

SUDDEN INFANT DEATH

The sudden and unexpected death of a baby is one of the most distressing events that can occur.

We are so sorry that your precious baby has died

- You will now have to make a number of important decisions. It is important to remember that it is **your** baby who has died, and that the arrangements should be as **you** want them. Whatever you wish to do is what is right for you. The best advice we can give you is to take your time, consider all the options and satisfy yourself that you are doing what you feel is right.

This page may help you with immediate decisions.

- Where will the baby stay before the funeral?
 - **In the hospital**, but make sure you are welcome to be with your baby as often and for as long as you want.
 - **In a funeral home or parlour**: Again, make sure you have open access and that a Moses basket or cot is available.
 - **At home**: This option may give you and your children the opportunity to say goodbye at your own pace. On a practical level, the room must be unheated. In summer, a cold fan is advisable. Your baby can be placed in a cot or Moses basket. Be careful of lighted candles. Ask the hospital/public health nurse/funeral director or clergyman to help at the time of coffining.

- **Clothes and mementos;**

Your baby can be dressed in clothes you choose, you can do this yourself or with help from hospital staff.

Mementos may be placed in the coffin e.g. flowers, family picture.

Ask for mementos. The hospital can provide a lock of hair, handprints and footprints.

Photographs can be taken of your baby after death, particularly if your baby is very young and you have no photographs. Do remember that your baby's appearance may change after death.

- **Funeral Arrangements**

If a family grave is already available, you may consider this a good option, as you may feel your baby will not be alone after the funeral. Do consider, however, how you may feel in later years, as you may not be able to be buried with your baby.

Financial issues will not be your priority now, but should be considered. For your child's funeral, you need to provide a coffin and a grave. The cost of a grave can vary enormously and can be especially high in cities. The Community Welfare

Officer will give a substantial grant towards this cost to medical cardholders.

In Dublin and some larger cities, part of each graveyard is specifically set aside for the burial of small children. These graves are marked, with three or four children in each. Many parents find it comforting to think of their child at rest in the company of other children. Check regulations at individual Angels' plots to see if they suit your needs.

A hearse is not necessary for a child's funeral. The coffin can be carried on the parents' knees in the back of the car.

- **Religious Services**

Your baby, no matter how young, is a very important individual and is entitled to whatever form of service you choose. There is no 'right' form of service – the wishes of the family should dictate what happens.

Having a service of some kind is helpful – it marks the baby's life as being as significant as an older person. It gives a focus to the day of burial. Ritual is a very important part of grieving. Make sure the clergyman/woman involved is made aware of the important details of your family life and your baby's life.

Some suggestions for the funeral service:

- Children need not be taken to rest overnight in a church,
- A service with appropriate child-centred music, readings and/or prayers you think are important,
- A service in your own home,
- A service in the hospital chapel,
- A service in a funeral parlour,
- Again, there is no right or wrong form of service: do whatever makes you feel comfortable.

- **Your other children**

You included your children when welcoming the baby into the family. It is now vital that they have a chance to say good-bye; in other words, it is important that they see their dead sister or brother. Allow them the opportunity to hold the baby if they so wish. Let them place mementos in the coffin, e.g. toys or other special mementos. Allow them to attend the funeral service and burial with you.

Research shows that children who are involved and supported at the time of a death are less likely to suffer long-term effects than children who are excluded.

Go home, discuss the above with your family and then make your decisions – decisions you are comfortable with.

PART 1

SUDDEN INFANT DEATH SYNDROME – SIDS ‘Cot Death’

SIDS is the medical term for what in Ireland is commonly called cot death. Throughout this booklet the term SIDS is used.

WHAT IS SUDDEN INFANT DEATH SYNDROME?

Sudden Infant Death Syndrome, or SIDS, which is commonly called Cot Death, is best explained by describing a typical example. A baby is put down to rest. Some time later the child is found dead. There has been no sound, no struggle. A post-mortem fails to show an adequate cause for the death. Sudden Infant Death Syndrome (SIDS) occurs all over the world. In 1999 35 babies died of SIDS in Ireland and in the year 2000 49 babies died of SIDS.

SIDS, (Cot Death) does not necessarily happen in cots. It may occur in a pram, bed, car seat or anywhere a baby is resting.

