

Handout from lecture given at FSID's AGM 29 February 2008

Responding to unexpected childhood deaths Dr Peter Sidebotham, Senior Lecturer in Child Health, University of Warwick

In spite of huge advances over the last century, and a fall in overall child mortality. 5,000 children under 16 die each year in the UK (Sidebotham & Fleming, 2007). In an "average" Local Safeguarding Children Board (LSCB) area, a population of 500,000, this equates to approximately 25-30 infant deaths and 15-20 child deaths per year. It is important to recognise the variation across the UK: there is a north-south divide in childhood mortality and repeated studies have shown huge social class variation, with the highest risks from all causes being for children from deprived areas. If all regions of the UK shared the mortality rates of the best, over 1,000 infant deaths and nearly 500 child deaths could be prevented each year

Childhood deaths can be divided into a number of categories:

- Expected deaths from natural causes
- Unexpected deaths from natural causes
- Unexpected deaths from unnatural causes
 - Accidents
 - Homicides
 - Suicides
- Unexpected deaths that remain unexplained

It will often be clear from quite early on which category the death falls into. However, many deaths, particularly in infancy will not have a clear explanation and may remain unexplained after all investigations are complete.

We need to be clear about the terminology we use:

SUDI *The sudden death of an infant which was not anticipated by any professionals or carers involved with the child 24 hours prior to the event that led to death.* (Fleming et al., 2000)

The term SUDI is applied to all unexpected deaths in infancy at the point of presentation. These will include unexpected deaths from natural causes, unnatural or suspicious deaths and unexplained deaths.

SIDS *The sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and review of the clinical history.*

SIDS should only be used at the conclusion of the investigation when no other cause is found. In those situations it should be used consistently, rather than using terms such as unascertained. In using the term according to this definition, we acknowledge that we do not know the cause of deaths, and that deaths classified as SIDS will include some deaths from unidentified natural

causes, and some deaths from unrecognised external causes (including both accidental and deliberate smothering) (Willinger et al., 1991).

The important thing is to emphasise that at least 50% of SUDI remain unexplained (in many areas much higher); there is a clear, well thought through and internationally agreed definition for SIDS which we must use consistently; the use of the term SIDS implies that we have carried out a thorough investigation and have not found a specific identifiable cause of death; we recognise that by using the term SIDS, we are simply saying this is an unexplained SUDI and that these unexplained SUDI fit a particular epidemiological profile within which we can identify modifiable risks; within those deaths categorised as SIDS, there will be some from unidentified natural causes (whether cardiac, metabolic, infectious etc.), and some from unidentified unnatural causes (including some intentional and some non-intentional suffocations); we need to ensure the highest level of consistent thorough multiagency investigation as recommended by Kennedy.

Based on the Children Acts 1989 and 2004, *Working Together to Safeguard Children* (2006) charges Local Safeguarding Boards to take responsibility for responding to and learning from childhood deaths. There are two basic components to this:

- a rapid response by a group of key professionals who come together for the purpose of enquiring into and evaluating each unexpected death of a child
- an overview of all child deaths in the area, undertaken by a panel.

Different individuals/groups of individuals may have different needs and priorities in response to an unexpected child death, e.g.

- **Family:** need for information, understanding and support
- **Police/forensic:** need to identify unnatural causes
- **Paediatric/public health:** need to identify natural causes: infectious disease, genetic/metabolic disease
- **Primary care:** ongoing support for family
- **Social services:** need to safeguard the welfare of children

Effectively, all those involved when a child dies want to answer this key question: Why did my (this) baby die?

A number of principles underpin the rapid response process:

- Most SUDC are natural tragedies – very few are from non-accidental harm; the family must be at the centre of the process, fully informed at all times, and be treated with care and respect.
- All agencies must communicate with each other, and co-ordinate their activities: *No single profession has a monopoly of understanding or knowledge*
- We need to be systematic and thorough yet sensitive in our investigation: the two are complementary not mutually exclusive
- The “**golden hour**” principle applies equally to care, support, and investigation – i.e. rapid responses help.

How do we investigate a sudden unexpected childhood death?

