

When a child or young person dies- a guide to the Child Death Review Process for non-paediatricians.

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Abbreviations:

SUDI - Sudden Unexpected Death in Infancy

SIDS - Sudden Infant Death Syndrome

CDRP - Child Death Review Process

DCSF - Department for Children, Schools and Families

ONS - Office for National Statistics

WTSC - "Working Together to Safeguard Children" (HM Government 2006)

LSCB - Local Safeguarding Children Board

CDOP - Child Death Overview Panel

Introduction

The death of a child or young person from whatever cause is always a tragedy for family and friends, but is even more devastating if that death was preventable. When a child dies unexpectedly, parents want an explanation as to why this has happened. In the past the investigation of child deaths was a patchwork and a lottery. At best parents were treated sensitively but often left with unanswered questions. At worst innocent parents were suspected of having caused their child's death. The Child Death Review Process, a new statutory requirement for the multi-agency investigation of child deaths in England, Wales and Northern Ireland, came into force in April 2008 with the aim of standardising the investigation and management of sudden unexpected child deaths so that parents receive the support and explanations to which they are entitled, miscarriages of justice are avoided, but also that unnatural deaths are detected. It is essential that all agencies analyse their performance in caring for a child and family and that lessons are learned so that care is improved and similar deaths avoided. This process does not just involve paediatricians but potentially all

clinicians, as a child is defined in UK law as any person aged from birth to their 18th birthday.

Child Deaths in the UK.

Approximately 5000 children die each year in the UK, 49% of whom are aged less than a month and 83% under five years¹. At all ages slightly more boys die than girls. Child death rates are increased in areas with a higher index of socioeconomic disadvantage (ONS). The major causes of death in children and young people vary considerably according to age. Figure 1 shows the percentage of child deaths from birth to 19 years due to congenital and external causes.

Causes of death at different ages

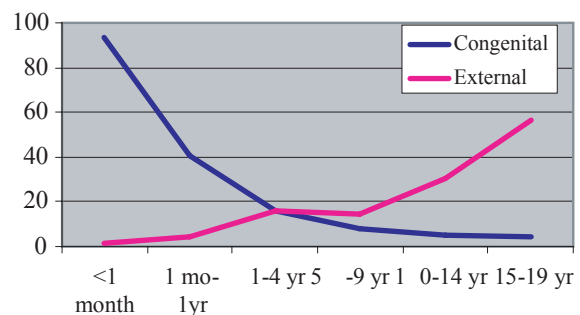


Figure 1. Percentages of child deaths from congenital and external causes at different ages. Source: Office for National Statistics, 2006

In infants less than 1 month 93% of deaths are caused by congenital anomalies, or adverse events during pregnancy and birth, whereas only 4% of deaths in teenagers are from congenital or perinatal causes. Less than 2% of deaths in the first month of life are due to external causes such as accidents or homicide, while nearly 60% of teenage deaths are the result of accidents, suicide or homicide. In 2005, 23% of deaths in young people aged 15-19 years

were from organ diseases, 13% from cancer and 2% from infections (ONS). We expect to see approximately 50 deaths in children and young people each year in County Durham and Darlington.

The Kennedy Report

It is recognised that the majority of sudden unexpected deaths in infants (SUDI) are due to natural causes, but a small number may be the result of neglect, abuse or murder. Following several high-profile cases where mothers were prosecuted for allegedly causing the death of their infants, concerns were raised about the thoroughness of the investigations, both medical and criminal, and the quality of the evidence put before courts. Baroness Helena Kennedy QC was asked to chair a working party by the Royal College of Pathologists and the Royal College of Paediatrics and Child Health to develop an agreed national protocol for investigation and management of SUDI, encompassing the work of health care professionals, police, pathologists, lawyers, judges and coroners. The conclusions in the report, published in 2004, were that :

- It is every family's right to have their child's death properly investigated
- Proper management of SUDI involves an intensive, inter-agency approach
- The three prime objectives are
 1. Establishing the cause of death
 2. Identifying contributory factors and learning lessons
 3. Supporting the family²

She recommended that each area should have an identified SUDI paediatrician who would undertake - jointly with police and other agencies - a detailed investigation of sudden infant deaths which would include a joint home visit with a police officer. This caused concern amongst paediatricians, who felt that they were not

adequately trained to undertake such a role. The lack of free time in job plans or any initial funding to establish this national protocol meant that, with a few exceptions, it was hardly implemented.