SIDS, at present, cannot be prevented by parents or doctors. As yet no one knows what causes SIDS. The babies appear healthy prior to death.

SIDS is not contagious. It does not threaten other family members or neighbours.

SIDS does not generally run in families. The risk of it occurring to a subsequent child is minimal.

SIDS is not new. It has been known since ancient times. The reason why it has come into prominence now is that advances in medical knowledge have eliminated so many of the other causes of infant deaths.

Even though you will hear and read many opposing claims and theories about SIDS, no one yet knows what causes it or how to prevent it. However, over the past thirty years, researchers have made significant advances in their understanding of SIDS and now recognise that it has no single cause. Research continues in Ireland and in other parts of the world to identify the causes and means of prevention.

THESE ARE SOME OF THE QUESTIONS MOST OFTEN ASKED ABOUT SIDS:

WHAT CAUSES SIDS (Cot Death)?

The causes of SIDS are not known. Recent guidelines, based on scientific research, while appearing to reduce the risk, DO NOT prevent Sudden Infant Death. Research clearly shows that SIDS is not caused by suffocation, vomiting or choking. Sometimes, milk or even blood-tinged froth is found around the baby's mouth, clothes or on the bedding. This happens during or after death and is NOT the cause of death.

WAS THE BABY'S DEATH OUR FAULT?

Parents often feel responsible for the death of their child. They go over and over in their minds whether there was anything they did, or did not do, which could have led to their child's death. Parents needlessly blame themselves, each other, relatives or minders – even the family doctor is sometimes blamed.

Sudden Infant Death Syndrome occurs in families, rich or poor, no matter how competent. SIDS can occur in hospital to healthy babies admitted, for example, for minor surgery. While feelings of guilt and blame are a normal part of grieving, it is essential to realise that no one yet knows what causes SIDS or how to prevent it.

COULD OUR BABY HAVE SMOTHERED?

If you found your baby face down, wedged into a corner of the cot, head covered by blankets, it is natural to think that your baby may have smothered. However, many babies sleep face down or have blankets over their faces with no harmful effects. Smothering is NOT the cause of SIDS.

DID OUR BABY SUFFER?

SIDS occurs very rapidly during sleep, perhaps instantaneously. There may be some movement during the last few seconds of life, accounting for tossed blankets or unusual position in the cot. Parents' experience tells that their babies do not cry out and very often do not show the slightest trace of having been disturbed in their sleep. It is safe, therefore, to assume that SIDS does not cause any pain or suffering.

DID THE WAY THE BABY WAS FED MATTER?

Breast-feeding does not prevent SIDS. Irish and international research has shown that SIDS occurs in breast-fed and bottle fed babies.

WHY ARE THE GARDAI INVOLVED?

The Gardai are always involved in unexpected adult and children's' deaths. It can be very distressing for parents to have the Gardai involved but if we know the reasons, it may make it easier to understand. It does not mean that the Gardai think you have done something wrong. They are there to help you. When a previously healthy person adult or child dies suddenly and unexpectedly and for no immediate apparent cause, a doctor may not, by law sign a death certificate. He/she must notify the Coroner whose duty it is to establish the cause of the death. To do this, the Coroner asks the Gardai to ascertain the circumstances of the death on his/her behalf and then requests the pathologist to perform a post mortem and report back the findings. Understanding these requirements can help to alleviate some of the distress experienced at this most difficult time.

IS A POSTMORTEM NECESSARY?

A post mortem is a legal requirement following a sudden unexpected death. In order to establish the cause of death, the coroner requests a pathologist to perform a post mortem examination. The thoughts of a post mortem often evoke fear and distress at the time of death, but it has been found to be a source of reassurance for the family in the future. You will still be able to hold your baby following post mortem. You should be given the opportunity to discuss the postmortem results with your own family doctor, a paediatrician, or directly with the pathologist involved.

WHAT WILL HAPPEN IN THE POSTMORTEM?

A thorough postmortem may require the retention of one or more organs for a period of time. This is because some tests require longer than others to complete. If this is the case, you should be informed of the retention and the hospital personnel should take account of your wishes in decisions regarding the retained organ/s when all the tests are completed.

