

# MEDICAL PRACTICE

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## Contemporary Themes

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### Support for families bereaved by cot death: joint voluntary and professional view

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"I don't think the horror of turning my baby over and realising he was dead will ever leave me." The many problems facing families who experience a cot death were sensitively described five years ago by Emery,<sup>1</sup> and their counselling needs have been discussed by one of us.<sup>2</sup> Our experience suggests, however, that despite steady progress in understanding the nature, if not the causes, of cot deaths, the difficulties for bereaved families remain great and have received too little attention, especially from health professionals. Our description of these difficulties and suggestions for easing them are based on contacts made by the Foundation for the Study of Infant Deaths with over 1000 families bereaved by cot death from all parts of Britain, and on home visits made by a paediatrician to over 50 such families on Tyneside, which formed part of a continuing study of post-neonatal mortality.<sup>3</sup>

#### The problems

The death of a child is a heart-rending tragedy in most circumstances. When it occurs suddenly, unexpectedly, and for no obvious reason in an apparently normal infant whose symptoms of illness, if any, were considered minor, the shock, guilt, and bewilderment are much more severe and long-lasting than after a death that is expected or understood.

#### FAMILY PROBLEMS

The parents' search for commissions or omissions in the way they cared for their baby at home, which they see as their responsibility, may haunt them to a point of personal or family breakdown. Often the house seems irredeemably tainted. Death most often occurs in the puerperium, when the mother's emotions are especially vulnerable. As well as their own grief the parents may have to cope with that of their surviving children, with its often puzzling manifestations, and many have difficulty in explaining the death to the grandparents and other relatives. The coroner's investigation, which often entails a home inspection by one or more uniformed police and sometimes removal of the cot and bedding for forensic examination, even when gently handled, adds distress. Many parents, facing their first major crisis, do not know how to set about making funeral arrangements, which often include collecting the coroner's certificate and registering the death, often with the same registrar with whom the baby's birth was happily registered a few weeks earlier.

Our society is peculiarly death-shy: "People pretend you aren't there or that the baby never existed." Uncertain neighbours and friends often react inappropriately to the baby's death, either by avoiding the parents or the subject, or by misplaced cheer, or sometimes even by malignant gossip based on public confusion between cot death and battering, many not realising that unexpected infant deaths from natural causes vastly outnumber deaths due to non-accidental injury.

#### PROFESSIONAL HELP

The professionals are often ill equipped to help. The family doctor and health visitor may have had little experience of cot death, and the doctor will rarely have attended the necropsy. "My GP, who is usually very good, was totally at a loss and unable to offer any advice. I later learnt that there had not been a previous cot death in his practice and he was terribly shocked and found it very difficult to cope with the situation." The relationship between the practice and the family is sometimes strained by resentment or loss of confidence on the part of the parents, especially if their baby had been seen and not recognised as being seriously ill shortly before death. Furthermore, not all families are registered with a practice when the baby dies.

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Often the parents are told the necropsy result by the coroner's officer or a policeman, who, however sympathetic, cannot be expected to give adequate answers to questions about medical terminology and interpretation. "To be told by a complete stranger, the coroner's officer, that the baby had died from something as common as bronchiolitis or pneumonia makes the bereaved mother feel almost criminal in not getting the baby to the doctor or noticing symptoms." Paediatricians, despite their experience with children dying in hospital and their willingness to help, are rarely informed quickly enough to be able to offer their services at the appropriate time. Few pathologists recognise the bereaved parents' need for clarification of the cause of death, and few make themselves available for discussion.<sup>4</sup>

## Recommendations

### THE ACCIDENT AND EMERGENCY DEPARTMENT

"Casualty department was very efficient but offered no further support once having informed us the baby was dead." Many babies who are found suddenly and unexpectedly dead or dying at home are rushed to hospital with hopes of resuscitation, and the first and most painful phase of supporting the family may fall to the staff of the accident and emergency department. If the infant appears to be dead on arrival, it is preferable for certification of death to be made in the casualty department rather than in the ambulance.

