

Facts You Should Know About Sudden Infant Death Syndrome

Sudden Infant Death Syndrome:

- Is the third leading cause of death for infants between one month and one year of age
- Cannot be predicted or prevented at this time
- Is not caused by neglect or child abuse
- Is not caused by vaccinations or toxic gases
- Is not contagious or infectious
- Is not considered hereditary
- Is not a new medical problem
- Occurs rapidly and silently, usually during periods of sleep
- Probably has more than one cause (although the final death mechanisms appear to be similar)



The Canadian Foundation for the Study of Infant Deaths, a registered, national voluntary charitable organization is dedicated to:

- Providing information and emotional support to families who are stricken by the sudden and unexpected death of their baby
- Providing programs of public education and awareness
- Supporting research activities into the causes of Sudden Infant Death and its effect on families

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The Canadian Foundation for the Study of Infant Deaths

When Your Baby Has Died of SIDS



The death of your baby is a devastating experience

Canadian Foundation for the Study of Infant Deaths

Bringing Hope & Life to Canadian Families



This section is for parents and families of babies who have died. It has been prepared by parents who have survived the nightmare of their baby's death. We have tried to tell you the things we wanted to know when our babies died and to share our experiences with you. We will talk about the feelings, the family, friends and the future. Families do learn to smile again.

THE FEELINGS

Guilt

Your questions are unending.

Why did this happen?
Why our baby?
What kind of a parent am I?

There are no answers for these questions. No rational reasons "why". As parents we want to place blame somewhere: doctors, nurses, mother, father, God. Most often we blame ourselves. You are not to blame.

Most grieving parents have the same kinds of feelings, but they may behave in different ways.

"I needed to talk about Adam, to remember him, to try to find some meaning for his death. I would end up crying. My husband wouldn't talk about the baby, he couldn't cry. Does he feel as deeply about Adam as I do?" (Mother)

"I can't talk about Adam in front of my wife. She always cries. I can't cry. Someone has to be strong in this family. The only time I can cry is in the shower—then no one knows." (Father)

Shock

"I thought there was something wrong with me. For the first few days I couldn't cry—I couldn't feel anything at all"

For some people shock leads to emotional outbursts. But for others shock is a sense of numbness that takes away all their emotions for a time.

Unfortunately, some people may feel your baby's death is an end to one stage of your life. You may hear that it is time to "get on with your life". Many people do not realize that by encouraging you in such a way they are denying you a much needed period of grief and readjustment.

You are not the same person you were before your baby died.

Your friends don't know how you feel and don't know what you need. Tell them how to help or share this section with them. Whether it is a phone call, a visit, a baby sitter or a shoulder to cry on, most people are happy to be able to help.

It helps to talk to another parent whose baby has died. The Canadian Foundation for the Study of Infant Deaths is able to put bereaved parents in touch with each other.

THE FUTURE

The deep desire to hold and love a baby again is very natural. What each parent wishes is to hold and love the baby who has died.

Each baby brings with him or her, a special mix of happiness and sadness. A new baby will not replace the baby who has died.

For some parents, the need to give birth to other children is very strong. The decision to get pregnant and have another baby is a very personal one. This decision is based on many different things.

For some, the answer to their grief is to become pregnant, for others, that option is not one which will help them through this time.

For some parents, the option to have another child is not there.

For some parents, the baby who died was to be their last child. These parents may have had surgery to make sure that they did not become pregnant again. It is important that these parents are able to talk to each other and to their doctor about that decision and how it affects their lives now.

These parents need to grieve this lack of choice as they grieve for their dead baby.

All parents and families need time to grieve. It takes time to come to terms with life without that little child, to find meaning in life again.

That time will come. When it does you will be able to look to the future with hope.

If your children cannot understand the idea of death, they may simply need reassurance and love at this time.

Do not use words like “gone to sleep” or “gone away” when you mean “dead”.

Many words that we use to mean death can be very upsetting and scary for children, especially if they have no clear understanding of what has happened. For example, to tell children that the baby has gone into a long sleep may lead them to fear their own sleep. Words such as loss can be very frightening. Some children will fear separation from their parents in case they get lost, or the parent will go and never return. Others may be afraid they will find the dead baby.

It is simpler to explain that your baby has died. When they ask why or how it is okay to say that you do not know. These are the same questions we are all struggling with.



Grandparents

For grandparents there is a “double” grief, the loss of a grandchild and the knowledge of the pain of their own child. This grief may not even be recognized by the baby’s grieving parents.

“I was brought up to hide my emotions. I don’t think my daughter knows how my heart goes out to her. I don’t know how to tell her”. (Grandfather)

Grandparents often have a special bond with their grandchildren, a relationship that is uncomplicated by parental responsibility. For some grandparents, there is the added grief of never having seen their grandchild.

