Support for Families
after the sudden and unexpected death of a baby or young child
We are truly sorry for your loss and extend our sympathy to you.
When your baby dies suddenly and unexpectedly, your hopes and dreams for your family are shattered. When the loss is without explanation, it can feel even more unbearable.

You have been given this booklet because your baby or young child has died suddenly and unexpectedly. We hope that it helps you to find some answers to your questions and provides some comfort knowing that the Scottish Cot Death Trust is here to offer you both practical help and emotional support.

Cot Death is a traditional term which used to be used in death certificates at the time the charity was founded over 30 years ago. Not all babies die in cots and toddlers and young children also die suddenly and unexpectedly. Please be assured we are here to support these families too.

You may experience feelings of grief and helplessness, and question why and how your baby or child has died. At times you may feel alone and isolated.

The **Scottish Cot Death Trust** is here to support you in the days, months and years after the death of your baby or child.
Why did my child die?

After the death of your baby or child, the lack of answers or explanation may add to your feelings of utter devastation. You will probably ask why this has happened to you and at some point you may even blame yourself for the death or feel guilty that this has happened to your family.

You may have heard the term ‘cot death’ being used to describe what has happened, or you may have been spoken to about Sudden Unexpected Death in Infancy (SUDI) or Sudden Unexpected Death in Childhood (SUDC), you may have read the words ‘SUDI’, ‘SUDC’ or ‘Unascertained’ on your child’s death certificate. These terms mean, that at this stage no one knows exactly why your baby or child has died.

Professionals are working together to try and find answers for you; at times this may make you feel like you are under suspicion. This can be very difficult for you and your family but everyone involved wants to help find why your baby or young child has died. The Scottish Cot Death Trust is here to support you during these early days and for as long as you feel you and your family need in the future.

Going home without your baby or child

If your baby or child was taken to hospital, leaving without them can be very difficult. Seeing your child’s toys and possessions can be very hard. Family or friends may want to remove these items but it is important that you make the decision when the time feels right for you. Let family or friends know your wishes, many parents find that going through their child’s things is a very important part of grieving.

It can be common for newly bereaved parents to feel reluctant to return home and some parents decide to move house as it holds too many painful memories. Although your home may be the place where you have many painful memories around the death of your child it will also hold many happy memories. It is important to take time to decide what is best for you and your family and it is often best not to rush into any decisions concerning your baby or child’s possessions or your home.

If your baby or child was a twin your family doctor may refer the surviving baby or child to hospital for examination to make sure all is well.
What happens next?

In Scotland, any sudden and unexpected death is reported to the Procurator Fiscal, this includes the death of a baby or young child. The Procurator Fiscal will instruct the police to carry out an investigation into the circumstances of the death and will require a specially trained paediatric pathologist to carry out a post mortem examination.

The Police:
The police have to ask a number of questions that may be upsetting; however these are necessary and important. They may take photographs or videos of your home, and are likely to remove various items; such as bedding, toys, food or milk from your home or where your baby or child was found. This is part of the detailed investigation which aims to find the reason why your child has died. You may be required to leave your home; if this is necessary it should be explained to you by the police. The police will also check if you have had any previous involvement with Social Services. This is all a normal part of the process and you should be supported by a family liaison officer who will try and help you understand the investigation process. Once they have completed their investigation a report will be submitted to the Procurator Fiscal.

The post-mortem:
The initial results of the post mortem examination are usually available within a few days, after which your baby or child’s funeral can take place. These early results are unlikely to give all the detail needed to find out why your baby or child died. It may be necessary for samples of tissue and blood to be kept for possible further tests. These tests should be completed within 2-3 months but it can sometimes take longer. Sometimes the test may reveal the cause of death; or factors which contributed to the death. However, you should be prepared for the fact that sometimes no cause of death can be found and your baby or child’s death will remain unexplained.

A named hospital doctor will be available to support you. They will help explain the ongoing process and any of the medical reports.

“ The police have to ask a number of questions that may be upsetting ”
Coping with grief?

When someone we love dies, feelings of denial, unreality and numbness are real and a normal part of grieving. Everyone’s grief is different and grieving is a difficult process. You may find it difficult to support others close to you or find it hard to express your feelings. It can sometimes be helpful to talk with someone else outside of the close family.

You may also find you experience physical symptoms of grief. These symptoms may include nausea, pain in the chest and arms, and exhaustion. You may imagine that you hear or see your baby or child and your arms may ache to hold them. You might also experience vivid dreams or flashbacks about the death of your child. This does not happen to everyone but can be frightening. This may make you feel like you are losing your mind, but sadly, it is a natural and normal part of grieving.

