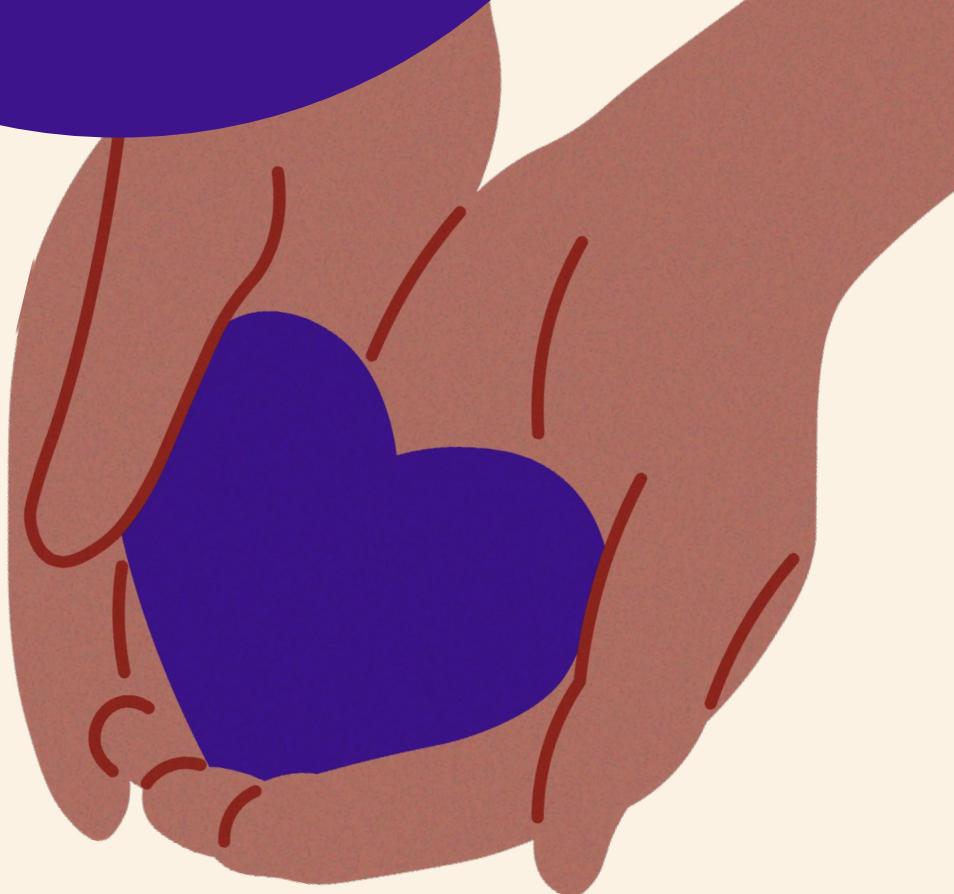


# When a baby or young child **dies** suddenly and unexpectedly in Scotland

the  
lullaby  
trust



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## Introduction

We are so sorry that your baby or young child has died. The sudden and unexpected death of a baby or child is a terrible shock and one of the most devastating things that can happen to a family. This booklet is designed for parents whose baby or young child has died. The Lullaby Trust hopes to explain what you might experience now and in the future. This booklet will explain what needs to happen after your child's death. It will also discuss the complex thoughts and feelings of grief and loss.

If you are a professional reading this you may also want to take a look at the advice for professionals on our website [lullabytrust.org.uk/professionals-hub](https://lullabytrust.org.uk/professionals-hub) and [healthcareimprovementscotland.scot/inspections-reviews-and-regulation/national-hub-for-reviewing-and-learning-from-the-deaths-of-children-and-young-people/](https://healthcareimprovementscotland.scot/inspections-reviews-and-regulation/national-hub-for-reviewing-and-learning-from-the-deaths-of-children-and-young-people/)

There is a glossary of terminology at the back of this booklet.

We understand that this booklet contains a lot of information and might feel overwhelming. It is designed so you can revisit it if and when you need to, using the glossary and contents pages.

## Introduction

In this booklet, you will find experiences shared by bereaved parents. The death of a baby or child is the most devastating experience a parent can face. It defies the natural order of life. It can be extremely difficult to make sense of. Grief can be very isolating. No two losses are ever the same. The parents who have contributed to this booklet hope that their words may be of some help to you as you go through this experience.

You may wish to read this booklet immediately, or you may wish to look at the headings and keep it for later. It's okay to take your own time. It could also be helpful to share this booklet with others, such as family members and friends. This may help them understand what you may be feeling.

We offer our deepest sympathies to anyone affected by the death of a baby or young child. If you would like to talk to someone or to be put in contact with a Befriender who is also a bereaved parent, you can call us on:

**Helpline: 0808 802 6868**

Mon to Fri 10:00am - 2:00pm

Sat and Sun 6:00pm - 10:00pm

**Website: [lullabytrust.org.uk](http://lullabytrust.org.uk)**

## Terminology

**'Sudden unexpected death in infancy'** (SUDI) is the term used to describe the sudden and unexpected death of an infant (a child under the age of one year) when the death is initially unexplained. A term that is often used if a child over one year (and up to 17 years) dies unexpectedly is **'sudden unexpected death in childhood'** (SUDC).

