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# Unexpected death in infancy: helping parents to understand why their child has died

## Why did my baby die?

I recently visited a young mother whose baby had died suddenly and unexpectedly at two months of age. I had met this mother at the time, and now, a few months later, I was returning with the lead investigating police officer to feedback the results of our investigations and to offer what support we could to the parents and family. As is often the case, the post mortem examination and all our enquiries had failed to discover any specific cause of death and the child's death remained unexplained: one of the 200 babies who die each year in England under the category of sudden infant death syndrome (SIDS).<sup>1,2</sup> In contrast to many of the families we see following a sudden unexpected death in infancy (SUDI), however, this mother had followed all the advice on safe sleeping. She was not a smoker and she was exemplary in her care of her infant.

Over the past 20 years I have had the privilege of meeting many parents whose children have died unexpectedly. Each one of these deaths is a tragedy, and each family has had their own unique story and their own journey of grief. For all of them, however, one burning question prevails: "Why did my baby die?" While for many this question can never be answered, by carrying out a full, thorough and systematic investigation we are at least able to assure the family that no stone has been left unturned, and where there is an identifiable cause of death or where we can identify factors that may have contributed to the death – such as an infection, a metabolic disorder, or unsafe sleeping practices – this can help the family to understand and come to terms with the death, and potentially reduce the risks of future child deaths.

Working with bereaved parents in these circumstances has highlighted a number of key things that parents want from professionals following their child's death:<sup>3</sup>

- As far as possible, parents want to know how and why their child died and any factors that may have contributed to the death.
- Parents, whatever the circumstances of their child's death, want to be treated with sensitivity, compassion and respect.
- Parents need time and privacy to grieve in their own way, to say goodbye to their child.



- Parents want to be kept informed of what is happening as part of the investigation and to be offered support with the practicalities of adjusting to life without their child.
- Parents want to know where and how they can access support – both practical and emotional.
- Parents do not want other families to go through what they have gone through. Almost invariably, parents want to contribute to research and learning that might help prevent future child deaths.

## A joint agency approach to responding to unexpected deaths in infancy and childhood

It is with these perspectives in mind that the Royal College of Pathologists, together with the Royal College of Paediatrics and Child Health, have produced a revised set of multi-agency guidelines for care and investigation following sudden unexpected death in infancy and childhood.<sup>4</sup>

The guidelines have been produced by a working group chaired by Baroness Helena Kennedy QC and including representatives of both colleges, the police, the chief coroner, and the Lullaby Trust support organisation for bereaved families. They are informed by the best available evidence in the field and are in keeping with the statutory English national guidance outlined in *Working Together to Safeguard Children*.<sup>5</sup> In many ways these multi-agency guidelines provide an operational model of best practice in responding to unexpected child deaths.<sup>6</sup> They are grounded in respect for the child and family, which is clearly laid out in the introduction to the guidelines:

### Nomenclature

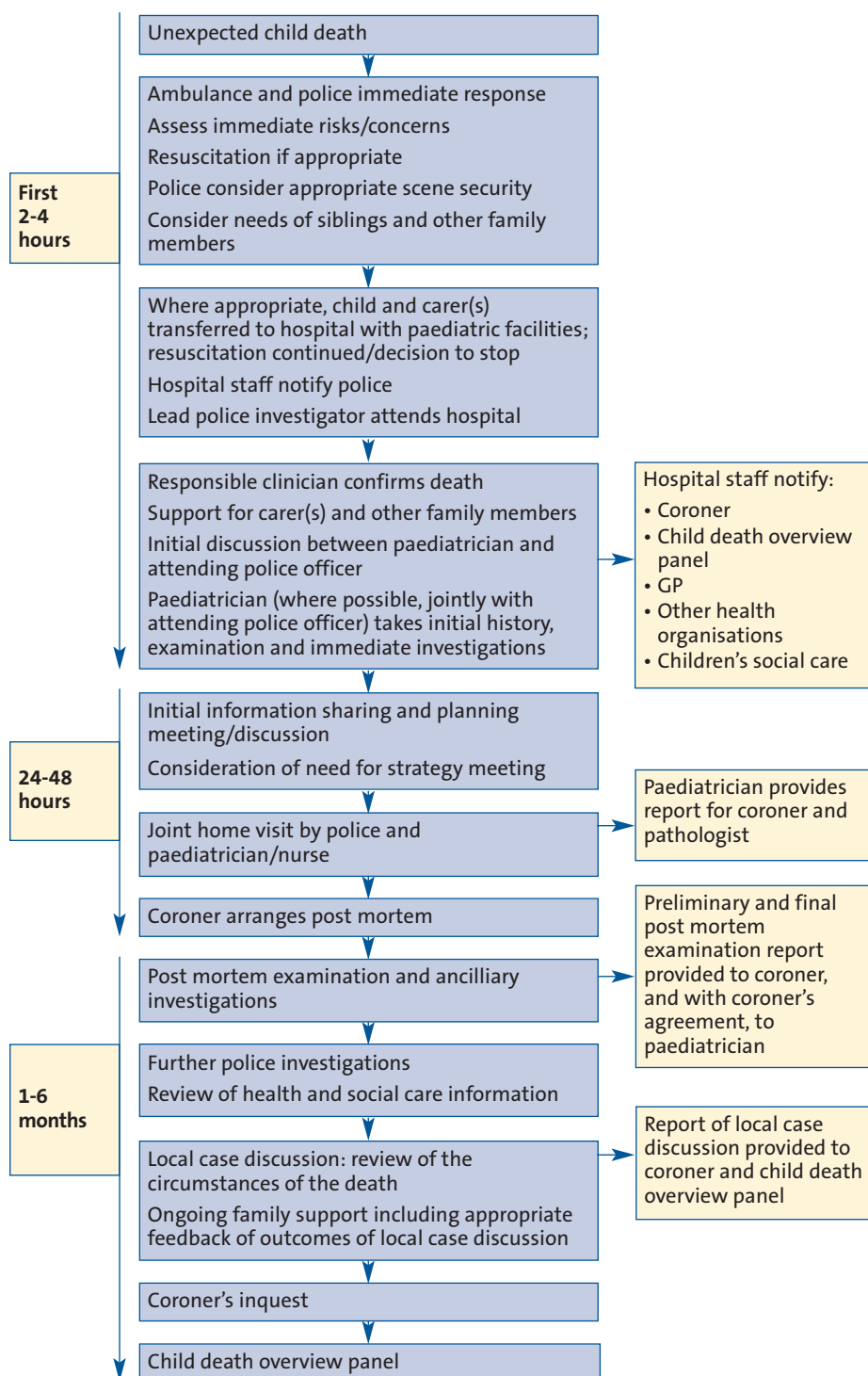
The term sudden unexpected death in infancy (SUDI) encompasses all unexpected infant deaths, both explained and unexplained. Sudden infant death syndrome (SIDS) refers to the sudden and unexpected death of an infant that remains unexplained after a thorough investigation and post mortem examination.

