

Childhood deaths: how to respond and what we can learn

New procedures for reviewing child deaths should improve support for families and enable action to reduce mortality. **Peter Sidebotham** and **Gale Pearson** explain how they work

Although child mortality has fallen significantly over the past century,¹ there is still scope for improvement. In 2005, over 3200 infants (5 per 1000 live births) and 1200 children under the age of 15 (14 per 100 000 population) died in England and Wales,² with large discrepancies in mortality between different areas and between different socioeconomic and cultural groups. Many of these deaths are preventable—whether they are from external causes or from natural conditions that are not normally fatal. Several studies have concluded that as many as 29% of child deaths may be preventable or contributed to by potentially avoidable factors.^{1,3,4} It is important, therefore, to examine the causes of child death and learn from them.

The highest risk of death is in infancy, particularly in the first month of life. Risk tails off to low levels in middle childhood before rising again in adolescence. The causes of death also vary with age (fig 1). Perinatal and congenital conditions predominate in the first month. However, in later infancy and middle childhood years, most deaths are

from medical causes, although up to a quarter are related to external causes or remain unexplained, including deaths from sudden infant death syndrome. The pattern changes in adolescence, with half of deaths being from external causes.

Whatever the underlying causes, each death is a tragedy for the affected family and the wider community. After the death of a child, the experience of families varies enormously, and for many, professional responses to their bereavement compound rather than help their trauma.⁵⁻⁷ In a study of bereaved families in England and Wales in the 1990s, Dent et al found that although many were satisfied with the care given by the emergency services, some thought that the police could have been more sympathetic and less accusing; many were not given appropriate information or offered support; and more than half were not offered follow-up care by the hospital.³

In response to some of these issues and in line with a broad emphasis on safeguarding children and promoting their welfare, the

government brought in new legislation and guidance through the Children Act 2004 and revised multiagency guidance, *Working Together to Safeguard Children*.⁴ This guidance places a responsibility on local safeguarding children boards and their constituent agencies (health, education, social services, police, and other services for children and families) to put in place procedures both to respond rapidly to individual unexpected childhood deaths and to review all childhood deaths systematically. Below, we outline these two processes and the implications for health professionals. Research in this area is extremely limited, and the new processes are largely based on perceived good practice rather than a robust evidence base.

Responding to unexpected child deaths

One of the key components of the new government guidance is a coordinated multiagency approach to investigating the unexpected death of a child and supporting the bereaved family.^{5,6} An unexpected death is defined as one that was not considered a serious

