COT DEATH

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Every fourth morning in Melbourne a mother goes to pick up her baby from its cot only to find that her baby is dead. This statement, which ignores the seasonal incidence of cot death, does indicate however both the frequency and the tragic drama of cot death.

The first recorded case of probable cot death in Australia was recorded in 1810[1]. I say probable as we have no means of knowing whether it would really fit the currently accepted definition of cot death which is "the sudden and unexpected death of an infant in whom a thorough post mortem examination does not disclose an adequate cause of death". Some infants do die suddenly and unexpectedly from diseases such as myocarditis, meningitis, and gastro-enteritis. But these conditions are readily recognised by the pathologist who examines the baby after death. It is when he is unable to find evidence of any such lethal disease after a thorough examination that he records his verdict as cot death, or as it is usually labelled these days, Sudden Infant Death Syndrome or SIDS.

SIDS has almost certainly been with us for centuries. It seems probable that the death of the baby which caused Solomon's wisdom to be perpetuated through the ages was due to SIDS (1 Kings, Chapter 3, verse 19). However it is only in relatively recent years that the gravity of the SIDS problem has been recognised both by the medical profession and the public. In developed countries it is now the most common cause of death between the ages of one month and one year. There are several reasons why SIDS has been recognised as a problem only in relatively recent times. Until the 1950s many infants died from infection e.g. pneumonia, gastro-enteritis, whooping cough and from conditions such as Rhesus imcompatability. The last 40 years have seen these conditions virtually disappear as a cause of infant death. Thus the infant mortality rate in Victoria in 1940 was 34/1000 live births. It is now 10.5/1000 live births. However, we have every reason to believe that a 2/1000 incidence of SIDS has been constant throughout this period. The other reason for the fall in the infant mortality rate has been improved medical care resulting in the deaths of fewer premature babies and babes with congenital malformations. These have always been responsible for many infant deaths but in recent years the advent of sophisticated and extremely costly intensive care units for premature babies and the development of successful surgical techniques to deal with some malformations has steadily decreased these conditions as a cause of infant deaths. So prior to the 1950s in Australia, SIDS was hidden in the main mass of infant deaths.

The incidence of SIDS has also been largely hidden from the medical profession. Until very recently it has not been mentioned in the undergraduate medical course. Individual general practitioners are involved relatively infrequently with such a tragedy, perhaps only once or twice in ten years. Paediatricians, most of whom have worked in hospitals, were aware of these babies only as they passed through the revolving door of the hospital Casualty Department on their way to the City Morgue. At the City Morgue forensic pathologists, not trained specifically in diseases of infancy, tended to record vague diagnoses such as suffocation, viral pneumonitis or bronchopneumonia in these infants, being unable to believe that no recognisable cause of death was present. To be sure some Coroners' Pathologists e.g. Dr. Keith Bowden in Melbourne and Drs. O'Reilly and Tonge in Brisbane did become interested in cot deaths in the late 1950s and early 60s but it was probably not until the 1970s that the incidence and frequency of this condition were really recognised in Australia.

The realisation by several paediatric pathologists in USA and UK that these babies who died suddenly and unexpectedly did so without an obvious cause of death being detected at necropsy led to several international conferences. At these conferences, the first of which was held in 1963, the prevalence of SIDS as a cause of infant mortality in many countries was established and the currently accepted definition was proposed. Prior to these conferences suffocation, inhalation of vomitus and a variety of similar diagnoses, which incriminated the parents through circumstantial evidence, appeared on the death certificates of these infants. With the acceptance of SIDS as an entity and a natural cause of infant deaths, parents came to realise that they should not feel guilty and in USA and UK self-help groups were founded. In the USA these parent bodies put pressure on the Federal Government for research funding with considerable success.

The problem has now been recognised and in many countries throughout the world research is occurring. It is not proposed to deal with the current state of research in this article but only to say that unfortunately it is still true that at this moment SIDS can neither be predicted nor can it be prevented and in all developed countries between one and three infants in every 1000 born alive will die before their first birthday from SIDS.

