The Foundation for the Study of Infant Death's
'Responding when a baby dies' campaign

Sudden unexpected deaths in infancy: suggested guidelines for Accident and Emergency departments

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Introduction

This document aims to provide guidelines on good practice in dealing with babies who are brought in to accident and emergency departments dead or moribund, and to help staff cope with what is inevitably a difficult and painful situation for all concerned.

Objectives

The main objectives of management in the accident and emergency department are:

- to check whether there is any prospect of survival, and to carry out resuscitation as appropriate
- to provide support for the family
- to collect evidence that might help determine the cause of death
- to ensure compliance with the law and the meeting of forensic requirements.

The coroner

Sudden unexpected deaths have to be reported to the coroner, who has jurisdiction over the body as soon as death has been confirmed. Coroners vary in what procedures they wish to be followed, and it is advisable to discuss this document with your local coroner to ascertain whether the recommendations meet with his/her approval.

Content of guidelines

These guidelines are divided into two parts: the first part deals with the advance planning that is required to ensure that unexpected infant deaths are handled satisfactorily, the second outlines the actions that need to be taken when the event occurs.

Part I - Planning

Facilities

The needs of bereaved families should be taken into account in planning the layout and equipment of accident and emergency departments. Facilities should include the following:

- A room where the family can go when their baby is brought in. This room should be near to, but out of earshot from, the resuscitation area, should be conducive to grieving, and should be equipped with a telephone, a kettle and toys for children.
- Another room where the baby can be visited when resuscitation has been abandoned and death has been confirmed. This room should have a peaceful domestic décor, a cot or Moses basket for the baby, and a dimmer switch on the light.
- New clothes in a range of suitable sizes in which the baby can be dressed before viewing, including a shawl, a nappy and a bonnet.
- A camera, preferably one that produces an instant picture, and cards on which mementoes such as footprints can be saved. These items should all be kept together in an easily identifiable box.
- A folder of relevant information, which should include: contact details for paediatrician designated for cot death; phone numbers of coroners, and of local religious leaders; information on different cultural practices with regard to death and bereavement; information about the procedure for death registration and for inquests; copies of the

Department of Health leaflet "*Guide to the post-mortem examination: brief notes for parents and families who have lost a baby in pregnancy or early infancy*"; a list of local funeral
directors; details of support agencies, including the national and local services offered by FSID; FSID's Helpline number (0870 787 0554); and copies of FSID's leaflet *"When a baby dies suddenly and unexpectedly."*

Staff training and support

All medical and nursing staff who work in accident and emergency departments should be trained, by means of a thorough induction reinforced by periodic follow-up, in how to deal with a family whose baby is brought in moribund or dead. The training should be concerned mainly with communication skills, such as the breaking of bad news, sympathetic listening, responding to questions, non-verbal communication and dealing with anxiety, grief and anger. It should also include awareness of different cultural attitudes.

A system should be set up to ensure that whenever staff have to deal with the death of a baby they receive routine debriefing followed by counselling as necessary.

Audit

The department should regularly audit its facilities and procedures for dealing with infant deaths, comparing them with recognised standards of good practice.

Part II - Action when a baby is brought in moribund or dead

Resuscitation

- Resuscitation should always be initiated, unless it is clear that the baby has been dead for some time (for example when rigor mortis or blood pooling are evident).
- If the medical staff involved agree, the parents should be given the option of being present during attempted resuscitation. A nurse should stay with them to explain what is going on, particularly procedures that may look alarming, such as cutting off clothes or intubation.
- Laboratory samples can be taken while resuscitation is being attempted. They may be useful for management if the baby survives, and may help to identify the cause of death if the baby dies. Once death has been confirmed samples may be taken only with the coroner's permission. *For details of these samples, see appendix.*
- The doctor in charge, whenever possible in consultation with the parents, should decide how long it is appropriate to continue attempts at resuscitation. It is usual to discontinue resuscitation if there is no detectable cardiac output after 30 minutes (including any resuscitation prior to arrival).