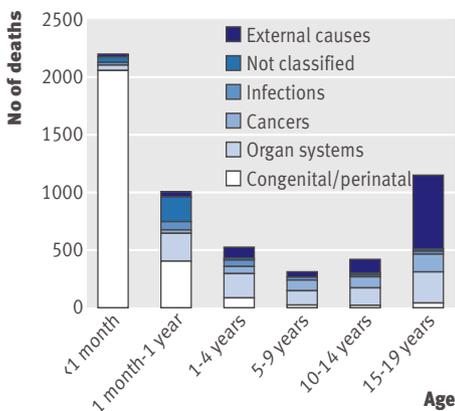


Fig 1 | Causes of death in childhood in England and Wales, 2004¹

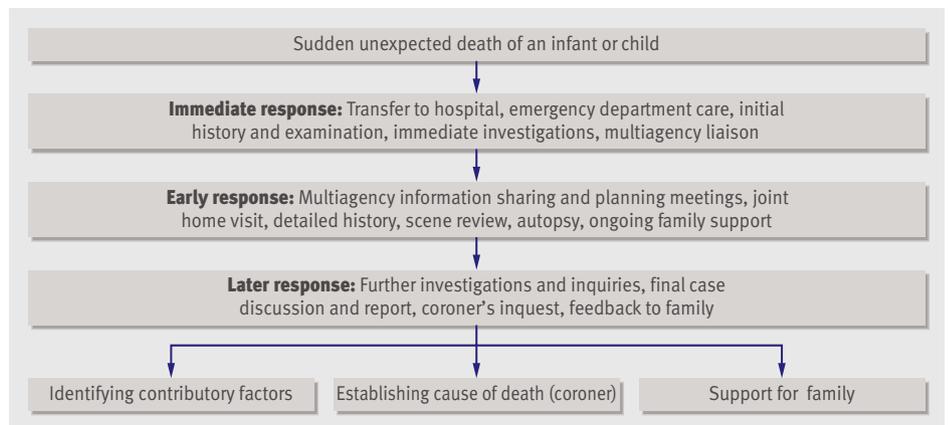


Fig 2 | Responding to an unexpected child death

Box 1 | Core components of response to unexpected child deaths*Information gathering*

Including a thorough medical history, examination of the child, investigation of the circumstances of the death (including where appropriate, a visit to the home or scene of death), and a structured postmortem examination with appropriate ancillary investigations

Collation and evaluation of the information gained

Through ongoing liaison between the professionals involved and a final structured case discussion

Ongoing support to the family

Includes providing them with information and linking into sources of bereavement support

possibility 24 hours before the death itself or any unexpected collapse or precipitating event that led to the death.⁷ It would not normally include the death of an infant or child in a hospital or of a child with a known life limiting condition. Response to an unexpected death has three primary purposes: to establish, in conjunction with the coroner, a cause of death; to identify any contributory factors; and to provide ongoing support to the family (fig 2). Central to this is a thorough and systematic investigation that remains sensitive to the needs of the bereaved family. Certain core components of the process require the input of health professionals (box 1).⁸

Many areas of the UK are exploring team based approaches to these responses, drawing on the relevant skills of primary and secondary medical and nursing staff. Experience suggests that each unexpected death in infancy requires about 16-20 hours' input from the paediatric team, mostly concentrated in the first 48 hours, and a primary care trust with a population of 500 000 would experience 10-15 unexpected deaths a year, of which at least half would require a full multi-agency response, and the remainder a less intensive response—for example, where the cause of death is apparent at presentation.

Most parts of the country have clear protocols for responding to sudden unexpected death in infancy, and many places are exploring how to extend these processes to deaths of older children in the community.

Experience in the southwest of England has shown that, with appropriate support, local teams can achieve a rapid response to an unexpected infant death in at least 90% of cases (P

Fleming et al, unpublished results). Our experience in talking with bereaved families suggests that these processes are well received by parents and that they can improve the ascertainment of causes of death and potential contributory factors.

Child death review processes

The principles of multi-agency reviews of child deaths to learn lessons and safeguard children's welfare is long established in the UK. Serious case reviews

(part 8 reviews) are implemented when abuse or neglect is thought to be a factor in the death or serious injury of a child.^{9 10} In addition, there is a long history of more health oriented approaches, most notably the confidential inquiries into stillbirths and deaths in infancy.⁷ Experience in the United States, where teams to review child deaths have been in place since the 1970s,^{10 11} has shown appreciable benefits. Other countries have also reported benefits (box 2 on bmj.com).

In their review of the published literature on child death for the Scottish Executive, Axford and Bullock concluded that "there is some evidence of the impact of reviews on *immediate* and *intermediate* outcomes—insofar as they shape policy, guidance, training and, to some extent, practice—but benefits for *ultimate*

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outcomes, measured in terms of children's well-being, are less apparent."¹¹ More robust evaluation of the impact of these review processes on outcomes for children is needed.

Local lessons

We have led two recent studies of the processes for reviewing child deaths in the UK.^{16 17} Box 3 summarises some of the key outcomes from these studies. The reviews are carried out by child death overview panels that meet 4-12 times a year for around two to three hours. Panels typically have a core membership drawn from key agencies and include other members with specific expertise on particular cases as required—for example, a transport police officer for deaths from road traffic collisions or a cardiologist when looking at deaths from congenital heart defects. Although it is helpful to have panel members with local knowledge and experience, some independence is needed to enable a more objective review. This can be achieved through an independent chair who is not directly involved in providing services to children, through incorporating lay membership on the panel, or through robust lines of accountability and reporting to the local safeguarding children board.