Working through your grief takes a very long time and no one should tell you how long to grieve for or in what way you ought to grieve. Everyone grieves differently and this can sometimes cause tensions between family members. You may find that your partner has difficulty expressing their grief while you want to talk about it almost constantly, or vice versa. If you are a single parent, you may feel that you have no one to share how you are feeling with someone who really understands. Perhaps you are reading this booklet as a grandparent or friend; you may not know where to turn to for advice or whether there is support available for you. The Scottish Cot Death Trust is here to offer both advice and support to anyone affected by the sudden and unexpected death of a baby or young child.

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If you have other children:

Like adults, children also have their own way of grieving. They may appear unconcerned or may become desperate for attention. It is common, due to exhaustion and the physical effects of bereavement to feel irritated by your other children at times. This is normal as you all try and cope with your own grief as best you can. Try not to feel that you have to hide your grief from your children. By openly expressing your emotions, you will show them that it is okay to be open about how they are feeling.

It can be helpful to provide a ‘safe’ person for children to talk to, perhaps a close friend or teacher they trust. Sometimes children can be anxious about talking to parents in case they upset them. Suggesting that it is okay to talk to the ‘safe’ person gives them a place to go with any worries.

Toddlers may not understand what has happened but will sense your grief; this may make them feel insecure and need extra loving care in order to feel safe. Younger children tend to cope and try to understand death by dipping into the subject of death, perhaps asking ‘why their brother or sister has died’, before moving quickly on to another unrelated subject such as asking ‘what is for dinner?’ This is normal behaviour; try to answer their questions honestly. If you don’t know the answer, it is okay to say that.

Children need simple explanations for what has happened. It is best not to say ‘your brother/sister died in their sleep’ as this may make children afraid to go to bed. They should be reassured that the death was nobody’s fault; this is especially important if the child was jealous of a new baby. You should explain the death to your children in terms of your own beliefs, but they should be helped to understand their brother or sister has died and cannot come back.

A child’s ability to understand changes as they develop, they may therefore need more complete information over time.

We have resources for parents to use with their children to help talk through what has happened and we will work with you to provide the best support for individual children.
Where can I get help?

Remember, you are not alone. Regardless of where you live in Scotland, the Scottish Cot Death Trust is here to support you through this very difficult and distressing time. As a Charity we may not always have been informed about your family’s loss so we may not know how to contact you. If you would like our support, please make contact with us using the details on the back of this booklet. Anyone can make a referral for you, providing you have given your permission. There are also additional sources of support listed at the end of this booklet.

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 Support Worker may visit you at home to provide support, practical advice and information that you may need to help cope with your child’s death. Time can be spent listening to you and discussing the range of support services that are available to help you cope with your loss. Again, the Scottish Cot Death Trust covers the whole of Scotland, so regardless of where you live we can offer support.

**Befriending**
We can put you in contact with another person who has also experienced the death of a baby or child. You can meet them in person or speak to them by email, phone or text message. We also have a closed facebook group, which you can be invited to join.

“Many families find it comforting to meet other families who have had a similar experience”
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 comforting to meet other families who have had a similar experience.

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

Counselling
A professional Counselling service is available for individuals directly affected by the loss of a baby or child.

Next Infant Support Programme and Apnoea Monitor Loan Service
After the death of a baby or child, the arrival of a new baby can bring huge anxieties that this might happen again. The charity offers a ‘Next Infant Support Programme’ to support you during subsequent pregnancies, after the birth and for as long as you need us.

We can provide an Apnoea (breathing) monitor, on loan for up to 12 months, to bereaved parents - for some families this helps offer peace of mind with a new baby.

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

**Winston’s Wish**
Support for bereaved children and their families
08088 020 021

**Child Bereavement UK**
For support for bereaved children and their families
01494 568 900 or 0800 028 8840

**Sudden – An initiative by the charity BRAKE**
Supporting people bereaved by sudden death

**The Samaritans:**
116 123 (UK)

**SiMBA (Simpsons Memory Box Appeal)**
Provides memory boxes and offers support groups across Scotland
[http://www.simbacharity.org.uk/](http://www.simbacharity.org.uk/)
01368 860 141

**Baby Mailing Preference Service (MPS):**
You can register online to stop or reduce baby/child related advertisements, mailings and emails from companies you may have registered to join baby clubs.