Jurisdiction of coroner

Once the baby has been pronounced dead, the body comes under the jurisdiction of the coroner, who has control over any subsequent measures that affect it. Before proceeding with the actions recommended below, you should make sure that you have the consent of the local coroner, either by advance agreement in principle and/or by consultation at the time. In addition, you should remember that any records you make may become legal documents, so they should be detailed and legible, should give the time as well as the date, and should be clearly signed.

Informing the coroner and the police

As soon as death has been confirmed the doctor in charge should report the case to the coroner or the coroner's officer. Agreement should be sought to proceed with any measures already agreed in principle. If the circumstances are suspicious the police should also be contacted immediately. In some areas the police may wish to be informed of all unexpected infant deaths as soon as possible as a matter of routine.

Other measures immediately after death

- Ensure that the baby is taken to the appropriate part of the department, even if he/she appears to have been dead for some time. The baby should not be taken straight to the mortuary.
- Call the paediatrician designated to deal with cot deaths. If not available, inform the consultant paediatrician on call.
- Find out the names of the people who have come with the baby and their relationship to him/her. Make sure you know the baby's first name.
- Allocate a nurse to look after the family. She should stay with them, so far as possible, and keep them informed about what is happening.
- A doctor (or a nurse) should take a brief history of events preceding admission, including the baby's past illnesses and recent health, and any resuscitation already attempted.

Physical examination

This should be carried out as soon as resuscitation has been completed or abandoned, and should be done by an experienced paediatrician. An immediate careful record should be made, including the use of a body chart when relevant. Features to be recorded include the following:

- The baby's general appearance, state of nutrition and cleanliness
- The weight, freshly measured, without clothes or equipment, and position on centile chart
- Rectal temperature
- Marks from invasive or vigorous procedures, such as venepuncture or cardiac massage
- Rashes and other skin conditions
- Any other marks on the skin, including bruises and abrasions, with an estimate of their age
- Appearance of the retinae
- Any lesions in the mouth (allowing for effects of intubation)
- Any signs of injury to the genitalia or anus.

Additional measures

The following measures will depend upon

a. the wishes of your local coroner

b. the requirements of your pathology and radiology departments, with whom there should be advance discussion.

- Gently clean the baby's face, making a record of any substance that is wiped off. Put on a clean nappy and wrap the baby in a shawl or blanket.
- Keep all clothing removed from the baby in labelled specimen bags. The clothing may assist the pathologist or may sometimes be required for forensic examination. Explain this to the parents.

- Remove equipment inserted during resuscitation, such as endotracheal tubes or intravenous cannulae, having first made a note of where they were sited to inform the pathologist who does the post-mortem examination.
- Arrange for the collection of relevant laboratory samples not already taken (*see appendix for details).* Make a careful note of the samples taken, and the site of any invasive procedures.
- Arrange for a skeletal survey.
- Arrange for photographs to be taken and other mementoes to be kept, such as a lock of hair or prints of hands and feet.
- Allow the parents and other family members time to hold the baby. The support nurse should stay with them. Some coroners may require a police officer to be present as well.

Care of the family

- If the parents don't speak English well, call in an interpreter urgently.
- Be sensitive and sympathetic throughout.
- Ensure that the family have privacy.
- When referring to the baby, try to use the first name. If you don't know the first name, say "your baby," or "he" or "she." Never refer to the baby as "it."
- Ensure that someone is looking after other young children in the family.
- Offer to contact other family members or close friends.
- Offer to telephone the parents' employers and explain that they can't get to work.
- Contact the hospital chaplain or other religious leader, if the parents so wish.