While resuscitation is attempted or the baby's physical condition is being evaluated one member of the staff should stay with the parent (or parents) in a private area and ask for details of the baby's health and recent events. If possible a paediatrician should be called. All information should be reviewed briefly before breaking the news that the child is dead. If only one parent is present efforts should be made to contact the other. In the absence of obvious injury or diagnosed fatal illness the parents may be told that, although a necropsy will be needed to establish the cause of death, it seems likely that the baby has died as a cot death, described as sudden infant death syndrome, a well-recognised but little understood condition.

Many, but not all parents want to see or hold their baby before the body is taken to the mortuary; they should be offered the opportunity to do so and the baby should be made as presentable as possible. Discretion will be needed if the baby has been disfigured during resuscitation attempts, but some parents need this opportunity to accept the reality of death and will want the doctor to be present to answer their questions about changed appearances.

The hospital chaplain, if available, may be wanted to baptise the baby. He, or a senior member of the hospital staff, may be needed to accompany the parents to the hospital mortuary if the coroner's officer or police require identification of the body. The parents and any accompanying children need continued support until satisfactory transport is ready to take them home. The hospital chaplain may be able to comfort the casualty staff after a harrowing experience.

When telling the parents that the coroner will be informed, it is important to explain his function and helpful to give the parents the leaflet *Information for the Parents of a Child Who Has Died Suddenly and Unexpectedly in Infancy*, available from the Foundation (see below). This tries to answer the most usual questions and explains what the necropsy may show and the coroner's role. It describes normal grief reactions and where to seek further help. The leaflet is often referred to later when the parents are alone, and it may be passed to baffled relatives and friends to explain the baby's death. Before the parents leave the casualty department the staff should telephone both the family doctor and the paediatrician and then explain to the parents the arrangements for continuing support.

### CORONER'S INVESTIGATION AND REGISTERED CAUSE OF DEATH

Although efforts are now made in most parts of Britain to handle the coroner's investigation sensitively, all those concerned need constantly to remember how vulnerable the parents are to the slightest implication of blame. Since identification of the body before necropsy is not routinely required by all coroners, many of whom accept labelling of the body when death is confirmed, could not this distressing procedure be reserved for times when it is really necessary? Formal identification of the body is obligatory only if an inquest is to be held. Some circumstances justify an inquest but a few coroners still hold inquests routinely, and this can cause unnecessary anguish. The co-operation of some coroners in notifying the health authority of unexpected

infant deaths is welcomed since it enables community health staff to obtain without delay a history of events and to identify families not in contact with the Health Service.

We urge that coroners and pathologists should arrange for necropsies on unexpected infant deaths to be performed in hospitals with facilities for microscopical examination and if possible a special interest in paediatric pathology. We also urge that in the absence of an adequate explanation for death, pathologists should avoid the use of misleading terms which may arouse fear and guilt as well as masking the true incidence of these causes of death. To ascribe death to inhalation of vomit or asphyxia, when these are considered terminal events and not the underlying cause, can induce fear in the parents that they might have prevented the death. The terms broncho-pneumonia, bronchiolitis, or tracheobronchitis alone, when used fictionally or to describe evidence of minor respiratory infection not normally fatal, while kindly intended and spuriously satisfying some parents' search for a cause of death, can lead other parents to reproach themselves or their doctor for failing to notice their child's fatal condition. The registrable term "sudden death in infancy syndrome" (cot death) is in our experience acceptable to parents, signifying that the pathologist could not find a complete explanation for death, but that no blame can be attributed to the parents. The term may be used on its own, or coupled with other terms if the pathologist wishes to mention pathological findings not normally fatal. Most parents await the initial results of the necropsy very anxiously. Occasionally they are not automatically told, and their efforts to find out may cause additional stress and anger. Parents seem to have been helped best when their general practitioner or paediatrician has taken the trouble to be the informant and has given an explanation at this time, and later if microscopical evidence clarifies the cause of death.

