

Support for families after the sudden and unexpected  
death of a baby or young child



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# When a baby or child dies suddenly and unexpectedly.

When your baby or child dies suddenly and unexpectedly, your hopes and dreams for your family are shattered. When the loss is without warning or explanation, it is even more unbearable.

You have been given this leaflet because your baby or child has died suddenly and unexpectedly and we hope that you will find some answers to your questions and find some comfort in the support we, at the **Scottish Cot Death Trust**, can offer.

No matter how deep your grief and how great your pain, remember that you are not alone. The Scottish Cot Death Trust is here to help you through the difficult times following the death of your baby or child.

*We are truly sorry for your loss and extend our sympathy to you.*

# Why did my child die?

When a baby or child dies suddenly and unexpectedly the impact is one of utter devastation. Initial feelings of shock and disbelief will often give rise to questions about what happened and why it has happened to you. Often, the lack of answers to these questions adds to the overwhelming feelings of grief and helplessness.

It may only be a few days since your baby or child has died, but you can be assured that the professionals are trying to find answers for you. Some of the professionals may have mentioned the term cot death to you; or you may have read the words "SUDI (Sudden Unexpected Death in Infancy)" or "Unascertained" on your child's death certificate. This means that, at this stage, no-one knows why your child has died.

The investigation into your child's death will be thorough and at times you might feel like you are under suspicion. You should take comfort from the fact that every effort will be made to try and find a reason as to why your child has died.

We know that this can be a very difficult and distressing time for you and your family, but the Scottish Cot Death Trust is here to support you through these difficult times.

## What happens next?

In Scotland, the sudden and unexpected death of an infant must be reported to the Procurator Fiscal. It is the responsibility of the Procurator Fiscal to exclude any possibility of criminality. He/she will instruct the Police to carry out an investigation of the circumstances and will also require a Pathologist to carry out a post mortem examination.

Whilst you might find the involvement of the Police very upsetting, you should be assured that the purpose of the investigation is to find out, if possible, why your baby/child has died. The Police have to ask a number of questions that may be upsetting, but these are necessary and important. The information you provide will be valuable and will be passed to the Procurator Fiscal.

The Police may take photographs or video footage of your home and they will be required to remove various items from your home (or the place where your baby or child was found), as part of their forensic investigation. These items can include the bedding, toys, food, milk, medications and any other items they feel are relevant. In some circumstances, your family may be required to leave your home until the police investigations have been completed. If this is necessary the Police will explain it to you. The Police will also routinely check if you have had any previous involvement with Social Services. When the Police have completed their investigation, they will submit a report to the Procurator Fiscal.

The Procurator Fiscal will also instruct a Paediatric Pathologist to carry out a post mortem examination on your baby/child's body to try to find a cause of death and again this is a legal requirement.

The first results from this examination will be available within a few days and after this your baby/child's funeral can normally take place. However, these early results are not able to give all the detail that can help to tell if your baby/child had a rare disease or if there was anything unusual that might help to explain why they have died suddenly and unexpectedly.

During the post-mortem examination samples of tissue and blood will be taken for further tests, to try and explain your baby/child's death. These samples will be kept as a permanent part of your baby/child's medical record.

The results of these further tests should be available within 2-3 months, but can sometimes take longer. In a small number of cases these additional tests may be able to reveal the cause of death. In others, a possible contributory factor to death may have been established although this does not adequately explain the death. However, you should also be prepared for the fact that sometimes no cause of death can be found and your baby or child's death will remain unexplained. It can also take several months for the investigation to be completed.

## Coping with grief?

Feelings of denial, unreality and numbness are common and these intense emotions are real and a normal part of grieving. Grief is a process of trying to cope with your loss and make meaning out of life without your baby/child.

Grieving is not easy. It is long, unpredictable and requires a lot of patience. Grief is a very personal emotion and everyone will grieve differently. You may feel emotionally drained and unable to support others close to you. It can be very helpful to share what you are feeling with someone outside the family such as your doctor or social worker.

Some of the physical manifestations of grief can be very hard – nausea, pain in the chest and arms, exhaustion. You may also fear that you are losing your mind. You may imagine that you hear or even see your baby or child and your arms may ache to hold them. These are all normal parts of the grief process.

Grief is not something which can be measured in terms of time. The emotions involved can resurface for many years, particularly at anniversaries, birthdays, family celebrations and special landmarks, such as when the child would have started school. Although the acute pain will gradually diminish, your child will never be forgotten.