Some sudden and unexpected deaths can be explained by the post-mortem examination (a careful external and internal examination of the body performed by a trained specialist, a paediatric pathology). The examination could show a cause of death, for example, an infection or other illness such as a genetic disorder. Deaths that are still unexplained after the post-mortem are usually registered as **sudden unexpected death in infancy** (SUDI) for babies under a year old (deaths of children up to two years old are sometimes also recorded as 'sudden infant death syndrome'). Sudden unexplained death in childhood (SUDC) is sometimes used for children, over the age of 12 months, who die without a known cause. The term 'unascertained' may sometimes be used. This is another way of saying that the cause of death cannot be found.

**'Cot death'** was a term often used in the past to describe the sudden and unexpected death of a baby. It is used less often now because it wrongly suggests that sudden infant death can only happen when a baby or young child is asleep in their own cot or bed.

# What happens immediately after a sudden and unexpected death of a baby or young child?

At this deeply distressing time, we hope this booklet will help explain some of the procedures that have to happen and guide you through the important decisions that need to be made. You can call The Lullaby Trust on **0808 802 6868** if it would help to talk things over, or you can ask someone to call us on your behalf.

From the moment a baby or child dies suddenly and unexpectedly, it triggers an ongoing and established multi agency response. This can last 12 months or longer, and involves many professionals including:

- your GP
- health professionals
- teachers
- police officers
- ambulance staff
- social workers.

Reviews can be called different things. The name given to a review often reflects the circumstances of a child's death. For example, a child death review, or a fatal accident inquiry, among others. They all aim to understand how and why your child died, and learn lessons that may help prevent other children or young people dying from similar causes.

## Immediate response – straight away

Most babies that die suddenly and unexpectedly are found by their families who will call an ambulance. The initial 999 call will request an ambulance and also notify the police, who will also attend.

The Procurator Fiscal is informed of all sudden and unexpected deaths. The police investigate the circumstances of the death on their behalf.

Your baby or child is usually transferred to an emergency department in the hospital.

This will be an extremely distressing experience, often families do not expect the police to attend, but this is a standard procedure for all sudden deaths of a child.

Your baby or child may be carefully examined by a paediatrician or another doctor. If they do not know the cause of death, they must inform the Procurator Fiscal.

You will be asked a number of questions by the police and health care staff involved. These questions will be asked separately to your partner or other family members. This may be upsetting but is necessary and important and the information you provide will be valuable. It will be shared with other professionals to avoid you having to repeat your answers.

You have the right to be given as much opportunity as possible to be with your baby at this stage. You should be offered the opportunity to have a memento, such as a lock of hair or hand and foot prints from your baby or child. It is fine to ask for this if it is not offered to you. The health professionals can arrange a photograph of the whole family. This may be important for brothers and

sisters to help them remember their sibling as they grow up, or for siblings born afterwards. Support from the hospital chaplaincy team should be available, but you can ask for a minister from your own faith to attend.

You may not wish to return to your home if this is where your baby or child died, and you can ask for support arranging where to go.

You should be allocated a key health professional; a single, named point of contact to whom you can turn to for information on the next stage of the child death review process.

This could be a:

- healthcare professional
- social worker
- police officer
- bereavement support worker
- education representative or
- another person involved in the review of your child's death.

If you do not have a key contact, ask for one from whomever has spoken to you about your child's death. They can signpost you to sources of support.

Your contact can be the 'voice' for you. Contact details of support organisations and bereavement services should be given to you before you leave the hospital.

The national child health record system will be contacted to prevent you receiving appointments for routine events such as immunisations which could be very distressing.

## Before leaving hospital

Before you leave the hospital, you should be told that your baby or child will be transferred to the mortuary, before being transferred to the hospital where the post-mortem examination will take place. You should also be given the contact details of your key contact.

Going home without your child can be very difficult for parents, so take your time when leaving the hospital, and try to have a loved one or friend to go home with.

If you were breastfeeding your baby or child when they died, ask your health visitor, midwife or doctor for advice on managing your milk supply. Your GP can prescribe medication to stop milk production more quickly and help with the physical discomfort you may experience.

Some families may choose to donate their breast milk to a milk bank. More information can be found at these web addresses:

[ukamb.org/donate-milk](http://ukamb.org/donate-milk)

[humanmilkfoundation.org/hearts-milk-bank](http://humanmilkfoundation.org/hearts-milk-bank)

[nhsggc.scot/hospitals-services/services-a-to-z/milk-bank-scotland/](http://nhsggc.scot/hospitals-services/services-a-to-z/milk-bank-scotland/)



## Early response

- usually in the first week

## Home visit

As soon as possible after your baby or child's death, if they died at home, you will be visited at home by a police officer. Their role is to establish what happened to your child and report the circumstances to Crown Office and Procurator Fiscal Service (COPFS). If your child died away from home, the police may visit the place of death and may visit you later to ask you further questions.