“Working Together to Safeguard Children”

The government response to the Kennedy Report and to Lord Laming's report on the death of Victoria Climbié³ - whose preventable death due to neglect and abuse at the hands of her carers shocked the nation - was the publication of WTSC in 2006⁴. This described the reforms of the agencies overseeing child protection and welfare and established Local Safeguarding Children Boards (LSCBs). These were given the responsibility to collect and analyse information about all children and young people dying in their area in order to identify common themes that may have implications for the welfare and safety of local children, or wider public health or safety issues. The LSCBs were required to set up Child Death Overview Panels with representatives from health services, social care and police, and appoint a designated paediatrician for child deaths, whose role is to act as medical adviser to the Overview Panel, to ensure that the requirements of the Child Death Review Process are being carried out in local health services, and to chair local case discussions about individual child deaths.

The Child Death Review Process

A diagrammatic overview of the process is shown in Figure 2. The three essential aims are to support the child's family, establish the cause of death and identify contributory factors⁴. If a child dies suddenly and unexpectedly at home ambulance staff are trained that, unless the death is obviously suspicious, resuscitation is commenced and the child taken to the nearest Emergency Department (see Figure 3).

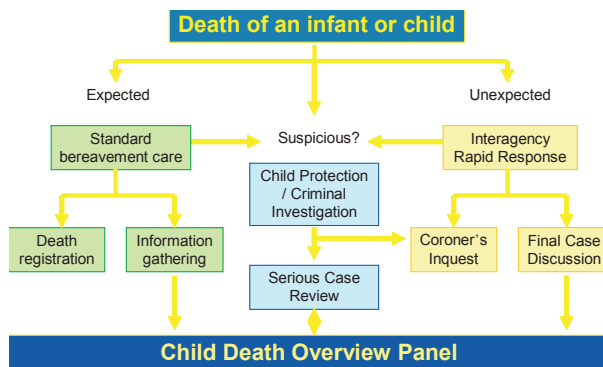


Figure 2. An overview of the Child Death Review Process.
 Source : Department for Children, Schools and Families, 2008

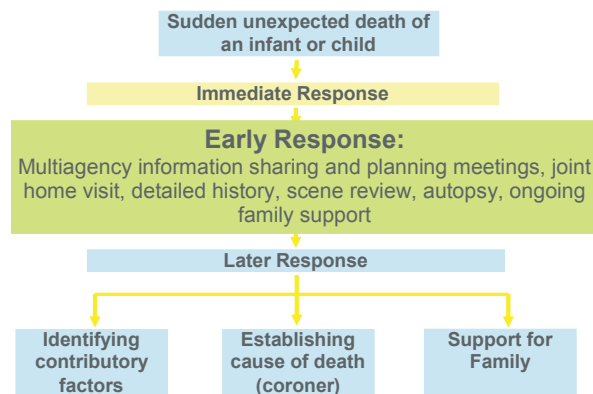


Figure 4. Early Response to SUDIC
 Source : DCSF 2008

This is co-ordinated by the Senior Investigating Officer from the police and a senior health professional, with the aim of finding out as much as possible about the child's health and family background, and a detailed account of the circumstances leading up to the child's death. All this information will be vital to the paediatric pathologist performing the autopsy. The information-gathering will usually include a joint visit to the child's home or scene of death by a health professional and police officer, discussions with the child's general practitioner, health visitor, school, social worker and any other agencies involved with the family. The immediate and early responses together comprise the Rapid Response. If at any stage in the process suspicions are raised that the death may have been unnatural, or that neglect or abuse were contributory factors, then a Child Protection Strategy Meeting is held to plan the next steps and ensure that any other children in the family are safeguarded.

Preliminary results from the autopsy are usually available within a few days, but the final report, taking into account the results of histology, microbiological cultures, cytogenetic studies and metabolic tests may take three months or more. In the meantime information is collected from all agencies involved with the family using the Agency Report Form⁵, in which responders are asked to summarize their knowledge of the

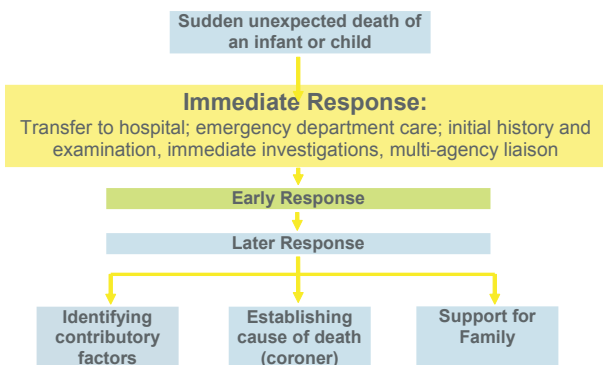


Figure 3. The Immediate Response to the sudden unexpected death of a child
 Source; DCSF 2008

Once death has been confirmed an initial history is obtained and the child examined in detail, usually by a consultant paediatrician or emergency physician. Samples of blood and body fluids are taken according to a protocol agreed with the coroner, since the diagnostic yield of these investigations is likely to be greater than if these samples are taken at the autopsy, which may be delayed by several days.