NB

Please ensure that all parents are given a copy of the DOH's leaflet 'A guide to the post mortem examination procedure involving a baby or child' (reference 29768/A)
and that the content is discussed. Every parent should be given the opportunity to donate tissue for research, education and audit. Please ensure that the consent form for parents 'Post mortem examination on a baby or child ordered by the coroner' (reference 29773) is explained. Don't assume that someone else has already discussed the post mortem and tissue retention with the family. Always check with the parents. The leaflets are available to download from www.dh.gov.uk

Breaking the news

- When the death of the baby has been confirmed, a senior doctor, preferably the designated paediatrician, should break the news to the parents, having first reviewed all the available information.
- The interview should be in privacy in an appropriate room. The support nurse should also be present.
- The family should be treated with respect and honesty, and 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. It may be appropriate to explain that in most sudden unexpected deaths in infancy a cause cannot be found, and the death is then usually registered as Sudden Infant Death Syndrome or a similar term.
- Explain that any sudden death of unknown cause has to be reported to the coroner, who will require that a post-mortem examination should be carried out and that the coroner's officer should visit the home.
- Explain that before he/she starts the post-mortem examination the pathologist will

need to know everything about the baby's previous history and health. Arrange a time when you (or another health professional) can visit the home to collect this information. Explain that the information may be shared with the police.
- Explain that the police are required to investigate all sudden and unexplained deaths as a matter of routine.
- At some stage before the post-mortem examination, for example at the home visit, the parents should be told what the post-mortem investigation involves. They should be given a copy of the DoH leaflet *"Guide to the post-mortem examination: brief notes for parents and families who have lost a baby in pregnancy or early infancy."*

Support for the family

The following further measures can be taken to help support the bereaved family before they leave the department:

- Give them a copy of the FSID leaflet *"When a baby dies suddenly and unexpectedly."* Tell them about FSID's Helpline (**0870 787 0554**).
- Offer to put them in touch with local support organisations, such as FSID befrienders.
- If the baby was a twin, recommend immediate admission of the surviving twin, with the mother, for monitoring and for investigation of possible metabolic disorders.
- If the mother is breast-feeding, discuss suppression of lactation.
- Explain where the baby's body will now be taken, and when and how they can see the baby again if they wish.
- Advise them about what to say to older children in the family, and explain that a child psychologist may be able to help them all come to terms with their loss.
- Encourage them to phone the paediatrician if they would like to talk about anything before he/she comes to visit them.
- Arrange transport to take them home.

Communication

The following should be informed about the baby's death as soon as possible:

- Coroner
- Coroner's officer
- Police
- Family doctor
- Health visitor
- Consultants (if any) who see the baby
- Social worker (if any)
- Medical records
- Immunisation office

Appendix

This appendix gives details of post-mortem samples that may help determine the cause of a sudden and unexpected death in infancy.

Note that the taking of these samples is dependent upon

i. the wishes of your local coroner. Some coroners may stipulate that post-mortem samples are taken only by the pathologist instructed for the post-mortem examination.

ii. the practices of your hospital laboratory. The recommendations below are as reported from the West Midlands [1].

Blood

Perform a cardiac puncture within 30 minutes of death if possible and preferably not over four hours after. Drop some blood onto blood spot cards directly from syringe (for acyl carnitines). Allow to dry at room temperature. Split the remainder into lithium heparin for metabolic tests spin (store plasma at –20 C); plain bottle (clotted blood) for toxicology spin (store serum at –20 C); blood cultures to incubate at 37 C; and consider blood for chromosomes, especially if dysmorphic.

Urine

Suprapubic aspirate of bladder. Divide urine into three plain bottles. For microbiology store in fridge at 4 C; toxicology, spin and freeze supernatant at –20 C; biochemistry, for metabolic tests (amino and organic acids), spin and freeze at –20 C.

Microbiology

Nasophyngeal swab (if less than eight hours after death) for virology into transport medium. Any other body fluids, swabs, etc, store at 4 C for microbiology.

Skin biopsy

Send to a metabolic laboratory in culture medium. Store at 4 C.

Muscle and liver biopsy

Consider if there is suspicion of inherited metabolic disease - for example, death of sibling or consanguinity. Contact regional metabolic laboratory for advice.

Reference

1 Moore A, Debelle G, Symonds L, Green A. Investigation of sudden unexpected deaths in infancy (letter). Arch Dis Child 2000; 83:276.

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