WHAT IS THE POSITION ABOUT RELIGIOUS RITES?

Whatever your religious beliefs, you will find support and understanding from your spiritual advisor. All religions provide appropriate and sympathetic services.

If your child has not been baptised and you are concerned about this, discuss it with the hospital chaplain.

In all Christian denominations a funeral service can be held for baptised and non baptised children alike.

PART 2 - GRIEF

PARENTS' GRIEF

When someone we love dies, we grieve. Feelings of grief can be intense and even frightening, but it is important to realise that these feelings are a normal and natural expression of our love and sense of loss. It can be helpful to know some of the reactions and feelings you may experience following your baby's death.

THE FIRST FEW DAYS

Parent's immediate reactions to the death of their baby vary, but the most common initial reaction is shock. Some cry or scream, others are numb to feeling anything, dismissing the event as unreal or just a bad dream, wishfully thinking that they are to be told it's all over. These are all ways of coping with the traumatic event. On the other hand, you may feel a strong sense of reality, yet a certain detachment as though you are an onlooker.

If you have other children, you may find it difficult at this time to attend to their needs. They, too, are hurt, confused and grieving in their own way. It may be helpful to ask a close relative or friend to assist you.

For the mother who was breastfeeding, engorgement of the breasts may be very uncomfortable and also a sad reminder of the baby. Seeking your family doctor's advice can be helpful.

A special case, which may arise, would be the loss of a twin. This will inevitably make parents very anxious about the surviving twin and they may feel the need for additional paediatric support at this time. Indeed, paediatricians are an important source of advice and help for all parents whose child has died.

THE EARLY WEEKS

Parents often say their arms ache to hold their baby. For weeks, parents may find it difficult to believe their baby is really dead. They may imagine they hear their baby cry, or think they see their baby's face. Some find it hard to sleep or may have distressing dreams. There can be feelings of guilt and inadequacy. Parents blame themselves and each other. They live and relive every minute of that tragic time, wondering what they could have done, or failed to do.

Feelings of intense anger can be experienced. Some parents find they cannot concentrate or cope with their ordinary daily routine. There may also be physical symptoms such as exhaustion, dizziness, or loss of appetite. Gradually, these symptoms should lessen. If there are any sensations such as hollowness in the stomach

or tightness in the chest, it is wise to check with your family doctor to rule out any medical cause. Otherwise, these sensations are a normal part of grieving.

Some parents have an irresistible urge to get away, while others dread being left alone. Sometimes, they withdraw emotionally from their other children or from each other, perhaps feeling irritable with them, and then suffer guilt feelings because of this. They may become excessively concerned for their own safety and that of their other children, and have heightened fears of danger.

All of these emotional reactions are part of the normal grieving process. Talking them over with your family doctor or public health nurse can be helpful. Medication such as tranquilizers or similar drugs should have no place in the grieving process.

You may also find it helpful to share your feelings with a close friend or with another bereaved parent. A good listener is therapy in itself.

THE FOLLOWING MONTHS AND YEARS

The sudden and unexpected death of a baby is one of the most distressing events that can occur in a family and people expect to recover much sooner than they actually do. Intense grieving can last for a short or long period, possibly with a great upsurge of grief at occasions such as anniversaries of the baby's birth or death. People grieve in different ways and for different lengths of time, sometimes for several years.

An important part of what is called the grieving process is to talk through the grief again and again. Parents need compassionate listeners: family; friends; clergy; doctors; counsellors, social workers and public health nurses. At this time, they can benefit greatly from the support of parents who have experienced a similar loss and who have literally worked through their grief. ISIDA offers this through its befriending service and telephone helpline. It can give newly bereaved parents comfort and hope for the future.

MOTHERS AND FATHERS MAY GRIEVE IN DIFFERENT WAYS

When a child dies, both mother and father grieve intensely. Sometimes, this draws the partners closer together, but in many cases, it can cause strain in the relationship and may lead to further loneliness and isolation. A mother's grief tends to be more obvious, while fathers tend to suffer in silence and suppress their feelings. Fathers frequently think they are supporting the mother by not talking about their baby. Bereaved couples need to understand these differences and it can be helpful to talk it over with another parent or couple who have themselves experienced a sudden infant death. ISIDA can arrange this through its support service. Please understand that *grieving is a healing process* which takes place gradually over a long period of time. It is unique to each person and does not follow a set pattern.