Tragedy does not end with the death and burial of the baby. A young family whose life has been suddenly shattered is left behind. Inevitably intermingled with the sense of acute loss is an overwhelming sense of guilt. This guilt feeling is explicable, for the infant, usually between two and four months of age, was totally dependent on his parents for everything — and now he had died. What have they done that has been wrong? What have they neglected to do? And when they, the parents, ask "Why did our baby die?" — no one can tell them.

If one defines social pathology as abnormal functioning of groups within our society then one has to agree that considerable social pathology is associated with SIDS. No matter how one defines "family", the welfare of society is related to the welfare of the family. Whilst families will obviously differ in their reactions to a cot death, certain reactions are reported as occurring in significant numbers of families both in the overseas and the Australian literature. Some reactions to the loss of the baby are rapid whilst

https://doi.org/10.1017/S1035077200902864 Published online by Cambridge University Press

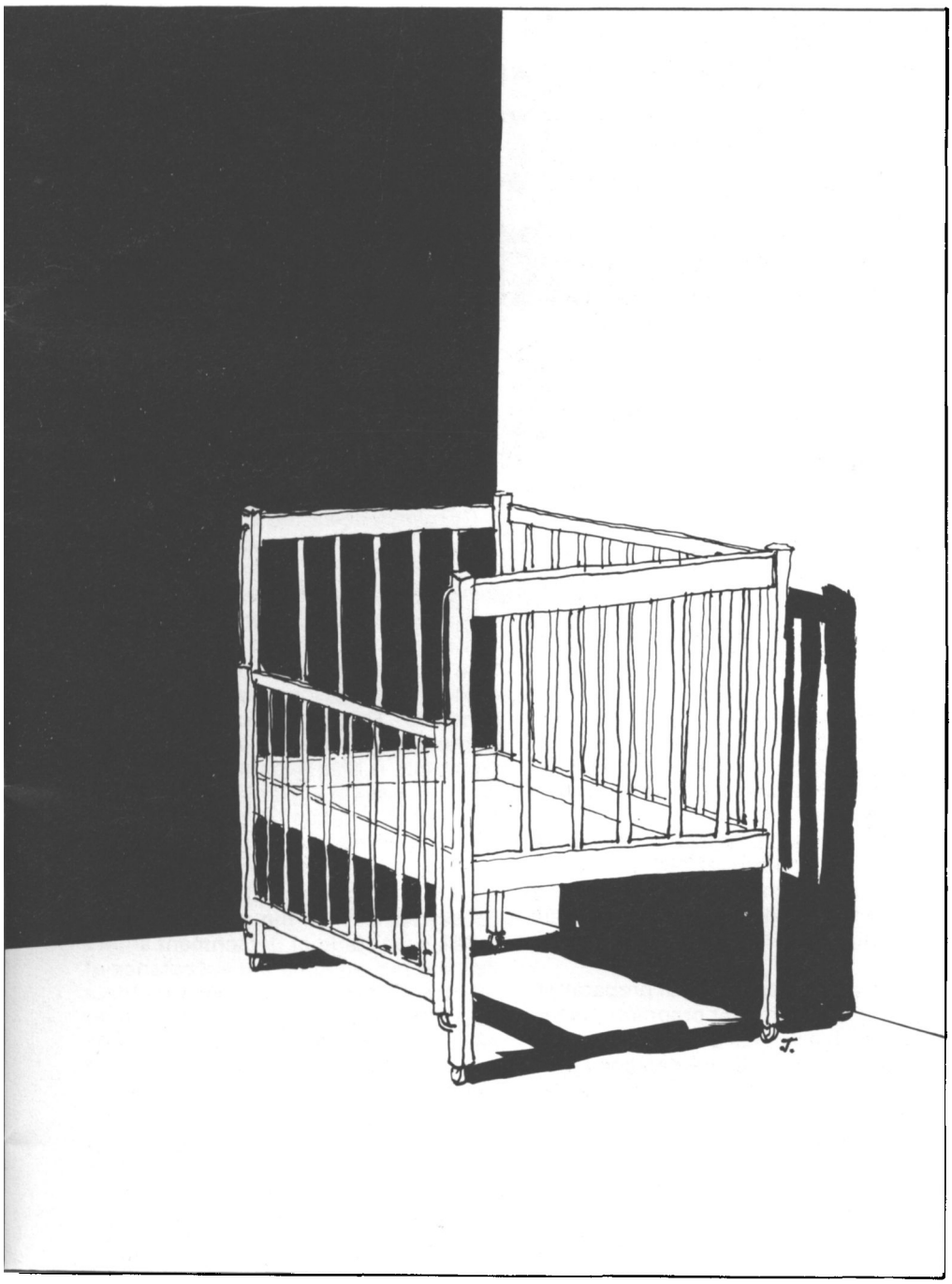
others persist for many years. Many parents will not enter the room in which the baby died and as a result of this one third of families in Melbourne change their residence quite quickly. An identical number followed the same course in a survey undertaken in Ontario, Canada.[2] Many fathers on their return to work have been unable to concentrate on their job and in Melbourne we have seen a few lose their positions. Of even more serious consequence is the marital disharmony which may occur. One parent blames the other for the babe's death, either by spoken or unspoken words. One parent, usually the mother, wishes to talk about the babe whilst the other doesn't — just wishes to forget it. Or one imagines the other to be blaming them, and an inability or unwillingness to communicate reinforces that idea. In the Ontario study actual marital breakdown occurred in 7.2% of families, most of them relating this directly to their experience with SIDS. In Melbourne we have seen this happen but to a somewhat less degree (less than 3%). Unfortunately, as mentioned, many of these families move residence and it is difficult or even impossible to follow them up to obtain a true estimate of what happens to them after