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

Sudden unexpected deaths in infancy: a model of good practice for paediatricians

Accepted by the Royal College of Paediatrics and Child Health as a Good Practice Statement

Sudden unexpected deaths in infancy:
A model of good practice for paediatricians

Introduction

Whenever a baby dies paediatricians have an important part to play, whether the death occurs in hospital or unexpectedly at home. Each hospital Trust or area should identify a paediatrician who has designated responsibility for cot deaths. Paediatricians will need to ensure that these guidelines form a part of the Primary Care Trust (PCT) strategy.

Principles

The responsibility of the paediatrician with regard to cot deaths should be directed to these main objectives:

- To ensure that bereaved families are kept fully informed and are given all the advice and support they need, both immediately and when they start another pregnancy.
- To provide the fullest possible information and advice for pathologists and for coroners, in order to give the best opportunity of making a specific diagnosis in the majority of deaths that are natural, and of identifying the minority that are unnatural.
- To ensure that professionals and parents are made aware of any lessons that can be learnt from each death.

Content of this model

The model is divided into two parts: the first part recommends the system that the paediatrician should set up in advance, the second suggests the steps that should be taken after a death has occurred. This document should be read in conjunction with the FSID leaflet *"Guidelines for unexpected deaths in Accident and Emergency Departments."*

Stage of development

It is recognised that arrangements for responding to cot death will be in varying stages of development in different areas. Essential measures are therefore outlined in bold, and are followed, in standard type, by suggestions on how they might be implemented.

PART I - Setting up a system to ensure a proper response to cot deaths

1 Make yourself known to the coroners in your area, and discuss how they wish you to help in the investigation of cot deaths.

The aim should be to achieve a proper balance between medical and forensic requirements, bearing in mind that the large majority of cot deaths arise from natural causes.

2 Make yourself known to the senior police officer responsible for investigation of unexpected infant deaths.

The main purpose is to discuss how police and medical inquiries can best be coordinated. A leaflet giving advice for police officers in the handling of cot death is available from FSID *(Sudden unexpected deaths in infancy: a suggested approach for Police and Coroners' Officers)*.

3 Set up a notification system that will inform you of any unexpected infant death in your area.

The system should notify you of every death as quickly as possible, preferably within 24

hours. Sources may include general practitioners, health visitors, the ambulance service, accident departments, other paediatricians, mortuary attendants, pathologists and coroner's officers. The notification system could be built on the network used for the CESDI rapid report form.

4 Ensure that accident departments in your area are aware of best practice in dealing with families whose baby is brought in dead or moribund.
Full details are given in the FSID leaflet *"Guidelines for unexpected infant deaths in Accident and Emergency Departments."*

5 Make yourself known to the pathologist who is most likely to carry out the post-mortem examination on cot death victims.
You may sometimes need to remind coroners of the recommendation that a paediatric pathologist (or, failing this, a pathologist with paediatric expertise) should normally be instructed following a sudden infant death, and to remind the pathologist of the value of following the recommended protocol (Sudden Unexpected Deaths in Infancy, the CESDI SUDI studies 1993-6, Stationery Office 2000, chapter 4).

6 Make contingency plans to leave yourself free to deal with cot deaths as a priority whenever they occur.
It might be worth sounding out colleagues in advance as to whether they would be willing to help with some of your other responsibilities at short notice. You will also need to make arrangements for holiday cover.

7 Find out what resources are available in your area for supporting bereaved families.
For example, FSID has a national network of befrienders. It is helpful if you make yourself known to the key people involved. If a family who has lost a baby is planning to have another, make sure that they know about the operation of the CONI (Care of the Next Infant) scheme within your area.

PART II - Action when a death has occurred

1 See the parents as soon as possible.
It is best if you can get to the accident department as soon as possible after a baby has been brought in moribund or dead. You can then help to organize the immediate response, as described in the FSID leaflet "*Guidelines for unexpected infant deaths in Accident and Emergency Departments"*. Introduce yourself to the parents, take a quick history of the circumstances of the death, and keep them informed about what is going on.

In addition to this, you should arrange to visit the parents at home as soon as is convenient for them. A home visit will be much more acceptable to them, and more informative to you, than a clinic consultation. Allow a long time, at least an hour, for this visit. Let them tell their story at their own pace, and try to answer their questions. If you are participating in a survey of cot deaths, you can use the visit to collect the necessary data; a narrative account is also valuable. You may need to make a second visit. Ensure that the parents are put in touch with people who can give them appropriate support, and leave them a copy of the FSID leaflet "*When a baby dies suddenly and unexpectedly."*

2 Participate in an initial strategy discussion

Essential participants are the designated paediatrician and the supervising police officer, plus other lead professionals as appropriate. The purpose of the discussion is to agree the best approach to the investigation and to ensure continuing collaboration.

3 Collect all relevant records about the baby and the family.

These will include notes from the general practitioner and health visitor, maternity and paediatric records, accident department records (sometimes at more than one hospital), and sometimes social service records. The child protection register should be consulted as a matter of routine.

4 Compile a report for the pathologist who will do the post-mortem examination.

This report, which is of great importance, will be based mainly on your interviews with the parents and your perusal of the records. It will have to be completed very quickly: you should liaise with the pathologist over this.

5 Try to attend the post-mortem examination in person.

Direct dialogue with the pathologist can be very helpful, and you will then be in a better position to discuss the results with the parents (you need the coroner's permission to do this).

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

6 Arrange and chair a multi-disciplinary discussion about the death.

This should be held as soon as the results of the pathologist's ancillary investigations, such as histology, are available (this will usually be about four weeks later). Essential participants include the general practitioner and the health visitor as well as the pathologist, and the meeting should be arranged at a time and place that suit the primary care team. Others who have been professionally involved with the family, such as midwife or social worker, may also be invited. The meeting should collate and scrutinise all the antecedents and circumstances of the death so that possible causes or contributory factors can be identified, any lessons for professionals or for the parents can be learnt, and support for the family can be planned, both in their present bereavement and for when they have another baby.

You should discuss the results of this meeting with the parents, and give them a written report. Make sure that they are in contact with people who can support them, and that they have the relevant telephone numbers. Assure them that they are welcome to make an appointment to see you again if ever they wish.

7 Co-operate with the police and with the coroner throughout.

In some areas the paediatrician's visit to the home will be made jointly with the coroner's

officer or a police officer, but in others visits will be separate. In any case you should liaise with the police in assessment of the circumstances of the death and of the medical records. If you can show at an early stage that the death resulted from natural causes, you may be able to prevent an investigation that would have been difficult for the family and time-consuming for the police. Before you start talking with the parents you should warn them that information will be shared with the police (it has to be accepted that, exceptionally, some parents may then not be willing to talk with you). In some areas the police may want to attend the case discussion as a matter of routine, as for a child protection case conference. Some coroners may wish to have copies of your report to the pathologist and of the report of the case discussion. Occasionally coroners may wish to chair the case discussion themselves.

Note

Although many of these tasks require the training and experience of a consultant paediatrician, some of them, for example the home visit, might appropriately be delegated to another health professional, for example a general practitioner or a health visitor who has had special extra training. However overall responsibility for policy and implementation should be vested in the designated paediatrician.

28 November 2003.
Last revised 9 March 2005.