The Procurator Fiscal is informed of all sudden and unexpected deaths. The police investigate the circumstances of the death on their behalf. You will be asked a number of questions by the police and health care staff involved. These questions will be asked separately. This may be upsetting but is necessary and important and the information you provide will be valuable. It will be shared with other professionals to avoid you having to repeat your answers. The police may also take some of your baby's things (such as bedding) to be examined. In most circumstances you will be able to get these back once a final cause of death is agreed.

## Post-mortem examination

All sudden and unexpected deaths of babies will have a post-mortem examination, which should be undertaken by a specialist paediatric pathologist. This often means your baby will have to travel, sometimes long distances, to a specialist centre. This is clearly upsetting for

families, and you should be kept up to date by Crown Office and Procurator Fiscal Service (COPFS) with where your baby has been moved to and when the post-mortem examination is going to take place.

A post-mortem examination is a careful external and internal investigation of the body to try to discover the cause of death. A cause of death, or possible factor contributing to the death, is found in approximately half of the post-mortems performed. When the post-mortem examination does not reveal a cause of death, then it is likely that a diagnosis sudden unexpected death in infancy (SUDI) or sudden unexplained death in childhood (SUDC) will be given. The term 'unascertained' may also be used.

It is a legal requirement for the Procurator Fiscal to instruct a specialist pathologist to carry out a post-mortem examination to try to agree a cause of death. The first results from this examination will be available within a few days, after which the funeral can usually take place. During the examination, samples of tissue and body fluids will be taken for further tests. Some results of these further tests should be available within 2-3 months, other results taken from tissue samples may take longer. Some of the tissue samples may be kept as a permanent part of your baby or child's medical information.

A full copy of the report is sent to the family with an offer to meet the pathologist to discuss the findings.

Performing a post-mortem examination is complex and it can take up to 12 months for all tests to be completed.

You may be asked whether you are planning a burial or cremation, so that the correct papers can be prepared. It can feel difficult to make this decision. If you are not

sure you can inform the funeral director of your choice later on.

You may wish to discuss possible options with your chosen funeral director, and take time to consider what would be most meaningful for you and your family.

## Tissue retention

As part of the post-mortem examination, the pathologist will take small samples of tissue (smaller than a postage stamp). These are then put into slides and may need to be kept a while longer for testing.

Some parents find great comfort in knowing their child's tissue might help research, or provide more answers from future medical advances. Even when no cause of death is found, advances in medical research open up the possibility that an answer may eventually be found.

It will normally be possible for you to visit your baby following the post-mortem examination at the mortuary and details of how to arrange these visits should be given.



## Care of your child after the post-mortem examination

After the post-mortem examination, a **death certificate** will be issued. You can then choose how and where you wish to care for your child before their funeral.

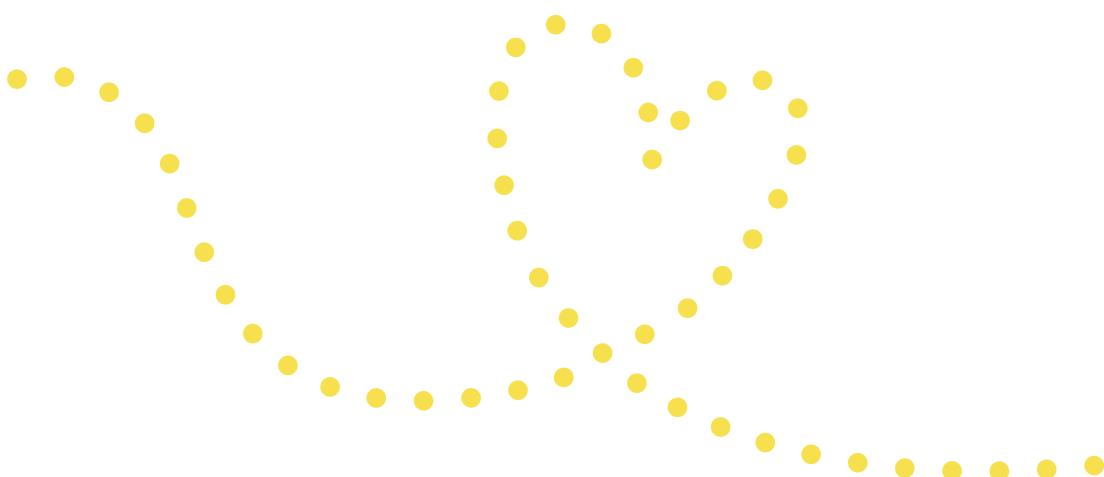
Many families choose to visit their child at the hospital or funeral home. Others choose to bring their child home for a few hours, or days, before the funeral. Some families find it comforting to say ‘goodbye’ in familiar and loving surroundings. Some families choose to invite a representative from their faith to say a prayer or give a blessing.