For a variety of reasons, some parents will be coping alone with the loss of their child. Often when such a loss occurs, the other parent may wish to return and/or participate in the funeral arrangements. This may place a strain on both parents.

In other instances, a parent will have to go through the grieving process without his or her partner. This can be a very lonely experience. The support of family or friends is much needed at this time.

Please talk to ISIDA about getting in touch with someone who can help.

CHILDREN AND GRIEF

Children are affected by a death in the family, a fact not always appreciated by older people. Parents should anticipate that their children will have problems for a while. Very young children see death as temporary and reversible. Older children become very intrigued by the concept of death and need some answers. It can be very difficult for parents to encourage their children to talk about what has happened and what they are feeling, when the parents themselves are grieving a very difficult loss.

Children are acutely aware of their parents' grief and are not deceived by pretended cheerfulness. They may then hide their own grief to protect their parents and suppress their natural curiosity about death for fear of causing their parents upset. An adult whom the child trusts may be able to deal with their questions, fears and feelings. Explain truthfully to your children at a level they can understand that the baby has died. Use factual language, for example use the word 'dead' instead of 'asleep' and 'coffin' and 'grave'. Answer the questions in a simple, direct way. It is very important to be honest with children and if they are very young to add to their knowledge of what has happened as time goes by. The more a child understands the less he or she will fear, or experience anxiety. Remember not to attribute religious reasons to cover up gaps in our current medical knowledge. The baby was not taken because God wanted him or her in heaven – this type of explanation can cause many problems for children. Using religion as a source of comfort and consolation may be beneficial to children in their grieving process. Parents can judge for themselves if this is appropriate.

In facing your own grief openly with your children, you show them that it is alright to cry, to be sad, to be angry, to laugh, and to use the baby's name. You should not keep up a pretence in front of the children. If you are evasive, children may feel guilty and responsible for the baby's death through something they have thought, felt, said or done perhaps in a moment of jealousy.

Parents may wonder how involved their children should be in seeing the baby and attending the funeral. Many specialists in child development believe that if children are old enough to say hello, they are old enough to say goodbye. While acknowledging the loss and love for the baby who has died, assurances of love, security and of safety to the other children are very important. Therefore, it is helpful

if children participate in the ceremonies and rituals by attending the funeral. It is important to prepare the children with honest, factual information about what will take place. Some parents may decide not to involve the child in the funeral service. It is important to answer any questions the child may have about what happened at the funeral. A child's grief can be expressed positively through, for example, drawing, writing letters, poetry, stories or planting a tree. These expressions should be encouraged. It is important to remember that not all parents are able to deal with issues their children bring up about the dead baby when they are grieving themselves.

Remember your children will continue to need information on your baby's death. Try to be open to their questions. Avoid being over-protective or over-indulgent. Bereaved children lose their sense of security; they will be made to feel more secure by having them follow the same rules, discipline and limits etc. that existed prior to the death. Expect your children to test the limits and rules you set.

If at any time you are concerned about how your children are coping, remember they too grieve in different ways at different times. It may be helpful to talk it over with your family doctor, public health nurse, other health care professionals or contact ISIDA's helpline for information on children's services countrywide.

GRANDPARENTS

The grandparents may be severely shocked and bewildered by a sudden infant death. A grandchild is very precious and important to them and to lose this child suddenly and unexpectedly can upset them greatly. Grandparents suffer a double grief – the death of a loved grandchild and the grief of seeing their own child's sorrow and pain. Sometimes, grandparents feel that they should set an example by being controlled and coping well and so may not get the opportunity to express their own grief.

Understanding by grandparents of details of the events surrounding their grandchild's death is vitally important because, otherwise, they may become unduly questioning about, or even critical of, the care that was given to the baby. This can add to the grief of the parents and sow the seeds of family disharmony. It can be useful to give grandparents a copy of this booklet or they may like to talk it over with their family doctor, or to contact ISIDA.