There are a number of components of the rapid response, all leading to three core outcomes of establishing, where possible, a cause of death; identifying contributory factors; and providing ongoing support for the family

The Immediate Response refers to those activities taking place in the first 2-3 hours after the child dies. The aims of this initial phase are to care for and support the family; and to start the process of investigating the death, ensuring that all statutory requirements are met and all appropriate professionals are involved

1. Transfer to an emergency department with paediatric facilities; unless there are clear reasons not to, e.g. an obvious homicide scene. This achieves a number of benefits: appropriate resuscitation and medical management can be continued, or the decision to stop made with care; care and support can be provided to the parents; the multiagency process can be initiated, ensuring the right personnel are involved; by taking the parents off the scene, it helps preserve the scene for any subsequent police investigation.
2. Emergency department management will involve appropriate resuscitation and the decision to stop resuscitation being made by a qualified senior practitioner. A qualified practitioner needs to confirm that the child is dead.
3. The police, coroner and social services, along with the SUDI paediatrician are notified and arrangements made for the joint investigation. Ideally this will include a joint meeting to plan the process of the investigation and agree different roles and responsibilities.
4. The parents are given time and support in the initial stages following their child's death; this may include taking photographs and mementoes; allowing the parents to hold, clean and care for their child; contacting friends and other family members; involving a bereavement support worker or religious leader. Support for the parents will also involve explaining to them the process of the rapid response, including the need to involve the coroner and to carry out a post-mortem examination. A note should be made of the demeanour and response of the parents to the death, bearing in mind that there is no "normal" pattern of grieving.
5. An initial history will be taken, ideally by a paediatrician jointly with a police officer and contemporaneous notes made by both, documenting verbatim responses where possible. The child's body is examined, and all findings and interventions documented. Initial investigations should be taken.

Early Responses involve those activities occurring in the next 24-48 hours. The aims of the early responses are to gather as much information as possible in a timely, systematic yet sensitive manner to inform our understanding of why the child has died, and to support the family through the process. This involves careful information sharing and planning between professionals involved; gathering further information from a more detailed history, through a review of the environment where the child died, through

reviewing agency records, and through a thorough autopsy. Throughout these processes, ongoing support is offered to the family and they need to be kept fully informed. This can be a very difficult time for the family: often will be the first time they have left their child with someone else; lots of different people will be coming into their home; their lives will be scrutinised; they may feel under suspicion whilst at the same time feeling all the grief, loss, guilt and bewilderment that any bereaved parent feels.

Later Responses take place over the subsequent 2-3 months, culminating in the final case discussion and feedback to family. Essentially this stage involves a process of collating and analysing the information gained on the case. It needs to be driven by consideration of the three main outcomes: establishing a cause of death, identifying contributory factors, and support for the family.

The final case discussion is one of the most important components of the management of an unexpected death; it is here that all the information is brought together and the investigation closed. It will normally take place 2-3 months after the death once all the information has been gathered. The timing of the review, and those professionals involved may be influenced by any ongoing inquest or criminal investigation. Ideally the case discussion precedes the inquest and can help to inform it.

Is it achievable?

DCSF Pilot study: in Oct 2006 50/60 (83%) LSCBs responding to the questionnaire had or were developing a joint agency protocol. In Feb 2008, this had increased to 79/79 (100%). Of those reporting an operational protocol, 23/42 (55%) reported that it was working well; 13/42 (31%) that it was working in part; and 6/42 (14%) that it was not working.

SWISS study outcomes: notified of a total of 155/157 (98.7%) of all SUDI in the study area within the research period. Of the 155 SUDI cases, 149 (96%) were notified within 3 days of death, 136 (88%) within 24 hours. The median time to notification was 2 hrs (interquartile range:1-4 hours). In all cases, following notification, multiagency discussions took place between the local paediatrician and hospital staff, primary care, the local police child protection team and the research team. Of the 155 SUDI cases, 132 (85%) received a joint home visit, the remaining 23 did not for various reasons; because a joint agency home visit was not deemed appropriate (because the death occurred in hospital on the day of birth; the death occurred out of the region; or there was serious concern about non-accidental injury). Overall, where deemed appropriate, a joint home visit took place within 24 hours for 106 (80%) of deaths. In 2003 67% of the home visits were conducted within 24 hours of the death, in 2004 this rose to 75%, and for both 2005 and 2006 the figure was 90%.

Does it make a difference?

