

for sids families:  
some answers  
to your questions

A booklet for parents about  
Sudden Infant Death Syndrome (SIDS)

**sids**<sup>and</sup> kids<sup>®</sup>



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# What is SIDS?

Sudden Infant Death Syndrome (SIDS), previously known as ‘Cot Death’, was originally defined in 1969. It is the name given to the sudden death of an infant or child which is unexpected by history and in which a thorough post mortem examination fails to demonstrate an adequate cause of death.

This is another way of saying it is not known why these babies die. In Australia SIDS accounts for the deaths of more babies between the ages of one month and one year than any known cause. This is because the treatment and prevention of other potentially fatal childhood diseases have become more successful.

The average incidence of SIDS in Australia, as in many other western countries, is now about one in two thousand live births – around 120 babies each year. This is a major improvement since 1990 when one in five hundred babies died of SIDS. Recent research has shown that the risk of SIDS has been at least halved in many countries by changing some child care practices. For example: it is now known that tummy sleeping is a risk factor, although it is not possible to identify which babies are at risk, and SIDS still occurs even when all the known risk factors have been reduced.

Although SIDS is most common between the ages of two and four months, it can happen to younger and older infants. SIDS occurs in both breast-fed and bottle-fed babies, and of those who die, approximately 60 per cent are boys and 40 per cent are girls. Infants have died from SIDS at all times of the day and night, in cots, prams, car seats, bassinets, even in parents’ arms.

# What causes SIDS?

By definition, the causes of SIDS are not known. Attempts to explain the sudden and unexpected death of an infant adequately have been difficult since earliest times. Initially, if a baby died suddenly and unexpectedly in a bed shared with adults, it was thought to be due to an adult rolling on to the infant during sleep. This was called ‘over-laying’.

Later, it was suggested that babies may have choked on something or that death was caused by parental neglect. It is clear now that in most cases, none of these explanations were correct – that they were, in all probability, the victims of what is now known as SIDS.

No consistent warning signs occur that might alert us to the risk of SIDS. Sometimes the infant was not feeding quite so well on the day he or she died, or there may have been symptoms of a slight cold or tummy upset. It seems that while minor infections of some sort or another are almost always found in SIDS babies, on careful post-mortem examination these infections are mild and seem in themselves to be an inadequate cause of sudden death. While we do not yet know the causes and mechanism of death, we do know that SIDS is not contagious.

If the baby was found face down or with bedclothes over the face, it might be thought that smothering was the cause of death. Sometimes babies are covered by bedclothes, but others are found uncovered and free of bedclothes entirely. While it is possible for an infant to smother accidentally, this is rare. Not uncommonly the child is lying undisturbed, as when last put to bed, without any possible interference to breathing.

In some cases blood-tinged froth is found around the mouth or on the bedding. This fluid comes from the lungs, which are always very congested in

a child dying of SIDS. Sometimes vomiting has occurred, but when the post-mortem examination is carried out, there is little or no inhaled food in the windpipe. These are normal occurrences during or soon after death, and do not cause the death.

Most SIDS deaths appear to happen quietly in sleep. Many of the infants are found in exactly the same position as they were when put to bed. Others may have moved but there is no indication that they go through any prolonged period of pain or distress. Facial or body discolouration may occur but this is caused by the position after death and will normally fade in a day or so.

## Why do the police call?

When **anyone** dies suddenly or unexpectedly, the law requires that the police attend and report to a coroner. The coroner has to establish the cause of death and to do this he or she must find out the circumstances surrounding death so as to distinguish between natural and unnatural deaths. It is the coroner's duty to investigate all sudden deaths to be sure that death is due to natural causes, as is the case with SIDS.

Understandably, these things are very distressing at the time. However, the fact that a post mortem examination has been done and the coroner has looked into each death is a safeguard against any possible doubt or criticism of the parents, the family, or whoever was looking after the child at the time of death.

# Was the death anyone's fault?

If someone dies from a known disease, the reason is obvious and publicly recognised. When an apparently healthy infant or child dies, with no obvious explanation, it creates special problems because the death cannot be understood or explained.

The fact that a baby is completely dependent upon those who care for him or her, means that parents, or whoever was responsible at the time of death, frequently feel guilty. They may try and think of something they did, or did not do, that caused the baby to die. This searching for a reason is normal, but there is as yet no way to recognise any signs that could indicate that a child is likely to die of SIDS.

When someone other than the parents, such as a grandparent, baby sitter, or Day Care Centre, is caring for the child, parents may blame them, or even themselves for leaving the infant in someone else's care. Sometimes the family doctor or child health nurse, who may have pronounced the baby healthy shortly before, is blamed. Nearly every caregiver suffers feelings of guilt, which are very real and painful. Although this is a natural reaction, any such guilt is unfounded.

*It is important to understand that no blame can or should be attached to anyone and to remember that, at this time, SIDS cannot be predicted and that the causes of SIDS are not yet known.*



# About grief

Your immediate reactions to your baby's death may be shock, denial, disbelief, or a sense of numbness or unreality. These feelings are completely normal and may cushion the impact of the loss until you are able to face the devastating reality of your baby's death.

Grief is not simply sadness, nor is it expressed only by crying. You, and other family members, will feel many strong emotions in the following days, weeks and months. It is not unusual to feel some of these emotions from time to time, for years to come.

Grief is not something which can be measured. It is very unlikely that any one person will feel exactly the same range of emotional responses as anybody else. Mothers and fathers may not experience the same feelings at the same time. This can make sharing one's feelings especially hard, and lead to a sense of great isolation, causing even more difficulties for each grieving person.