A phase of intensive information-gathering and sharing follows (see Figure 4).

child's health, circumstances leading to the death, parenting capacity, family and environment, services provided to the child and family and any suggested issues for discussion. The Later Response, which is carried out by the designated paediatrician for child deaths, collates all this information (see Figure 5).

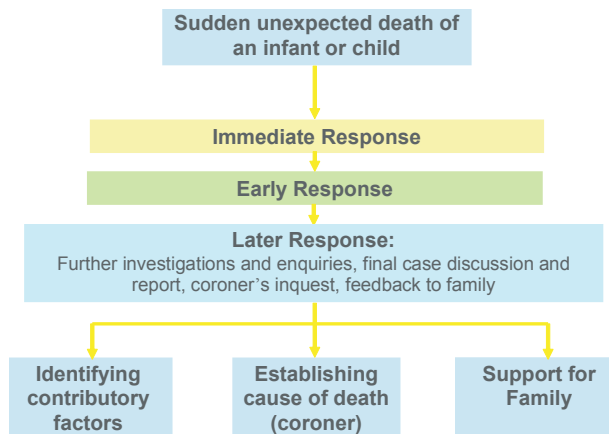


Figure 5. *The Later Response to a sudden death in childhood.*

Source: DCSF 2008

A local case discussion attended by all the professionals involved with the child reviews the information and completes an Analysis Proforma⁵ where the cause of death, contributory factors, issues identified and recommendations are recorded. The designated paediatrician is responsible for feeding back to the family the conclusions of the local case discussion, a role which demands tact and sensitivity. The fact that professionals are analysing why their child died and learning lessons that may benefit other families is sometimes a comfort to bereaved parents. The final phase of the CDRP is the discussion of the child's death by the Child Death Overview Panel, and submission of anonymised data to the DCSF.

Some children with life-limiting conditions are expected to die. Although a full Rapid Response is not invoked, information is still collected about those children, as there may be lessons to learn about improving palliative care and family

support. These deaths are also discussed by the Overview Panel.

The CEMACH Pilot of the Child Death Review Process

Although the government is often criticised for introducing major reforms without having piloted them first, the CDRP was piloted in Wales, Northern Ireland and 3 English regions in 2006 using the well-established death reporting mechanisms of the Confidential Enquiry into Maternal and Child Health (CEMACH). Data on all child deaths in the pilot areas were collected and local case reviews held for a proportion of the deaths, with a focus on recognising avoidable factors. The report, "Why Children Die- a pilot study", was published in May 2008 just after the nationwide rolling out of the CDRP⁶. Avoidable factors were identified in a significant proportion of child deaths, with failure to recognise serious illness in a child the most important. Taking an inadequate history, failing to examine a child properly or misinterpreting physical signs, failing to recognise the development of a complication or delaying treatment or referral all contributed to this lack of recognition. Other common themes which emerged in the deaths considered avoidable included not following published guidelines for managing a condition, junior staff not being supervised by experienced paediatricians, children being cared for in non-paediatric areas, children missing appointments or being lost to follow up, poor co-ordination between and within primary and secondary health care, and poor information-sharing and lack of co-ordination with social services⁶.

The Rapid Response in County Durham and Darlington.

The original description of the Child Death Review Process in WTSC envisaged that the Rapid Response would be co-ordinated and carried out by paediatricians. However, as child

deaths are infrequent and unpredictable, require a great deal of time to support the family, collect information and communicate with police, pathologist, coroner and others, it is difficult to make time in a job plan. In the large conurbations where there may be several hospitals more child deaths and many paediatricians, it has been possible to establish rotas of paediatricians who keep days free to respond to sudden child deaths. In rural areas where paediatricians are thinner on the ground and child deaths fewer, the model of using nurses for the Rapid Response seems to be more common. It was therefore decided that in County Durham and Darlington experienced paediatric nurses would undertake the training to become Rapid Response specialist nurses fitted in around their other jobs. Since October 2009 they have provided an on-call service from 7am to 10pm - including weekends and public holidays - to respond to a child death anywhere in the Trust area.

Child Deaths in County Durham and Darlington 2008-2009

In the first year of the CDRP 48 children and young people died in Co. Durham and Darlington. Sixteen of these were newborns and death was due to complications of prematurity in the majority of these. There were 12 expected deaths in children with life-limiting conditions including three from cancer, and five from degenerative neurological conditions. Three children died in accidents, although none involved motor vehicles. Of the four SUDIs a detailed paediatric post-mortem and thorough investigation identified an explanation for the death in three, including in one a previously unsuspected inborn error of metabolism which had important genetic implications for the family. Only one baby was classified as having died from Sudden Infant Death Syndrome.

