only, the SUDI specialist health visitor. Other participants will be invited as appropriate. The aim is to share information and build a picture of the circumstances in order to:
  - scrutinise all aspects of the death and consider possible causes and contributory factors
  - discuss any further action needed
  - identify any lessons for professionals or for the parents
  - plan any ongoing support for the parents, both now and for the future, if another pregnancy is planned.
- A written summary of the findings from the enquiries will be made and discussed at the CDOP. The group will decide whether any specific further action is needed and will be responsible for ensuring that such action is undertaken and monitored.
- After the CDOP enquiries have closed, the SUDI paediatrician will offer to meet with the parents to discuss the findings.

## **Appendix 1: Samples to be taken immediately after sudden unexpected deaths in infancy if post mortem will not occur within 48 Hours (i.e. Friday and Bank Holiday Deaths)**

Skeletal survey will be done as part of post mortem.

NB. After death has been pronounced, the coroner has jurisdiction over the body. The coroner has given prior permission for investigative samples as stated in this protocol and mementoes (e.g. footprint, hairlock) to be taken. It is important to record the time that death was pronounced so that jurisdiction over the body by the coroner is clear.

The preference of the pathologists is to do the samples themselves where possible, therefore prompt transfer of the child to Sheffield is optimal. Even samples taken after 48 hours may still be processed by the pathologist.

Post mortem samples should be taken by the examining paediatrician unless there is certainty about a post mortem being carried out within 48 hours of the death. Record carefully the time they are taken, site from which taken, person taking specimen.

Sampling from femoral or any peripheral vessels is the preferred sampling method. If cardiac puncture has to be performed to get blood, it is important not to deplete the heart of blood, so that the pathologist may still obtain some blood. It is acceptable but record this to avoid any misinterpretation at post mortem.

CSF should not be taken as any blood in the CSF is difficult to interpret at post mortem. The pathologists will take samples for toxicology in order to ensure the chain of evidence is preserved, in case of later criminal prosecution. They will also take skin biopsies for fibroblast culture. These can both be done a number of days after death if necessary.

The samples listed below have the consent of the coroner if taken in line with this protocol. Other samples may be taken if specific consent is sought, either from the coroner or from the parents - the parents' wishes with regard to disposal of any tissue should be clarified (this includes vomitus or stool).

See next page for sample table.

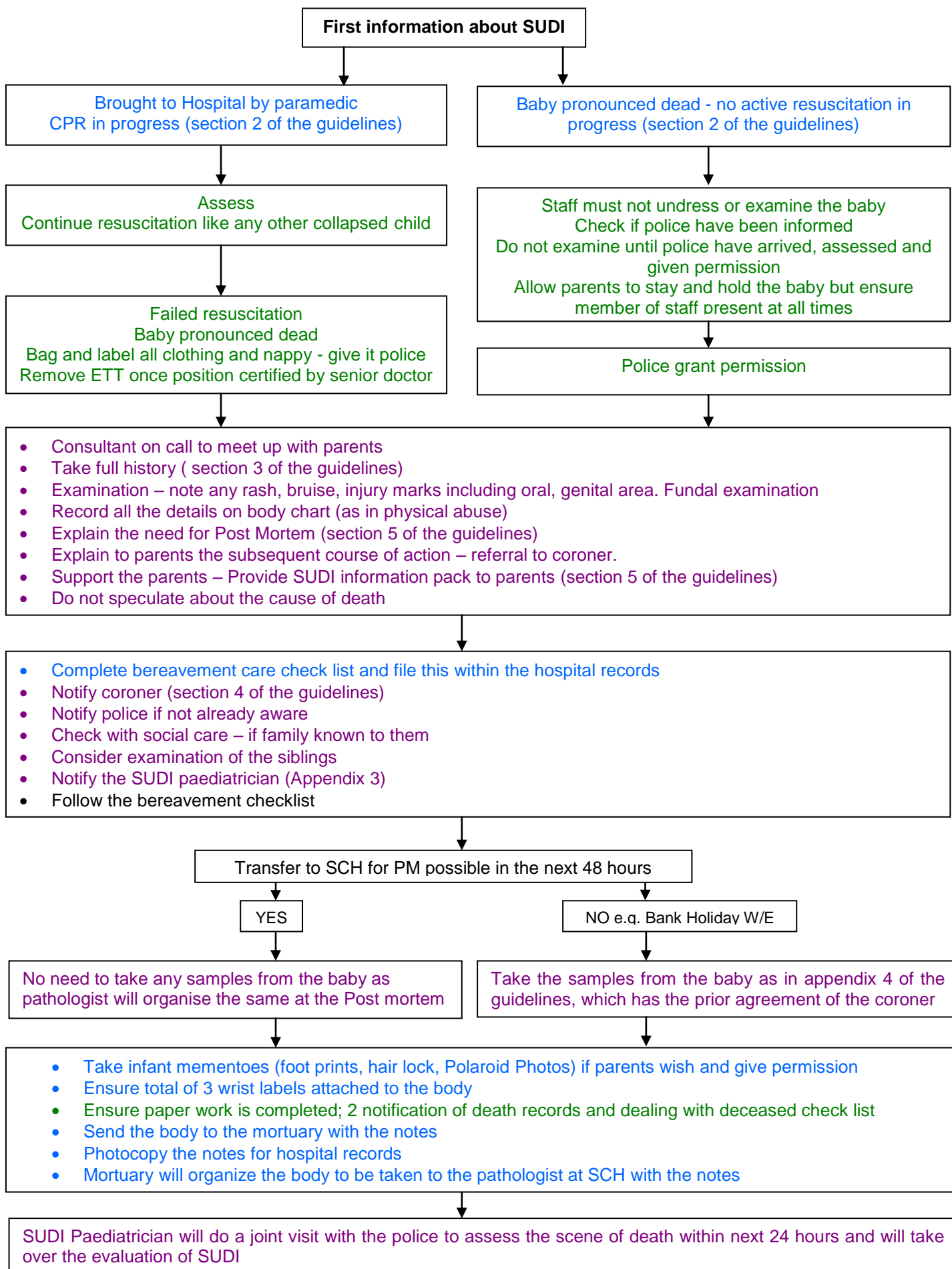
**Sample Table** – samples to be taken immediately after unexpected deaths in infancy. If post mortem will not occur within 48 hours