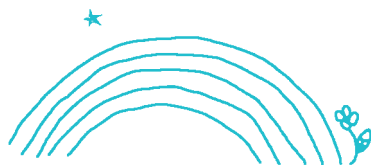
It is most important to recognise that grief must be allowed to be expressed. It is also important for the grieving person, and those around her or him, to understand that expressing feelings, even those that seem strange or shocking, is normal and healthy behaviour.

Some of the more usual emotions felt include guilt, anger, fear, blame and despair. Prolonged feelings of guilt can be destructive. Because the causes of SIDS are unknown, you may seek your own explanations for the tragedy and may blame yourself. (It is important that everyone is reassured that SIDS is nobody's fault.)

Some people will need to talk, to go over and over the events; others may withdraw into themselves and seem unreachable. Fathers, in particular, may find that in their role their grief may not be acknowledged to the same extent as mothers. Loss of concentration, sleeplessness, lack of appetite, even symptoms of physical illness can be experienced. It is common to find there are things or events that can trigger painful memories. Anniversaries, birthdays, family celebrations, a photo, a baby or child of the same age are some of them. It is important to know and realise that these are normal reactions, and that other grieving parents share this sensitivity.

Although grief is a normal process, and not an illness, often it is helpful for those who are grieving to share what they are feeling with someone outside the family such as a counsellor or another SIDS parent from your SIDS and Kids organisation, doctors, social workers, counsellors, nurses or religious advisers. Many parents and grandparents find it comforting and helpful to talk with someone who has shared a similar experience. Talking to another parent or grandparent can often diminish the sense of isolation.

If you are a single parent you may face extra difficulties after the death of your baby. If you have no regular partner with whom to share your grief, you might experience an overwhelming sense of isolation, loneliness and despair. Again, it can be helpful to talk to someone about your feelings.



# What about the other children?

Children are always affected by a death in the family. However, because they cannot understand or talk about death in the same way as an adult, they may sometimes appear to deny it or seem unconcerned. They may misbehave, have nightmares, revert to bedwetting or other habits, which they have previously outgrown. They may become ‘clinging’, withdrawn or even laugh without cause.

The youngest ones cannot tell of their fears, and may not understand explanations easily. But whatever their age, it is important they be told the truth as simply as possible. If they are told that the baby “went to sleep”, or “went away/to hospital/to visit someone”, they can become frightened of going to sleep or going on trips. Straightforward, truthful explanations are best such as, “The baby died from something called SIDS. We do not know what causes it but it will not happen to you or to Mummy or Daddy”.

Children need constant reassurance of their parents’ love and affection. However, this can be extremely difficult for parents, especially in the days immediately following the death. Some parents may have difficulty providing such reassurance while their own grief is acute.

It is important to include children in the events surrounding their sister/brother’s death. For example, they can be asked if they would like to see the baby, go to the funeral, do a drawing or write a story.

Children need reassurance that neither they nor anyone else was responsible for the death and that they will not die in the same way. Later, as children grow and their understanding develops, they will have further questions and may want to talk about why the baby died.

All children benefit from being allowed to express their feelings. Older children may need encouragement to discuss their worries openly. School age children can benefit from being asked how they would like their school friends to be told. For example, children may want to tell their friends themselves, or they may prefer a teacher to do it for them. This allows them to be part of the decision making too. Some SIDS and Kids organisations have special creative activities and groups for children.

## Having another baby

It is very common to raise the issue of having another baby immediately. Some parents feel that it is the best thing for them to do, others feel they can't face the prospect. It can be a difficult decision to make, because while there is often a longing to fill the emptiness and loneliness, there can be anxiety and panic that the same thing may happen again.

In making the decision, you need to be aware that:

- There is a better than 99% chance that another baby will **not** die of SIDS. It is highly unlikely it will happen again.
- No baby can replace another. Each child is an individual with his or her own personality and characteristics.
- If the next baby is born close to the first anniversary of the baby's death or birthday, conflicting emotions such as celebration and sorrow may be confusing and difficult.

- The decision as to whether, or when, to have another baby should be made when you feel ready. This may be immediately or it may be later.

Before you decide to have another baby you might like to talk to someone. Your local SIDS and Kids organisation has information about having another baby, including a brochure, *“Another baby? The decision is yours”* and will also be happy to talk with you.

## Research

SIDS and Kids and its member organisations fundraise for many research programs throughout Australia, encouraging liaison and interchange between different research groups to find the causes of SIDS and to reduce the risk of SIDS.

# Sources of information and help

A range of books, newsletters, research and articles on grief, tapes, brochures, and videotapes, are available on loan from local SIDS and Kids organisations. Subjects covered include factual information about SIDS, the impact of SIDS on the family and the community, how to cope with children's reactions, having another baby, research and different support services (ambulance, police, clergy, doctors, nurses and others).

## Publications available from your local SIDS and Kids office

*Always your child.*

*Choices in arranging a child's funeral.*

*Grandparent to grandparent.*

*To family and friends: you can make a difference.*

*Things about Zac, my baby brother.*

*Another baby? The decision is yours.*



# Acknowledgements

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# SIDS and Kids Organisations

For more information, further reading materials or if you would like to talk to someone please contact the SIDS and Kids office in your area on 1300 308 307 or visit the SIDS and Kids website on [www.sidsandkids.org](http://www.sidsandkids.org)



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