Your child may feel different to touch and hold as a result of natural changes after death. You may ask your key contact, healthcare professional, or funeral director, about any ways in which their appearance might have changed. They can also tell you about any visible signs of the post-mortem examination (usually only visible if you choose to undress your child). It is helpful to know what to expect. If you have other children, you can then prepare them in the same way.

Some families find comfort in making new and lasting memories in these moments. Singing your child’s favourite song, or sharing meaningful stories might bring your family comfort. Inkless kits to take hand and footprints, without damaging your baby or child’s skin, are available. You may want to ask your funeral director if it is possible to use one of these kits to take hand and footprints of your baby or child before the funeral takes place. You might want to keep a lock of your child’s hair if they had some and this hasn’t already been done in the hospital.

## Registration of death

The Procurator Fiscal has to authorise the release of your child's body and written permission must be obtained before a cremation can be carried out. A form called an E1 is used and can be collected from the Procurator Fiscal's office. The funeral director will be in contact with the Procurator Fiscal and will be able to advise you about when to make the funeral arrangements. More information can be found at: [gov.scot/publications/death-scotland-practical-advice-times-bereavement-revised-11th-edition-2016-9781786522726/pages/8/](http://gov.scot/publications/death-scotland-practical-advice-times-bereavement-revised-11th-edition-2016-9781786522726/pages/8/)



## Expected deaths

If your child had a long-term illness or life-limiting condition and death was anticipated or inevitable, it is likely that you and the team supporting you will have made an appropriate 'care pathway' together.

This might include an end-of-life care plan for your child. Local health care staff or others, such as hospice or hospital staff, will work with you and your family to support you.

You should be able to register your child's death quickly and proceed with your family's planned funeral.

## Choosing a funeral director

Arranging a service with a sympathetic funeral director can be a big help. You can choose any funeral director; it doesn't have to be the one who took your child to the mortuary. It might feel helpful to seek advice from a representative of your faith, or you may wish to consider alternative forms of non-religious service. You can find funeral directors in your local area by contacting the National Association of Funeral Directors on **0121 711 1343** or search online at: [nafd.org.uk](http://nafd.org.uk)

## Funeral arrangements

You may choose how to commemorate and celebrate your child's life. You will be offered **different options**, including the following:

- A service at your own place of worship, and burial in your local cemetery/church.
- A service at your own place of worship or at the crematorium, and then a cremation.
- A non-religious ceremony. This can be arranged by you, by family or friends or by organisations including The British Humanist Association or an independent celebrant.
- A service, religious or not, in your own home.
- A service of thanksgiving, sometime after the funeral.

## Burial or cremation

Your faith representative or funeral director can help you decide whether to have a burial or cremation. You might like to ask what rights you will have concerning ownership of the burial or cremation plots, what type of memorial will be allowed such as a headstone or plaque, and the costs.

**You can discuss the choice of songs, hymns, music, readings and poetry for the ceremony with family, friends and those helping with the service. These decisions can feel very upsetting to make, so try to give yourself enough time to make the choices that are right for you.**

## Ashes

If you choose a cremation service, be aware that it is sometimes not possible for the crematorium to provide ashes. It is a good idea to ask if this will be the case and ask for details of a crematorium which can provide ashes.

Some families choose to scatter the ashes on the same day as the cremation, but you may need to have the cremation in the morning to fit both in the same day.

Some families choose to keep the ashes at home with them. Again, this can be a very difficult decision, so take as much time as you need in making it.

## Costs

Funeral directors in Scotland offer a simple funeral free of charge. However there can be additional costs such as order of service printing, coffin costs, flowers etc.

Parents or carers receiving certain benefits or tax credits may be eligible for Funeral Support Payment from Social Security Scotland.

You can use the Funeral Support Payment towards funeral costs for your child: [mygov.scot/funeral-support-payment](https://www.mygov.scot/funeral-support-payment)

To find out if you qualify, you can phone Social Security Scotland on 0800 182 2222 or go to Funeral Support Payment.

Your funeral director or Citizens Advice Scotland may also be able to help you.

## Other children

It can be helpful to involve brothers and sisters in the funeral, whatever their age. Give them a choice about whether to be there, and talk to them about what will happen so they are prepared. A member of your family or a friend could be asked to help care for them at the funeral.

It's generally best to give children **simple, straightforward explanations** about what is happening. It is also important to let the school know about the death of a pupil's brother or sister, so staff can provide support and be aware of any emotional or behavioural changes. There is more information on supporting brothers and sisters on page 40 onwards.

Child Bereavement UK have child-friendly animations which explain burial and cremation to children, which you might find helpful:

[childbereavementuk.org/what-happens-at-a-burial-animation](http://childbereavementuk.org/what-happens-at-a-burial-animation)

[childbereavementuk.org/what-happens-at-a-cremation-animation](http://childbereavementuk.org/what-happens-at-a-cremation-animation)



## Memorials

**Books of Remembrance can be found in many places of worship, hospitals, and funeral directors. You may wish to enter your child's name in these. If you would like to have a headstone or memorial plaque, you can seek advice from your funeral director. They will give you an estimate of cost, and how long it will be before a headstone can be put in place. There are regulations on the types of memorial stones allowed in cemeteries, and some churches have their own regulations.**

Some families plant a tree or bush or make some other form of permanent memorial. You could consider planting it in a large pot so that you can take it with you if you move home. There are also some memorial forests where you can have a tree planted in a protected and dedicated space.