Comparing the outcomes of our recent SWISS study with those of the CESDI study (post "back to sleep") the proportion with an identified cause of death has increased to over 50%. In part this may reflect differences in case

ascertainment, and in particular including deaths in the first week; but overall represents an improvement in ascertaining the cause of death. The proportion of unexpected infant deaths attributed to SIDS was considerably lower in the SWISS study than in the CESDI study, whilst the proportion of deaths attributed to congenital anomalies, to infection and to metabolic causes all increased, with no identifiable change in the proportion due to non-accidental or accidental injury. Need to ask also, does it make a difference to parents and to the professionals involved? Anecdotal reports that it does; need for further research.

Child Death Overview

The purposes of child death overviews according to Chapter 7 of *Working Together* are: Collecting and analysing information about each death with a view to identifying—

- (i) any case giving rise to the need for a serious case review;
- (ii) any matters of concern affecting the safety and welfare of children in the area of the authority; and
- (iii) any wider public health or safety concerns arising from a particular death or from a pattern of deaths in that area

There are 3 core strands to the child death review processes, depending on the nature of the death:

1. Expected deaths – the family receives standard bereavement care, including where appropriate planned palliative care. The doctor issues a medical certificate of the cause of death and the death is registered with the Registrar. Information is collected from all agencies and submitted to the child death overview panel which may then review the case in depth
2. Where the death is unexpected, the interagency rapid response process takes place, gathering information and supporting the family. This process helps inform the coroner for the inquest; information is collated through the final case discussion and a report from this case discussion is submitted to the child death overview panel.
3. Where, at any stage, suspicious factors are identified, there will need to be an interagency child protection and/or criminal investigation led by the police. The nature of the rapid response therefore changes. This investigation informs the coroner's inquest. In these circumstances, rather than holding a standard child death review, the case is subject to a more detailed serious case review.

Again some core principles underpin these processes:

- Every child's death is a tragedy - for the family and for the wider community
- By reviewing child deaths we can learn lessons to prevent future child deaths
- Joint agency working draws on the skills and particular responsibilities of each professional group
- Child death reviews should lead to positive action to safeguard and promote the welfare of children

The overall process of what happens following a child death involves a number of stages. This assumes that immediate management of the death, including issuing a death certificate; rapid response for unexpected deaths; bereavement care etc. will take place within the responsible agencies. Simultaneously all deaths need to be notified to the Child Death Overview Panel (CDOP) – reliant on multiple sources of notification for completeness. Once notified, the manager/administrator will request relevant information from different agencies. The CDOP meets regularly (normally around 4 times a year) to review the deaths – usually some months after the death. The process relates to children resident in the LA area; for other children there need to be reciprocal arrangements for notifying neighbouring authorities. Finally and most importantly, this needs to lead to preventive action through Children & Young People's Strategic Partnership and Constituent Agencies.

Is it achievable?

DCSF Pilot

LSCBs with Child Death Overview Panels in place:

- October 2006 - 3/60 (5%) 36 in development
- February 2008 - 26/79 (33%) 53 in development
- 9 Pilot sites
 - All working to Government guidance
 - 9 Panel meetings observed
 - 24 cases reviewed

Further experience has been gained from the CEMACH pilot and from the United States where child death review teams have been in place since 1973 and now exist in all States.

Of 20 deaths reviewed in the DCSF pilot, 55% were from medical causes; 30% the result of accidents and 15% unexplained (SIDS). Significant outcomes were achieved in:

- Public awareness campaigns
- Community safety initiatives
- Professional training
- Development of protocols
- Lobbying politicians

As we move to 1st April, a number of resources are being developed to support professionals. New legislation has been approved which will support the process, along with new government money (£55 million over 3 years). A national core data set and proformas are being developed, and national training materials will be distributed to all Local Safeguarding Boards and available on the DCSF website:

www.everychildmatters.gov.uk

Further training and resources are available through the Warwick course:

www.warwick.ac.uk/go/sudc

References

Fleming et al, 2000: *Sudden unexpected deaths in infancy. The CESDI SUDI studies 1993-1996*, London, The Stationery Office

HM Government (2006). *Working Together to Safeguard Children*.

Department for Education and Skills. London, DfES. **2006**.

Sidebotham, P. and P. Fleming (2007). Unexpected Death in Childhood: A handbook for practitioners. Chichester, Wiley.

WILLINGER, M., JAMES, L. & CATZ, C. (1991) Defining the sudden infant death syndrome (SIDS): deliberations of an expert panel convened by the National Institute of Child Health and Human Development. *Pediatric Pathology*, 11, 677-684