It is important to remember that grief takes time. Be patient, take life one moment, one hour, one day at a time. While you may never 'get over' the death of your baby or child, you can learn to live with your loss. Healing is an ongoing process, it does not happen overnight, but it will happen.

## If your child was over one.

The majority of babies and children who die of cot death are under 1 year old, and most likely to be under 6 months old. However, a small number of older children may also die suddenly and unexpectedly.

When a child over 12 months dies suddenly and unexpectedly the death may be referred to as Sudden Unexpected Death in Infancy (SUDI), or SUDC (Sudden Unexpected Death in Childhood).

For many parents, getting their child safely through their first year heralds a sign that "all is well", and they often heave a sigh of relief that cot death is one less thing to worry about. As with all sudden unexpected infant deaths, the shock is immense when it happens.

If your child was over one year old when they died suddenly and unexpectedly, please be assured that the Scottish Cot Death Trust is here to help and support you in any way we can.

## If you have other children.

If you have other children, they may react in their own way to the death of their brother or sister. Some may appear unconcerned, others may be especially demanding and irritating.

Toddlers may not really understand what has happened but they will sense your grief and need extra loving care to feel secure. Older children will understand and grieve. Don't feel that you must hide your grief from your children.

By letting them see your distress you may help them to express their own. Take care, however, that in your own pain you do not reject or neglect them. They need simple explanations and reassurance that the same thing will not happen to them or you, and that they need not be afraid to go to sleep. It's best not to say "Your brother/sister died in his/her sleep" or "The baby went away" to your other children. How you explain the death to them depends on your own beliefs and the age of the child but they should be helped to understand that their brother or sister has died and will never come back. They should be assured that it was nobody's fault. This is especially important if one of your other children was jealous of the new baby.

If your baby or child was a twin, your family doctor will probably examine the other twin, to make sure all is well. In some areas the other twin may be admitted to hospital for a few days.

With older children it is important to continue to keep the issue of the death open for discussion for years, as a child's questions and ability to understand change as they develop. They will need more complete information over time.

Often, children can be a source of strength for their families. Some children, on the other hand, because of circumstances of age or emotional makeup, can become very insecure. This loss of security can manifest itself as nightmares, bedwetting, difficulty in school and other disturbances. Any such problems should be discussed with the child's doctor.

## Where can I get help?

Remember, you are not alone. The Scottish Cot Death Trust is here to support you through this very difficult and distressing time; regardless of where you live in Scotland. You should be aware, however, that we may not have been told about the death of your child. Please don't assume that we already know about your family. If you would like our support, please make contact with us, using the details at the back of the leaflet.

We have a number of ways in which we can support you and your family, these include:

### **Home Visiting**

The Scottish Cot Death Trust's Community Services Nurse will visit you at home, (or another location if you prefer), to provide information about cot death and the services available from the Trust. Time will be spent listening to you and discussing the support available to help you cope with your loss.

### **Counselling**

A professional Counselling service is available to anyone affected by the loss of a baby or child to cot death.

### **Befriending**

The Scottish Cot Death Trust can put you in contact with another person who has also suffered the loss of a baby or child to cot death. You can meet your befriender in person; or speak to them by phone; email or texting – the choice is entirely yours.

### **Family Days**

When your baby or child has died suddenly and unexpectedly, it is common to feel very isolated and that you are the only person this

has happened to. Many families find it very comforting to meet other families who have had a similar experience.

The Scottish Cot Death Trust organises Family Days in different locations in Scotland at different times of the year. They are free to attend and are usually held somewhere like a science museum or the zoo. This means that as well as having a family day out, you can meet other bereaved families in a relaxed and more natural way.

### **“Precious Memories” – Garden of Remembrance**

Nothing can ever replace your child, but some parents find it helpful to create a lasting tribute to their child by setting up an online memorial in our garden of remembrance.

### **Next Infant Support Programme**

When you have lost a baby or child to cot death, the arrival of a new baby can bring huge anxieties that it might happen again. Through the Scottish Cot Death Trust's “Next Infant Support Programme” we aim to support you during your subsequent pregnancies; after the birth and for as long as our support is needed.

### **Apnoea Monitor Loan Service**

As part of our “Next Infant Support Programme” we can provide an Apnoea (breathing) monitor, on loan for up to 12 months to bereaved parents, to offer peace of mind with the new baby. The monitor will sound an alarm if the baby stops breathing. All parents will receive resuscitation training before receiving a monitor to ensure they know what to do if the baby has stopped breathing.

If you would like to find out more about the ways in which we can support your family, please contact us using the details at the back of the leaflet.