It can help to have some special items that help you feel connected to your child. You may like to create a memory corner in your home; or garden area to place particular items that remind you of your baby, or which are comforting.

You may want to keep your own memory box or a memory book, containing items that help you and family members commemorate your child's life. Creating your own boxes can be a special activity for your family, or you can buy boxes in various designs from several charities, such as Winston's Wish ([winstonswish.org](http://winstonswish.org)) and Child Bereavement UK ([childbereavementuk.org](http://childbereavementuk.org))

Some parents choose to have a piece of jewellery which could perhaps incorporate a lock of their child's hair, or ashes to carry as a memento with them. Others may choose to keep their baby's ashes in a precious box or a teddy bear. A weighted bear to represent the birth weight of your child might provide some comfort if you are experiencing the sensation of 'empty arms'. You might also consider having a quilt made using some of your child's clothing.

You may also like to create your own special memorial page in tribute to your child. It's simple, quick and free to set up a tribute page via our website at [lullabytrust.org.uk/tribute](http://lullabytrust.org.uk/tribute). This can be a wonderful way to remember your baby. Reading the messages and seeing the images left about a loved one can be a source of great comfort, and your tribute pages can be kept open for as long as you like.

It can also be used to collect and record donations given in memory of a loved one.



## The Child Death Review

All child deaths are reviewed in Scotland, usually with multi-agency input and led by a nominated chairperson. The chairperson is most often a health professional who works at the NHS board where your child lived, and they might have been involved in your child's care prior to their death.

Reviews are conducted into the deaths of all liveborn children up to the date of their 18th birthday. This extends to 26th birthday for care leavers who are in receipt of continuing care or aftercare at the time of their death.

The aim of these reviews is to identify learning to prevent future deaths and improve support to families. This process works alongside all the other elements of the investigation into a baby's death. Your key contact should inform you that the child death review process is taking place and how you can contribute your questions or experiences should you wish.

You can find more information about child death reviews in Scotland at: [healthcareimprovementscotland.scot/publications/supporting-families-in-scotland-with-the-child-death-review-process/](https://healthcareimprovementscotland.scot/publications/supporting-families-in-scotland-with-the-child-death-review-process/)

## Other practical things to think about

Unfortunately, there are other financial practicalities to sort out during this difficult time. It may be easier to focus on these after the funeral when you have a bit more time. You could ask a friend or family member to help you.

You will need to tell your Child Benefit Office about your child's death.

In Scotland, if a child dies, **Child Benefit can continue for up to eight weeks** after the child's death. To claim Child Benefit, you must inform the Child Benefit Office as soon as possible, including the date of death. You can do this by phone or post, and you will need to include the child's birth registration number or adoption certificate.

Your child's GP should have been notified of your child's death very quickly, but some families contact them directly as well. You could ask your GP to add a flag about your child's death on your and your family's records. The flag will remove the need to explain what happened at each visit.

There may be other organisations, such as dentists or opticians, that have your child's details. They will also need to be informed at some point. If you joined any baby or child groups, such as supermarket clubs or online clubs, you may want to tell them that you don't want to receive any more information. Otherwise they may continue to send offers and information relating to your child's expected progress. The Mailing Preference Service can help with this; you can register online at [mpsonline.org.uk](http://mpsonline.org.uk)

You may wish to reconsider your privacy settings on social media if there are photos of your child on there, as these could be reused without your permission if they are publicly accessible.

If you have been employed and your child was less than one year old when they died, you should still be entitled to statutory **maternity or paternity leave** and pay. It may be that you do not have to return to work for a year after

your baby was born, although some of this leave may be unpaid. Your employer may offer applicable extra maternity benefits, even though your child has died. Talk to your employer about what they can offer you or check your contract.

If you opened a savings account or an insurance policy in your child's name, it will need to be cancelled by contacting the bank, building society or other provider concerned.

There are other benefits that you are still entitled to if your child died under one year of age, such as free dental care and prescriptions.



## Grieving

**0808 802 6868**

**Mon to Fri 10:00am – 2:00pm,  
Sat and Sun 6:00pm – 10:00pm**

When someone we love dies, we experience overwhelming feelings of loss and sorrow, which we call **grief**. When a child dies, it is especially devastating and is often said to be the most painful experience anyone can go through.

You may also experience the profound effects of **shock and trauma** due to the sudden nature of the death. Many people experience feelings of guilt or regret as they replay events in their mind. All of these elements can feel completely overwhelming, and you may feel isolated and lost. Whatever your thoughts and feelings, grief is a deeply personal experience, it has no set time and everyone deals with it in their own way. There is no wrong or right way to grieve, and your feelings may seem strange at times; interchanging from crying one minute and laughing the next.