MEMBERS OF THE EXTENDED FAMILY

Extended family members and friends also experience shock, bewilderment and grief at this time. Cousins, aunts, uncles etc. may themselves have young babies and feel uncomfortable in the presence of the bereaved parents, however, their ongoing support is essential. If you would like advice in this area, please do contact ISIDA's helpline.

CARERS

Sometimes, the baby is in the care of grandparents, other relatives or minders when the death occurs. At first, the parents may tend to blame themselves for having left the baby. The minder will also feel shocked and responsible. These are natural reactions and will need sympathy, explanation and reassurance. It is also natural for parents to seek details of the events surrounding their baby's death.

Where a child dies from SIDS the carer in charge will need reassurance that he/she was in no way responsible for the baby's death. It is important for everyone to understand that, in our present knowledge, SIDS cannot be predicated or prevented, and that *no one is to blame*. It may be helpful to give a copy of this booklet to relatives, minders or friends.

PART 3 THE FUTURE

A SUBSEQUENT BABY

When a baby dies, many well meaning people try to persuade parents, the mother in particular, that having another baby as soon as possible is the best, the quickest and only way to get over the death of the previous child. However, when thinking about having another child, it must be clearly understood that having a new baby will not necessarily make the feelings of pain and loss caused by the death of the previous baby disappear more quickly.

The new baby will never replace the dead child, but will be unique and different and will develop his/her own personality as the weeks go by.

The decision to have another baby is a personal one. It should be made by the parents themselves, based on their own reasons, and with as little outside influence as possible. Many parents do want to have another child but if the only thing stopping you is your fear that your next baby will also die of SIDS, please remember that thousands of parents like you are now happily bringing up their later children. You may find it helpful to speak to a parent or parents who have had subsequent children. Seeking the support of your family doctor and obstetrician can also be helpful, or you may like to phone ISIDA's local helpline at

1850 391 391

CAN IT HAPPEN AGAIN?

Although many parents doubt their ability to cope with another child, there is no reason why you should not have another baby in due course, if you desire one.

ISIDA's REGISTER

ISIDA's National Register undertakes research and gathers information regarding Sudden Infant Death. The Register personnel can arrange to visit you, will willingly share up to date information about SIDS and invite you to take part in ongoing, much needed research once you are able to do so. **FREEPHONE NUMBER 1800 332 332.**

YOU ARE NOT ALONE

How can we help you?

- ISIDA offers a support service to parents whose child has died suddenly and unexpectedly. It is strictly confidential and is provided by parents who have themselves experienced the feelings of grief, loss and isolation which follow the loss of a child. This support service is co-ordinated by professionals.
- ISIDA can offer you counseling on an individual or partner basis.
- Group therapy is also available to individuals or couples who want to work through their grief in a group setting.
- Children's workshops are another part of the support service we can offer you. Children who come into the workshops are encouraged to talk about their grief through play and art.

All the services provided by ISIDA are facilitated by professional psychotherapists.

Contact can be made by calling ISIDA's helpline on **1850 391 391**

DO'S AND DON'TS – for anyone who wishes to help

If you have a relative, friend, neighbour or colleague who has had a Sudden Infant Death and you wish to help, you may find it useful to read the following which ISIDA has compiled through many years of listening to and supporting bereaved families.

DO let your genuine concern and caring show.

DO be available to listen or to help with whatever seems needed at the time.

DO say you are sorry about what happened and about their pain.

DO allow them to express as much unhappiness as they are feeling and are willing to share.

DO give time and attention to the child's brothers and sisters. They, too, are hurt and confused and in need of attention which their parents may not be able to give at this time

DO reassure them that they did everything that they could.

DO understand that the loss of a child is a very difficult and different loss from the death of an adult.

DO allow them to talk about their child as much and as often as they want to.

DO let parents know that ISIDA is there to help

DON'T try to find something positive (eg an angel in heaven, it could have been worse if.....) about their loss. There is nothing worse than the death of a child.

DON'T avoid talking about the child, you may think you are reminding the parents and upsetting them further, they are thinking about their child constantly.

DON'T try and make them feel better by reminding them they have other children. This sometimes makes parents feel worse. Children are not interchangeable

DON'T say that they can always have another baby. Even if they want to, or can, another child will not replace the baby who has died

DON'T let your own discomfort keep you from reaching out.

DON'T tell them what they should feel or do.