the loss of their baby. As might be expected the mother almost always feels the loss acutely and an occasional mother has attempted to take her own life, and tragically, in recent years at least one Victorian mother has been successful in her attempt. Most mothers lose confidence in their ability to care for a baby and this may be reflected in their attitude to the birth of a subsequent infant. Infants have had to be admitted for residential care, almost certainly the only reason being that the mother's previous babe died from SIDS. Another constant feature which has been observed is that many mothers are depressed and anxious for years. This depression may be periodic rather than constant but can be quite severe and necessitate professional help. Whilst the usual sequential pattern of grieving, namely shock, bewilderment, anger, sadness and finally acceptance is seen in most families, many parents never quite reach the stage of accepting the baby's death, possibly due to our inability to answer them adequately when they ask, "Why did my baby die?". This is probably the reason why many SIDS parents appear to react differently to parents who have lost a baby with congenital heart disease, leukaemia or even accidental death where they either know the reason for that death and may have had some time to prepare for it. One other unfortunate sequel to SIDS, which we have seen infrequently, is the occurrence of child abuse. It is not uncommon for the dead baby to have had a pre-school aged sibling. (SIDS infants are most frequently the second born infant.) The pre-school infant is aware not only of the baby's disappearance but of the unusual behaviour of his parents. The young child now thoroughly worried about his own future, clings to his parents and asks, "Where is our baby?" or even, "Why did you kill our baby?". This must try the patience of any mother. To date in our Melbourne experience I am only aware of one case of severe child abuse following the occurrence of cot death.

Where an extended family is present the inability of grandparents to comprehend the true meaning of cot death has led to recriminations between mother and mother-in-law and further unhappiness for the bereaved mother.

Thus cot death can be a shattering blow to the young family both psychologically, and also of course financially as they face a totally unexpected expense of $500 or more for a baby's funeral.