It can be a turbulent time, although there may be periods of calm. Intense emotions, which had seemed to fade, can return. You may feel confused or find it difficult to make decisions or concentrate for any length of time. Even if you can sleep you may still feel exhausted. Grieving people can sometimes fear they are going mad. Many parents say that their child is always on their mind, that they experience aching arms and hear their child cry.

Parents often go over and over in their minds everything they did or did not do, which they worry could have

caused the death. They sometimes blame themselves or each other, or feel angry with the doctor, health visitor or anyone who had seen the child recently. These feelings of guilt and blame are normal, very common, and will lessen with time. Talk to someone if you feel able to. Someone outside of the family can talk through those questions and thoughts.

Almost all grieving parents feel anger at some point. Parents sometimes find helpful outlets for anger, such as crying and shouting in an outdoor open space, or exercise like walking/ running/ jogging. Some people start to doubt or question their religious beliefs. It is also not unusual to feel anxious or to fear something happening to other family members, especially children.

If you are finding it hard to imagine carrying on, have suicidal thoughts or are thinking about harming yourself, it is important that you tell someone about the way you feel. If you can't face talking to your loved ones or friends, you can talk to someone at The Lullaby Trust, where we have a helpline especially for bereaved parents and family members. 0808 802 6868 Mon to Fri 10:00am - 2pm, Sat and Sun 6:00pm - 10:00pm.

The Samaritans are open 24 hours a day on **116 123**.



## Grieving

You can also talk to your GP or health visitor who should be able to offer support if they know how you feel. They will understand that a parent who has experienced the sudden unexpected death of their child may possibly be depressed or suffering from **Post-Traumatic Stress Disorder** (PTSD) and can help you to access services, such as counselling/therapy or mental health support, which will provide extra support for you. There may be waiting lists to access this support, but charities are always available to listen to you. You will be able to find the details for some charities at the end of this booklet.

If you believe you may be experiencing the ongoing symptoms of trauma following the death of your baby or child The Lullaby Trust has a resource that may be supportive: [lullabytrust.org.uk/resource/tips-for-coping-with-the-trauma-of-sudden-bereavement/](https://lullabytrust.org.uk/resource/tips-for-coping-with-the-trauma-of-sudden-bereavement/)

You will need to give yourself time to grieve. Be kind to yourself, avoid trying to block your feelings with drugs or alcohol, this only tends to postpone the grieving process. [lullabytrust.org.uk/bereavement-support/living-with-grief/alcohol-and-grief/](https://lullabytrust.org.uk/bereavement-support/living-with-grief/alcohol-and-grief/)

Take each moment as it comes, don't think too far ahead and give yourself credit for getting through each day.

## Other common feelings

Most parents who experience the death of their child describe the pain as the most intense they have ever felt. Feelings such as worry and guilt can feel overwhelming, but rest assured they are common and normal parts of grief. One mum described feeling this way:

**"For the longest of times I was blaming myself thinking I did something wrong."**

You may wonder if you will be able to tolerate it and survive or be able to feel that life has meaning again. A dad explained:

**"This is the most unnatural thing any parent can go through. We have so many regrets and self-blame moments, we know it wasn't our fault, but the pain and fear will forever scar us."**

It can feel as though you are functioning in a fog during the first few weeks after your child's death. The symptoms of grief can be physical as well as emotional. A mum told The Lullaby Trust:

**"People think losing a baby is the worst thing that can happen to you, and all I can say is that it is infinitely worse than anyone can ever imagine. The physical loss as I used to hold him all day, the emotional loss of never seeing him again, and the social loss as it changes the relationships around you."**

Grief can feel disorientating and can impact your normal routine and sleep patterns:

### **"Grief doesn't know what time of day it is."**

It is ok to focus on getting through one minute at a time, if that is all you can manage at first.

Some parents describe their experience of the funeral as of being an observer or not really being emotionally involved. One parent described how isolated they felt:

**"No-one can even try to understand what we're going through, which at times has resulted in us withdrawing from others because in reality they can't get it."**

Another parent told The Lullaby Trust:

**"I feel so different from everyone else, because until you're in this world of baby loss, no-one ever talks about it, so it feels very alien and taboo."**

Birthdays, holidays and the anniversary of the death can trigger periods of intense pain and suffering. These are all normal reactions. You and your partner may experience your grief differently, and may have difficulty in sharing feelings. You may feel isolated, even though you are part of a couple. One of you may want to talk often about your child while the other may not even want to hear their baby's name spoken. One dad said:

**"We coped in different ways - she grieved, I didn't."**

**I began to feel overwhelmed by the burden of supporting my wife and children while at the same time trying to cope with my own feelings."**

Friends and relatives often treat parents differently after the death of a child. Fathers are often asked

**"How is your partner?",**

and people may forget to say

**"How are you?"**

Fathers may feel it is their job to discourage looking back and to encourage facing the future. Men often refuse help or may not ask for support when it might be helpful.

Parents' relationship with each other may suffer further as one of you may find comfort in physical contact, but it is not wanted by the other. You may feel differently about making love or the possibility of having another baby.