Of the nine older children who died unexpectedly, two died from asthma at home, two were found to have septicaemia, and two died suddenly

during the early stages of cancer treatment.

What have been the problems?

For the first 18 months after the CDRP came into force the Rapid Response team was not in place, and this meant that families were not always receiving the level of support they needed. There have sometimes been long delays before the LSCB or I have been notified of a child's death. Due to administrative problems there have also been long delays sometimes between a child's death and the Agency Report forms being sent out to the involved professionals. Many of these forms have taken an inordinately long time to be returned, and are often poorly completed, so that phone calls have to be made to obtain the necessary information. The paperwork we are required to submit to the DCSF is somewhat long-winded and cumbersome, but as the CDRP is a statutory requirement we have no choice but to use the designated tools.

What have we learned?

My paediatric colleagues, the Rapid Response nurses and I have learned a lot about multi-agency working, and about how people cope with bereavement in different ways. I have found that the best way to engage GPs in the CDRP is to ask to hold the local case discussions at their surgery⁷. Some have been initially apprehensive that the case discussion would be an exercise in apportioning blame, but have said afterwards that they found it educational and valuable. Our local experience from case reviews has very much mirrored that of the CEMACH pilot. Some very good practice has been highlighted, but avoidable factors and deficiencies in care have also come to light. We have identified guidelines not being followed, juniors not being adequately supervised by consultants and making decisions beyond their competence, children being lost to follow up despite having a serious condition, and examples

where serious illness went unrecognised. Learning points and recommendations have been made for primary and secondary health care services, police, ambulance staff, and social care workers. The feedback from police colleagues and other agencies on the contribution of the Rapid Response nurses has been very positive. Most importantly, the response from families who have lost a child has been, for the most part, one of gratitude at the thoroughness of the investigation, and appreciation for the support they received from the Rapid Response team.

How the Child Death Review Process involves non-paediatricians

All young people up to the age of 16 years who are in-patients in the Trust will either have a paediatrician involved in their care, or be looked after on a paediatric ward. If one dies, the paediatricians will know about them and ensure that the CDRP is invoked. However, young people between their 16th and 18th birthdays may be admitted to other wards or the Emergency Department without any involvement by paediatricians. Should any of these die their death should be notified. If their death was expected then there is usually no need for the Rapid Response, and the team which has been caring for the young person will usually be best placed to offer support to their family. If the death was unexpected then the Rapid Response team would like to be informed and to attend so that they can offer support to the family, liaise with the police and help to guide clinicians unfamiliar with the CDRP through the statutory requirements. The Regional Maternity Survey Office (RMSO) in Newcastle has co-ordinated the information about infant deaths for many years, and has taken on this role for the deaths of all children and young people up to their 18th birthday, both expected and unexpected. The RMSO then passes details of the child's death to the LSCB. Out of office hours an answer-phone is available but please do not leave the child's

name or confidential details. It is sufficient to say that you have a child's death to report and leave your contact details, and someone from the RMSO will telephone you for further information.

Please inform the Rapid Response nurse on call. They are available between 07.00 and 22.00 every day. If a death should occur outside those hours there is an answer-phone in the Rapid Response office (the telephone number is the same) and a Rapid Response nurse will contact you as soon as possible.

It is also helpful if you could notify the Local Safeguarding Children Board for either Co. Durham or Darlington, according to the child's place of residence or death, although if the RMSO and Rapid Response nurse have been informed they will usually offer to do this.

Copies of the local protocol for management and investigation of sudden, unexpected deaths in children and young people are available in the Emergency Departments, on the children's wards and on the trust Intranet.

The LSCB will send the clinician responsible for the patient an Agency Report Form to complete, and if a local case discussion is held that clinician will be invited to attend and bring all the young person's medical records.

Conclusion

After initial concerns that the CDRP would require paediatricians to work outside their comfort zone and would be a bureaucratic process it is the view of most clinicians involved that the CDRP is a potentially powerful tool to collect information that will help to drive up standards of care for children and families. It will ensure that a child's death is thoroughly investigated no matter where in the country he or she lives or dies, and will ensure that families receive better information and support than they received in the past.

Contact Numbers

Regional Maternity Survey Office
0191 233 1658.

Local Safeguarding Children Board
(Co. Durham)
0191 383 3830

Local Safeguarding Children Board
(Darlington)
01325 388940.

Rapid Response Nurse on call
(and answer-phone overnight)
01388 455126

Heather Smith, Designated Doctor
07747 640939

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