For each case reviewed, leads in each agency need to review the information known about the child and family and prepare a report. Panels work best when the members are provided with clear summarised and collated information before the meeting, rather than trying to assimilate information from case files at the panel meeting. Participants in the studies raised several concerns relating to confidentiality and information sharing. Sharing personal and sensitive information is important to identifying matters affecting the safety and welfare of children. It therefore serves the public interest. However, such



Death Taking a Child engraved by Hans Lutzberger, c 1526-8

Box 3 | Lessons learnt from UK studies of child death reviews^{16 17}**Identifying modifiable factors**

One study identified avoidable factors in 26% of cases reviewed and potentially avoidable factors in a further 43%.¹⁷ Factors related to the child, parental care, wider family and environmental factors, and service need and provision. They included:

- Recognition of recurrent injuries in teenagers who had unnatural deaths (present in 8/14)
- Missed hospital or primary care appointments in teenagers at risk
- Delayed vaccination in infants born prematurely or with underlying congenital illness
- Failure of primary care practitioners and emergency departments to recognise severe acute illness
- “Dangerous” co-sleeping (eg, after drinking alcohol or smoking) leading to sudden infant death¹⁶
- Recognition of dangers on zigzag areas at pedestrian crossings (a factor in 12/19 child pedestrian deaths)

Identifying good practice**Examples of high quality care in the studies included:**

- Appropriate recognition and referral of severe illness in primary care
- High quality multidisciplinary palliative care for children with life limiting illness, chronic disease, or disability
- Good resuscitation technique among paramedics and in emergency departments

Responding to children with life limiting illness

77% of children who died had existing illnesses or complex needs. Reviews provide an opportunity to examine the children’s care and improve services for future children and their families

Focus on outcomes

Several important changes arose from the reviews:

- Public awareness campaign on holiday safety developed in response to the death of a child in a swimming pool abroad
- Revised policies for servicing gas appliances in social housing after the death of a child from carbon monoxide poisoning
- Improved services in bereavement support and information sharing with primary care

information should be treated with respect, anonymised where possible, and families informed of the process.

Implications for health professionals

In *Working Together to Safeguard Children*, the government set a target date of 1 April 2008 for implementation of child death review processes. Several months on, many local boards have developed and implemented both rapid response and child death review procedures. Last year, the government announced it would give £52m over the next three years to support these processes. Supporting materials, including training materials are available on the Every Child Matters website (www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview/). Given the paucity of current research in this area, the introduction of national systems provides a unique opportunity for national collation of data. Both systems must be rigorously evaluated so that further lessons can be learnt and procedures improved.

Our experience in talking to health professionals around the country is that there is a

mixture of apprehension and enthusiasm about these new processes. The apprehensions seem to focus largely around the resources required when services are already stretched. This concern is often compounded by a lack of clarity over what is expected of health professionals and a fear that they will be called to step outside their areas of expertise. That was never the intention. Rather, by working as a team, professionals should be able to draw on the complementary skills and knowledge of other members and so better support families and learn from children’s deaths. The enthusiasm comes in when professionals begin to recognise the potential of these processes to improve investigations, to improve the experience of bereaved families, and to take steps to reduce child mortality and improve the health and wellbeing of our children.

Peter Sidebotham senior lecturer in child health, University of Warwick, Health Sciences Research Institute, University of Warwick, Coventry CV4 7AL

Gale Pearson consultant paediatric intensivist, Birmingham Children’s Hospital, Birmingham B4 6NH

Correspondence to: P Sidebotham p.sidebotham@warwick.ac.uk

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