Now as I have mentioned we can neither predict nor prevent these infant deaths at present. Can we eliminate or ameliorate the subsequent social pathology? Help for bereaved family may come from the extended family and friends, from professionals and from other bereaved parents. Undoubtedly, support from surrounding family members who understand the nature of the infant death is probably the best support. Understanding friends are likewise invaluable. Professional help has been somewhat slow in arriving on the cot death scene. In 1968 O'Reilly and Whiley[3] in Brisbane published an article in which they stated that inspired by a SIDS mother, they commenced sending a social worker to the home immediately they learned of a SIDS death. The social worker was able to inform the parents of the nature of that death, answer questions and assist with funeral arrangements. As far as the author is aware this was the first occasion in Australia where routine counselling following a cot death was instituted. A similar system has been operating in Melbourne since 1974 where the pathologist who has examined the dead babe and made the diagnosis writes a letter to the parents which is taken to them immediately by a nurse or social worker. In this letter parents are informed of the nature of their babe's death and the fact they should not feel guilty. The parents are also invited to talk with the pathologist at a later date. This counselling for bereaved parents by professionals has been undertaken in most Australian cities for some years now. However this has usually consisted of one or two contacts only and as mentioned above the grief and depression following SIDS may be long-lasting and have grave effects on the entire family. Whilst professional help from psychiatrists and psychologists is occasionally necessary, much help for long term support has been provided by other parents who have "recovered" from the loss of their babe and through their own experiences can help others similarly afflicted. This has been an important feature of the work of the Foundations for Sudden Infant Death which have recently sprung up in the United States, Canada, United Kingdom and also more recently in the various States of Australia. The work of these various Foundations is similar and the functions are best exemplified by the history of the Victorian Sudden Infant Death Research Foundation (S.I.D.R.F.), an organisation with which the author is most familiar. This Foundation was started in Victoria in 1977 by two parents who had recently lost an infant. The aims of the Foundation are threefold. First to raise money for research into SIDS, secondly, education of the public and others concerning the nature of SIDS and thirdly, counselling for bereaved parents. In relation to raising money for research the S.I.D.R.F. has been extremely successful. Money has been raised by this body and its various support groups for several research projects in Victoria and also in N.S.W. It was largely through the instigation of the S.I.D.R.F. that Apex clubs throughout Australia adopted "SIDS — Pin down the Cause" as their national service scheme for 1980. As a result, Apex Foundation will be supporting many research projects into SIDS over the next few years.

Education, both of the public and also health workers has been undertaken. Education of the former is necessary so that they realise that SIDS is a natural cause of death which cannot be predicted or prevented and is certainly not due to parental incompetence. Education of health and allied professionals is necessary as these people will meet SIDS parents in their duties, e.g. the ambulance men who are called to the house where the baby has



died; the police who must also visit the home and question the parents; the undertakers and even the general practitioner who, until recently, had no mention of SIDS in his medical course. Also nurses, both in hospital and in the community, e.g. maternal and child health nurses, will be in occasional contact with SIDS parents as will some social workers, child care workers etc. Speakers from the SIDRF have given lectures during training courses for all of these professions. As a result one has some confidence that the suddenly bereaved parents will be handled with much more understanding than previously. Particularly in the hours and days immediately following the babe's death, delicate and understanding handling is necessary.

The Foundation has also formed many support groups in the metropolitan area and also throughout Victoria. These support groups consist largely of parents who have lost a baby suddenly and unexpectedly have raised money for research into SIDS. They also provide a valuable body of understanding people who can give a lot of moral support and comfort to recently bereaved parents, support which one hopes will prevent or minimise some of the after effects of a cot death.

The need for such help has been recognised by the Federal Government whose National Health & Medical Research Council has recommended to the Health Commissions in the various States that provision should be made for parent counselling following a cot death. The same Council has also made some comparatively small financial grants towards research projects into SIDS. Apart from this no Government in Australia seems to have given much recognition to the SIDS problem. This is a little surprising to this author when he sees a member of our community of Melbourne dying suddenly, unexpectedly and inexplicably every fourth day with an ever increasing amount of family and social pathology following that death. However, as one parent has stated, "These are not important company directors who are dying, they are babies known only to, and important to, their families".

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https://doi.org/10.1017/S1035077200902864 Published online by Cambridge University Press