Doctors and nurses should be familiar with the mechanics of funeral arrangements. Parents sometimes turn to them for advice, not knowing where to contact an undertaker. Often they also rely on help from the coroner's officer. We suggest that the size of the death grant (£9 for a baby) should be reviewed, since in most cases this covers only a fraction of funeral costs.

### THE GENERAL PRACTITIONER AND HEALTH VISITOR

In many cases the general practitioner and health visitor can provide all the immediate and continuing support that is needed. Cot death may, however, strain the relationship between the family and the primary-care team, and in our experience this is more likely to end in breakdown when the family doctor has been unable to visit straight away to share the family's grief. Sometimes this is because he does not know about the death for several days or weeks. Early contact is essential if the family's confidence in the practice is to be maintained or restored. Even if the doctor has little experience of cot death he will be able to explain its reality and inevitability in the light of present medical knowledge. It may be easier for him to leave counselling and fuller explanation of necropsy findings to a paediatrician, but this will depend on his own experience and the state of his relationship with the family.

Grief cannot be cured by drugs, and may even become complicated or prolonged if suppressed by anxiolytics and antidepressants. This is widely known, but needs restating because the pressures on the doctor to prescribe may be great. It often seems helpful to offer the parents a sedative that they can take at bedtime for a few nights if they cannot sleep. In our experience the period of intense grief may last for several months and may recur through the first year, especially on the anniversaries of the baby's birth and death. Many parents are frightened by the intensity of their reaction and need reassurance about normal responses to grief. Suppression of lactation is an increasingly frequent difficulty with which the mother may need help. The family may wish to discuss practical problems such as housing and the care of other children, especially if they are geographically or socially isolated.

In arranging continued support the doctor will need the health visitor's help. She may be welcomed as someone experienced in infant care who had followed the baby's progress, with whom the parents can discuss at length the events leading up to the tragedy. She will need to understand the psychological impact of bereavement and to know enough about cot death to be an informed but compassionate listener. She may be able to refer parents to the Foundation or to other similarly bereaved parents. The health visitor's participation is needed to maintain the family's confidence in her services, which may need to be specially strong for future pregnancies. Throughout their efforts to help the family the general practitioner and the health

visitor will want to be in touch with the minister of religion if he is also supporting the bereaved.

#### THE PAEDIATRICIAN

The paediatrician is potentially in a strong position to help families bereaved by cot death through his experience with child care and with children dying in hospital, his contact with the pathologist, and because he has usually not been directly concerned with the baby, and so can offer more-objective support and a less strained relationship than the primary-care team. He also has more experience in genetic counselling, and can provide extra surveillance if the parents need it for other children in the family and for future pregnancies. Furthermore, a paediatrician with a special interest in cot deaths can keep abreast with the changing state of knowledge about the condition, providing a source of help for both parents and primary-care teams. He can also help to organise appropriate management of families whose babies are brought dead to hospital, both in the casualty department and the mortuary.

We have found on Tyneside that these theoretical advantages are borne out in practice. Before we began paediatric home visits we wondered whether one more person offering help to the bereaved family would be too many. We now have no doubt that more rather than less support of this kind is needed. Once we have explained to the parents that the visit has been encouraged by the family doctor we find that the paediatrician can often help the family to regain confidence in their primary-care team, and that family doctors and health visitors therefore welcome such visits. In other areas the same function has been successfully carried out by a specially interested doctor from the community health services or a specially selected health visitor.

All parents are anxious to discuss in detail their baby's health, development, care, and any terminal symptoms. Structured questionnaires have been used for this purpose in many areas, and parents welcome sympathetic but detailed interest shown in their child, and are keen to give information to help medical research which eventually may prevent such tragedies. They sometimes have misconceptions about the cause of death that can be dispelled by explaining the necropsy findings. In most cases feelings of guilt or anger may be mitigated by emphasising that after a thorough study of history and necropsy findings nothing in the parents' management that might have been responsible for the death can be identified. Even when the necropsy reveals an explanation for death the parents will need advice and support. When the reason for death is still obscure it is helpful to explain that cot death is a well-defined syndrome, that 2000 families experience such a tragedy each year in all parts of Britain, and that research is likely one day to clarify the cause or causes. Parents also need to be reassured that the necropsy showed nothing to suggest that existing or future children will be at increased risk.