It is possible to misunderstand the reasons for each other's responses (sometimes one partner feels that the other's way of expressing their grief means they loved their child less intensely), so try to be open and honest about your own needs and feelings, accepting that each person's response is valid.

One mum told The Lullaby Trust:

**"We were from different cultures; had different beliefs. Our differences had always seemed as important as our similarities, they made us click.**

**Immediately after our daughter's death, it felt like we were submerged in the grief together, our tears fell in the same way. Soon though, it felt like we were on different pages, in completely separate books, in libraries continents apart! I felt jealous of the calm certainty his faith seemed to give him. He found it difficult to see how overtly broken hearted I was without our daughter in my arms; he wasn't used to such loudly open grief. With a lot of patience and understanding we got through it, we are stronger than ever, but for a while I wasn't sure we would.”**

In time, couples who can respect each other's different ways of grieving often find that they can begin to talk, share and support each other more easily. For some people, reading or hearing about others experiences can bring a sense of comfort and unity:

**“Later, in the depths of grief, I found reading books with other people's experiences made me realise what I was feeling was 'normal' and reading about how it does get easier further down the line gave me hope.”**

The Lullaby Trust have a list of helpful resources including books, podcasts and playlists which you might find helpful: [lullabytrust.org.uk/bereavement-support/practical-advice/podcasts-playlists-and-other-media/](https://lullabytrust.org.uk/bereavement-support/practical-advice/podcasts-playlists-and-other-media/)

## If you are on your own

For a parent on his or her own, the sudden and unexpected death of a child can be particularly difficult.

One mum told The Lullaby Trust:

**"It is very hard to describe the loneliness which grief brings when you have no partner to share the loss of a beloved child. The burden becomes only yours. You seem to dive into a dark world of your own, shutting out everyone around you. All you want is a partner to comfort you in the sleepless nights, to hug you and dry away the tears, to share memories. It is so easy to fall apart when you're on your own."**

Many parents turn to their own parents in times of need, but some have no family to support them. The Lullaby Trust's befriender service could be of some support to you. We can put you in touch with a befriender, who is a bereaved parent to talk about some of the thoughts and feelings you may be struggling with. Please phone The Lullaby Trust to talk to a befriender directly.

You may find this helpful straight after your child has died, or even months or years later.

If you do not feel up to talking, you may find it helpful to keep a journal or write letters. One mum told The Lullaby Trust:

**"I wrote letters to Michael all the time. I still have**

**those letters and although I don't write them anymore, I do sometimes still read them."**

Even if you are not on your own, you may find writing such letters to your child helpful.

You may find it useful to contact Gingerbread, an organisation who offer support to single parents. Visit [www.gingerbread.org.uk](http://www.gingerbread.org.uk) or call **0808 802 0925**

**Helpline: 0808 802 6868**

Mon to Fri 10:00am - 2:00pm  
Sat and Sun 6:00pm - 10:00pm

**Website: [lullabytrust.org.uk](http://lullabytrust.org.uk)**



## If a twin or multiple dies

If your child was a twin or multiple, you may feel that you are not able to grieve properly for the one who died. You have the surviving child(ren) that need your love. Continued caring with day-to-day routines can leave you with little time for your own emotions. Your feelings will also be mixed because your surviving child(ren) are a constant reminder that there should be more. It is likely that your anxiety around your surviving twins or triplets will be heightened. It can be particularly challenging to suddenly be caring for one baby and thinking about the sometimes identical twin that has died. Emotional support is available from **befrienders at Twins Trust.**

Although it is extremely rare for siblings to die, your doctor or the hospital may suggest that your surviving child(ren) go into hospital for tests.

Anniversaries such as birthdays may be especially poignant. It is important, as your surviving child(ren) grow, that they know that they had a twin/triplet, brother, or sister. Sharing your memories and photographs may help.

You may find it useful to visit Twins Trust Bereavement website: [twinstrust.org/bereavement](http://twinstrust.org/bereavement) who offer bereavement support groups and resources.

## If your child was over one

If your baby or child was very close to or over one year old when they died, this section is intended especially for you. The rest of the booklet has been written both for parents who have lost a baby or who have lost a child over one. If you have turned immediately to this section, you may also find some factual information repeated elsewhere in the booklet. We hope that you will find all or much of the information helpful.

### Some facts

The vast majority of SIDS deaths happen when babies are less than six months old; with the highest number happening at 1-3 months old. Parents naturally expect that after six months they may begin to feel less anxious about SUDI and that on their child reaching the first birthday (and the 'official' end of infancy), the possibility of such an event is now past.

Very sadly, we know that in the UK every year a small number of young children die suddenly and unexpectedly, in a manner which appears to be similar to SIDS, but is usually referred to as sudden and unexpected death in childhood.

A mother, whose daughter of 16 months died, describes feeling intensely "lonely" in her grief. Although she searched for stories and information, everything she read related to babies under a year old.