“Every infant who dies deserves to be treated with respect and care. This includes the right, in an unexpected infant death, to have the death fully and sensitively investigated in order to identify, where possible, a cause of death and to learn lessons for the prevention of future infant deaths. Thorough and sensitive investigations go hand in hand with a supportive approach to the family in their grief, and can help to ensure that all statutory requirements are met, and that

family members, the community and all professionals are supported through the process.”<sup>4</sup>

The aims of the joint agency approach are to:

- establish, as far as is possible, the cause or causes of the infant's death
- identify any potential contributory or modifiable factors
- provide ongoing support to the family
- ensure that all statutory obligations are met



**FIGURE 1** The joint agency response to an unexpected infant death (from *Working Together*, 2015).<sup>5</sup>

- learn lessons in order to reduce the risks of future infant deaths.

These aims are achieved through a coordinated approach encompassing a number of core components:

- careful multi-agency planning of the response
- ongoing consideration of the psychological and emotional needs of the family, including referral for bereavement support
- initial assessment and management, including a detailed and careful history, examination of the infant, preliminary medical and forensic investigations, and immediate care of the family, including siblings
- an assessment of the environment and circumstances of the death
- a standardised and thorough post mortem examination
- a final multi-professional case discussion meeting.

These different elements are described in detail across the guidelines, providing practical guidance for different professionals in relation to their responsibilities (**FIGURE 1**). There are detailed sections on family support; initial assessment and management, including front-line management when a baby is brought into hospital having been found unexpectedly collapsed or dead; the role of a joint home visit to assess the environment and circumstances of the death; and the post mortem examination, along with guidance on inter-agency working and pulling together the information gained. The guidelines provide details of the inquest and the role of the coroner, as well as information about the child death overview panels.

There are a number of helpful appendices including guidelines and proformas for history taking and examination, and a list of national support organisations for bereaved families.

### Unexpected infant deaths: a changing landscape

The introduction of the Reduce the Risks (Back to Sleep) campaigns in the early 1990s led to a dramatic reduction in SIDS rates.<sup>7</sup> This has been followed by a sustained gradual reduction in rates to their lowest ever recorded level in 2014<sup>2</sup> (**FIGURE 2**).

Along with this overall reduction in SIDS there has been a demographic shift

such that the majority of cases now occur in the most vulnerable groups in our society, particularly young mothers and those living in areas of social deprivation,<sup>8</sup> and in those with recognised risk factors such as parental smoking, alcohol and substance misuse, hazardous bed-sharing or co-sleeping on sofas.<sup>9</sup> Given these changes, it is now more important than ever that every SUDI is responded to with rigour, sensitivity and respect. Only then can we ensure we are doing everything possible to help parents understand why their child has died, to support them in their grief and to learn lessons for preventing future child deaths. In the words of Baroness Kennedy: "It is every family's right to have their baby's death properly investigated."

## References

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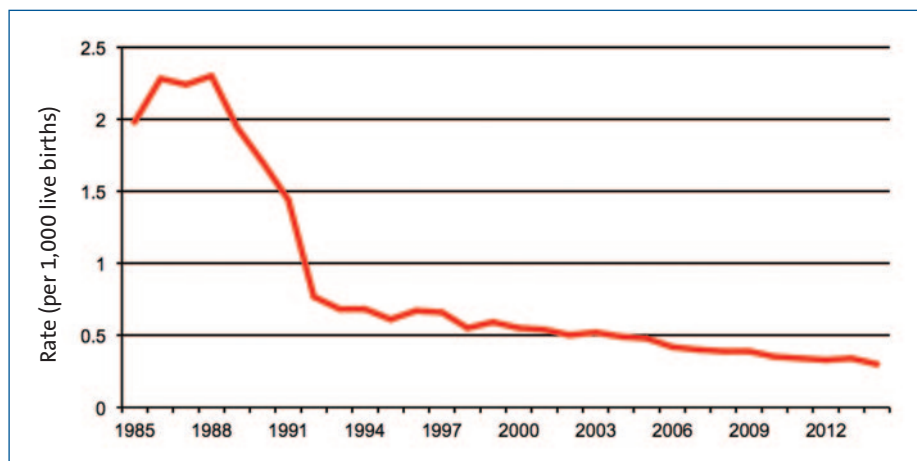


FIGURE 2 The incidence of SIDS, England and Wales, 1986-2014.<sup>5</sup>



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