At times of intense grief, talking together is difficult. Sometimes this can lead to feelings of anger, frustration and rejection.

Grandparents cannot make their child's pain go away or bring back their grandchild. They can help their child through the pain of this death with caring support.



FRIENDS

“I can remember sitting in the front porch waiting for somebody to come and visit....but nobody came...I felt so alone”. (Mother)

At this time, dealing with other people can be very stressful. Even friends can seem distant at this time. They may not know what to say, or end up saying things you may feel are inconsiderate.

Anger

“The smallest thing is enough to make me mad. I get so angry that my head feels it will blow apart.” (Mother)

Anger is a natural response after the death of your baby. This is one way of expressing your pent-up emotions.

It is important to understand that at times of high stress you or your partner may say things that you really don’t mean.

Be open to the other members in your family and try not to take hurtful remarks to heart.

This is a time of great pain. As you work through your emotions you will begin to see that there is no one to blame, but a great sadness that the whole family is struggling to live with.



Fear

After the death of your baby, nothing seems safe and secure any more.

Family members can become very fearful that something else is going to happen. Parents may become over protective with their other children. Children can cling to their parents, afraid of being separated from them. You need time to trust the world again, time to begin to feel safe.

“Shortly after our baby had died, my husband took the other two children down to the lake to skate. After about half an hour, I followed them down. I cried all the way to the lake, I was sure they were all dead. Now I have to be sensible and not allow my imagination to run wild.” (Mother)



Physical Symptoms

“It is important for parents and children to know that the pain... that immense pain, doesn’t stay. Every day it does get a little bit better.” (Mother)

It’s hard to cope with life when you have no energy, no appetite, when day and night become one blur.

Grief brings with it real physical symptoms. Heartache can be so severe that you may

be afraid that you are having a heart attack. Many parents feel an ache in their arms as they long to hold their baby. Others can find it difficult to breathe or have sharp pains in their stomachs. You may even hear your baby cry.

Don't be afraid to visit your doctor. Your doctor will be able to reassure you that you are not going to die and that you are not going crazy. As you work through your grief, these symptoms will fade.

Mothers who have been breastfeeding can have painful breasts from milk engorgement. Your doctor may be able to help you manage these symptoms.

"I remember locking myself in the bathroom. My breasts were leaking, aching, crying. I am crying from my body. My life-giving milk is dripping down the drain. My baby doesn't need it anymore; I sob and sob watching it." (Mother)

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THE FAMILY

Mothers and Fathers

Grief may make you very irritable. Small differences between partners may now be very hard to take.

You each have to grieve in your own way. At times you may be able to reach out to comfort your partner. At other times you may need comfort and find no one is there to hold on to.

It is sometimes hard for one partner to understand why the other partner has so many sad days. It may be just as hard for the other one to understand how the partner can seem to go on with life so quickly.

"I remember looking at the ceiling, listening to my husband cry. He cried like a baby. There was nothing I could do. I felt the same when my father came to the hospital. He couldn't make it right. He just stood there looking broken and old." (SIDS Mother)

It is important that partners share their feelings. For example, one may feel an intense need for the comfort of sex, while the other partner cannot imagine ever enjoying sex again. You need to talk—to understand each other. You are both normal and are just expressing your sadness in different ways.

Both women and men need to be able to express their grief. There is no proper way to grieve, everyone is different.

The memories of your child are very precious. Be kind to yourself. This is a very difficult time.

Your life has been centered around your baby. Now that your baby has died, there is a big hole left. It is normal to feel intense pain. Over time, with supportive friends and family, this pain will go away.

As you work through your grief, your "good" days will begin to outnumber your "bad" days. While you will never forget your baby, you will learn to laugh again!

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Single Parents

Your baby's birth was a very important time in your life. Whether or not the baby was planned, the birth marked a big change in how you see yourself and how others see you. For some, being a single parent may be extremely difficult. For others, the birth of your baby may have been a dream come true.

At the time of your baby's death, you may feel you do not have the full support of your family, friends or community.

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Children

No matter how young they are, children will understand that something terrible has happened.

There are many myths about children's understanding about death. We know that children need simple, true explanations of death that fit in with their family's beliefs.

Children between the ages of two and six may be very concerned about the physical comfort of the baby. They need to know that the baby is somewhere safe. They will find it very difficult to understand the finality of death.

Between seven and ten, the children come to understand that death is permanent. They may be interested in more exact explanations of the causes of the baby's death.

Only during their teens will children come to understand the concept that death comes to everyone—even them.

Talk about your baby with your children. One way to ease into it is to sit together and look at the family photo album. Allow the family to remember some of the less pleasant experiences as well as the pleasant ones. Let them discuss times when they may have been jealous of their baby. In this way children will learn that thoughts do not cause bad things to happen.