

SUDDEN INFANT DEATH SYNDROME:

HOW TO COPE

MYSTERY deaths worry us all, but none more for parents than cot death. Parents feel guilty when cot death happens to one of theirs. Some of this guilt is historical in origin, because the English legal tradition required doctors and coroners to record such deaths as 'suffocation', and suffocation implied neglect. We now know this was wrong.

Dr Mike Dwyer (Director Medical Services) reports on how police officers or families should handle a sudden infant death.*

One of the difficult situations for a police officer to handle is that of being called to a cot death. The difficulty is mostly due to the feeling of inadequacy we get when we simply don't know what to say.

The following notes provide a basis of fact from which we can at least say something useful, even though we cannot lessen the parents' sense of loss.

It is of help to a police officer to keep in mind the fact that he or she is present as a professional. In the eyes of the bereaved parents, the police officer is the one sane focus in a world suddenly gone mad. The officer needs to concentrate on his or her positive role in doing what is useful and necessary, e.g. taking a logical history, sending for medical support, suggesting the support of a close relative or friend, organising the removal of the infant's body, and arranging follow-up contact to give the results of pathology investigations, and so on. If these tasks are done sensitively and well, yet in an efficient way, the whole AFP benefits, and is seen as a community resource rather than as simply law enforcers.

What is Cot Death?

About one in every five or six hundred normally formed infants will die, unexpectedly, between the ages of six weeks and one year. Those babies are usually simply put down to sleep, and found to be dead in the morning. Sometimes the baby is found face down on a pillow, other times with the bedclothes over it. Sometimes there is evidence of vomiting, often not. Often there has been a history of a mild flu or tummy upset, but never any symptoms serious enough to make a parent, or indeed any doctor, feel that a child was in danger of death.

What causes Cot Death?

There have been three main areas of investigation of cot death — infection, suffocation, and allergy reaction. Suffocation has been regarded as more and



more unlikely in recent years, especially with the onset of 'breathe-through' bedding materials. Infections, and massive allergy reactions (from bacteria or foreign proteins) are regarded as much more likely. One interesting fact is that the condition is less common in breast fed babies. Other factors considered include cortisone insufficiency, parathyroid gland deficiency, spasm of the larynx, irregular heart action (accompanied by sudden cardiac arrest), abnormality of breathing due to immaturity of the respiratory centre in the brain, dust mite allergy, and raised carbon dioxide levels in the bloodstream.

This condition which is sometimes called 'cot death', 'crib death', or 'sudden infant death syndrome' is a well recognised condition, or possibly a group of conditions. The fatal symptoms come on so rapidly that clinical doctors have not been able to study it even though it sometimes occurs to babies while they are in hospital.

Most of our knowledge of the condition comes from the work of pathologists who examine these babies after death. They do not usually find things which are normally associated with what we call 'diseases'. What we call 'disease' (for example measles or chicken pox), is really just a collection of reactions of the body to a particular infection.

The infection was there before these symptoms appeared, and if a child dies before symptoms appear, he or she has not developed the recognisable signs of the disease.

So, we do not know why these children die, we cannot anticipate their deaths and we cannot advise police officers, or family doctors or anybody what they should or should not have done, or indeed, if there was anything they could have done. New ideas are put forward almost weekly, many with great publicity and enthusiasm, but none of the ideas so far put forward has been fully sustained.

MOST COMMONLY ASKED QUESTIONS

Was the baby's death in any way our fault?

If a baby or child is killed in a motor accident or is drowned, the reason for death is obvious and we, as parents, can accept this. If a child is born grossly deformed and obviously suffering, we

can also understand why a child like this dies, but when a normal child who has lived just long enough to make its parents conscious of it as an individual and their love to develop to the full, suddenly dies, this type of death is even more distressing.

Baby's death is a mystery and a terrible shock and, since he appeared to be absolutely normal, parents may feel that the death was in some way their fault. This is the perfectly natural reaction of any normal mother and father. They naturally feel that there was something that they should have done which could have prevented the baby's death.

You will realise from what you have already read that this feeling is quite unfounded, though natural. Those of us who see many of these babies feel that, if anything, the babies who die in this way have often been better cared for than many children who survive.

Did the baby suffocate?

Your finding of the baby perhaps face down in its cot or with bedclothes over it, may make you think that death was due to suffocation. Many babies normally sleep face down, or get blankets over their faces, with no harmful effects. While it is possible for a child to suffocate accidentally, this is, we are quite certain, not 'the cause of death' in children who have died in this particular way.

Was the baby's death a painful one and did he suffer?

We now have a large number of descriptions of how babies die in this way. These babies do not cry out as if in pain. Sometimes they simply go pale and die in their sleep, but it appears that whatever way they die, they first go unconscious. There is no indication that any of these babies go through any period of prolonged pain or distress.

What about our other children?

You, or your other children, may have had a minor infection at the time that the baby died, but it is not always the case. We have no evidence that a particular bacterium or germ causes the deaths of babies such as yours, nor it is in any way likely that you or your family carry a 'killing' germ. So, neither you nor your children are dangerous to other children in any way.

Is this condition likely to affect other children we have?

We have no evidence to suggest that it runs in families or is hereditary, and thus there is no reason at all why your next child should die in this way. Having a baby die like this, does not indicate any 'weakness' in you or your husband or

family. It does not in any way indicate that you should not have further children.

How soon should the parents have another child?

A baby dying in this way produces a severe psychological reaction in many mothers. The first reaction of parents who want further children is to think that they must first 'get over' the death of this baby before they have another.

Experience teaches us that, although a child dying in this way produces a very great immediate psychological disturbance, this usually disappears completely when further children are born. There is no point in delaying the start of another baby if you desire one. Delay is of no advantage to anyone.

Should we take particular care of our next child or the other children?

There is no need for you to take any extra care of your next child. As far as we know at present, there is nothing that you should or should not have done which would influence whether a baby dies in this unexpected way or not.

Coddling your child or keeping it away from apparent infection and from other children would, as far as we know, neither have affected the death of your child, nor help in any way your other children.

If you are worried, and it is quite natural for you to be so, do not hesitate to take your children to your family doctor. He will completely understand your fears and problems, and will doubtless give you reassurance and support.

Why did the coroner and police investigate baby's death?

The coroner is a sort of guardian for the general public, and he has to look into all unexpected deaths. Only a very small proportion of these deaths have anything criminal about them. The fact that he has looked into the circumstances of your baby's death and decided that there was no crime or negligence, is a safeguard to you, your family, and your doctor (who may feel that he had overlooked something) from all malicious tongues and 'busybodies'.

Is there anything we can do to prevent this condition or to help other children and other parents?

At present, the pathologist's investigation of your case has probably provided some extra knowledge. One way in which you can help is by giving any information to any authorised person who may approach you about your children from a research point of view.

*Much of the information in this article has been extracted from briefing notes compiled by the Capital Territory Health Authority.