We therefore strongly recommend that at least one paediatrician in each area makes cot death one of his special concerns. He must make a clear arrangement with casualty departments and pathologists that he is to be notified as soon as an unexpected death of a child occurs.

He can then telephone the family doctor to discuss the history, communicate the early necropsy findings, and offer to visit the family at home. We have found that the best time for this visit is soon after the funeral, about five to seven days after death. If the primary care team has given immediate support, the paediatrician's help may still be wanted a month or two later. One or more follow-up contacts with the family may be needed, and the door may be left open for the family to call for further help, especially with a future pregnancy and baby. Bereavement may revive memories of previous loss or emotional crises that were inadequately resolved, and psychotherapy or psychiatric help may be required.

#### Conclusion: the Foundation for the Study of Infant Deaths

"I desperately needed to talk to someone who had been through the same experience and understood how I felt." After any death the bereaved will want the comfort and practical help of their close family and friends, and many benefit from pastoral care. When the reason for death is obscure they need professional medical explanation and reassurance. Equally valuable is the emotional strength that many gain from sharing their feelings with someone who has come through a similar tragedy. As infant mortality declines such people are less easy to find.

Since its launching in 1971 as a registered charity the Foundation for the Study of Infant Deaths has raised funds to sponsor 25 research projects into the mechanisms of cot death and the possibilities for prevention. It has given support to over 1000 bereaved families by letter or telephone and to many more by its leaflets *Information for the Parents of a Child Who Has Died Suddenly and Unexpectedly in Infancy* and *Your Next Child*. The Foundation offers to put parents in touch with other suitable parents in their area or with one of 25 parent groups associated with the Foundation, who offer a befriending service. Many mothers continue to support each other when caring for subsequent babies. Nevertheless, supporting bereaved families by means of leaflets and self-help groups cannot entirely replace the help that can easily be given by a specially interested paediatrician who works closely with the primary-care team.

#### References

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*Has a vaccine against herpes zoster been produced? It would appear to be increasingly necessary to prevent much suffering among old people.*

A live attenuated vaccine against varicella-zoster has been produced in Japan.<sup>1</sup> Preliminary vaccine trials, so far restricted to Japan, show that this vaccine induces an immune response, does not produce reactions, and protects even if given within three days of exposure to varicella-zoster virus. Furthermore, it protects immunocompromised children.<sup>2</sup> Nevertheless, there can be no reason to suppose that after vaccination attenuated strains will not also become latent in posterior root ganglia, only to be reactivated and cause shingles in the future. Indeed, since the attenuated vaccine may induce a less durable immune response than naturally acquired disease, shingles may occur at an earlier age and more often than among those who have experienced naturally acquired varicella.

Shingles occurs more often in apparently healthy older people because during aging cell-mediated immune responses may diminish as a result of there being a lower proportion of circulating T cells. Theoretically both humoral and cell-mediated immune responses may be boosted by giving older persons an attenuated varicella vaccine. Carefully conducted trials, however, would have to be made to determine whether the vaccination of people with residual amounts of

varicella serum antibody would indeed enhance immune responses. A large group of vaccinees would then have to be followed up over a prolonged period to determine whether they experienced a significantly decreased incidence of shingles compared with an unvaccinated control group. There is no prospect of conducting trials with this vaccine in the UK in the foreseeable future.

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*A patient is said to be eating food to about 1000 kcal (4.18 MJ)/day yet she has lost only 0.5 kg in a month. What might be the reason for this?*

Although patients on weight-reducing diets must always be suspected of eating more than their dietary allowance, failure to lose weight may be partly due to low utilisation of calories. The usual reasons for this are (a) massive subcutaneous adiposity diminishing heat loss, (b) low exercise levels, and (c) maintenance of a hot environment. An additional point is that weight reduction is never steady (largely because of alteration in water loss) and plateaux occur.