Sample	Sent to	Handling	Test	Tick if done
<b>Blood</b> cultures – aerobic and anaerobic 1ml	Microbiology	If insufficient blood, aerobic only	Culture and sensitivity	<input type="checkbox"/>
<b>Blood</b> from Guthrie card	Clinical chemistry	Normal (fill in card: put in to paper bag provided)	Inherited metabolic diseases	<input type="checkbox"/>
<b>Throat swab</b>	Microbiology	Normal	Culture	<input type="checkbox"/>
<b>Nasopharyngeal aspirate</b>	Virology	Normal	Viral cultures, immune-fluorescence	<input type="checkbox"/>
<b>Nasopharyngeal aspirate</b>	Microbiology	Normal	Culture and sensitivity	<input type="checkbox"/>
<b>Swabs</b> from any identifiable lesions	Microbiology	Normal	Culture and sensitivity	<input type="checkbox"/>
<b>Urine</b> (if available)	Clinical chemistry	Spin, store supernatant at -20	Inherited metabolic diseases	<input type="checkbox"/>
(attempt 1SPA)	Microbiology		Culture	

The consultant in charge of the case must ensure that the results of all samples taken during the current episode are communicated promptly to the pathologist.

## Appendix 2: Flow chart for rapid response to sudden unexpected death in children up to age of 2 years

Colour coding: Blue – applicable to A&E, Violet – applicable to Paediatrics, Green – applicable to both



### **Appendix 3: References and useful sources of information**

- Sudden Unexpected Death in Infancy; the report of a working group convened by the Royal College of Pathologists and the Royal College of Paediatrics and Child Health (chair, the Baroness Helena Kennedy QC) September 2004
- FSID publications:
  - Sudden Unexpected Deaths in Infancy; Guidelines for Paediatricians
  - Sudden Unexpected Deaths in Infancy; A suggested approach for Police and Coroners Officers
  - Sudden Unexpected Deaths in Infancy; Guidelines for Accident and Emergency Departments
  - When a Baby Dies Suddenly and Unexpectedly (booklet June 2000)
- Coroner's Courts: A Guide to Law and Practice (2<sup>nd</sup> edition), Oxford University Press 2004, ISBN 1-84-174246-5
- Child Abuse and Neglect; a Clinician's Handbook (Chapter on fatal child abuse) – Hobbes, Hanks and Wynne 1999
- CSDI Studies, Rapid response to unexpected deaths in Infancy. Eds P Flemming P Blair, C Bacon and J Berry
- Working Together to Safeguard Children (2015) HM Government

### **Contact numbers**

- Police (24/7) - Tel: 101
- Coroner for Derby and Derbyshire, Dr Robert Hunter, Tel: 01332 613014
- CDOP Administrator, Tel: 01332 623700 ext 31526
- Lead Consultant Paediatrician for SUDI (South), Dr Helen Jacques, Tel: 07843761404
- Lead Consultant Paediatrician for SUDI (North), Dr Guggari Prasad, Tel 01246 513141
- Child Health Department, Cardinal Square, Tel: 01332 868816
- Community Safeguarding Children Unit Kingsway House, Tel: 01332 623700 ext 31537
- Sheffield Children's Hospital, Dr Marta Cohen, Tel: 0114 2717486