Another mother, whose daughter died at 13 months and three weeks, was told by her GP that “J’s death wasn’t a cot death” (at that age) and she felt “like an imposter” while suffering “the helplessness of not having a diagnosis.”

## Special issues in deaths of children over one

The shock and sense of isolation can be even more intense for parents who lose an older child, as much of the safer sleep information and advice no longer applies to them.

It can sometimes be difficult for people, even close friends and family, to know what to say or how to behave around you after the death of your child. They may try to discourage talking about your child for fear of upsetting you. Although this doesn’t mean that they don’t care, it can cause feelings of loneliness, which can make the grief even harder to bear.

If you find talking to friends and family too difficult, you can speak to The Lullaby Trust who has a bereavement helpline. The Lullaby Trust can put you in touch with a volunteer befriender, who is a bereaved parent themselves. Befrienders have proved to be a great comfort to many parents. You may find it helpful to talk openly to someone who understands your situation. If you are struggling to cope, you can also speak to your doctor who can help.

**Helpline: 0808 802 6868**

Mon to Fri 10:00am - 2:00pm

Sat and Sun 6:00pm - 10:00pm

**Website: [lullabytrust.org.uk](http://lullabytrust.org.uk)**

## **The investigation**

The shock of police involvement, as they look into the circumstances surrounding your child's death, can add to the sense of isolation and guilt for many parents. This is a legal requirement after a sudden death at any age, not only the death of a baby or child. Several parents have described feeling 'under suspicion'. This, along with the feeling that they 'must be to blame' if their child dies from no obvious cause, means the shock and grief may be heightened by anxiety and despair.

Many parents feel this way. However, there is a widespread lack of awareness, even amongst professionals, regarding sudden unexpected death in childhood. For parents of children who were over a year old, this lack of awareness can make those feelings even more difficult to deal with or to talk about. You may find it helpful to talk to your key worker for reassurance about police involvement.

# The paediatric pathology investigation

The investigation of a sudden death of a baby or young child, and the post-mortem examination, are carried out in the same way as would be the case where the death was expected.

In the UK, the post-mortem examination should be carried out by a specialist paediatric pathologist (a type of doctor who is trained to find out how a child has died).

Most SUDI deaths occur under the age of six months. It is more likely that a cause of death or a contributing factor will be found as a child's age increases. It is also more likely that the cause will be a previously undiagnosed condition. Sadly, for many babies and young toddlers it will still be unlikely that a definite cause for their death will be discovered.

The Lullaby Trust supports all bereaved families whose baby or young child dies, including those whose children were over a year old.

Within The Lullaby Trust, parents who have lost a child over one are available as trained Befrienders to offer personal support via telephone and email to all families who have experienced the unexplained death of a child.

## Life after your child's death

The death of a child inevitably changes the dreams and hopes parents have for the future.

One dad said:

**"I miss my son as much for the things we didn't do together as for the things we did. What strikes me most of all these days is the fundamental way in which his death has changed and continues to change us. He was only with us for five months, but I doubt if anyone else will make such a profound impression on our lives."**

People may suggest at some point that you should be 'over it'. This is a meaningless concept for a bereaved parent, so try not to let others suggest that you should be 'moving on'. You will make your own decisions about what helps you to cope and carry on. You may find support in doing this from friends and relatives and perhaps in discussion with a Lullaby Trust support adviser. It is almost always a good idea to talk things over when you feel especially low, or if you feel tempted to use alcohol, medication, or drugs to numb your grief temporarily.

Such a profound bereavement may change your priorities or make you look at life differently.

One mum said:

**"One thing that grief has done for me is to make me wiser and the future brighter. No matter what**

**comes along, you know that you can cope with anything; nothing can ever be as bad again for you. I will always keep my son in my heart and I am glad to have had such an angel share my life."**

## **Returning to work**

If you are employed, returning to work can be a difficult time. Your colleagues may be unsure of whether or not to say anything about your child's death and how you are feeling. Most people do care, but they can find it difficult to express their sympathy.

Some parents have found it helpful to ask their employer to speak to colleagues about what has happened before a return to work.

Some parents are not in work when their baby or young child dies. If parents had decided to leave work or take maternity/paternity leave, they may find it difficult to explain the change in circumstances when they return.

As a bereaved parent, you will be entitled to paid leave following the death of your child. This will be two weeks and there will be some flexibility over when you take this. It will be paid at a set amount, which much like a statutory sick pay, may be less than your salary.  
[gov.uk/parental-bereavement-pay-leave](http://gov.uk/parental-bereavement-pay-leave)

Talk to your employer as soon as you are able to. Many will be sympathetic and may offer more flexibility around when you return to work.

You can self-certify sickness absence for the first week, and then you will need to visit your GP for a 'fit note' to

continue to take sick leave. Try to contact your work, or ask someone else to if you need more information about your employer's position.

You may find this resource for employers helpful:

[lullabytrust.org.uk/resource/bereavement-support-in-the-workplace-leaflet/](http://lullabytrust.org.uk/resource/bereavement-support-in-the-workplace-leaflet/)

## The brothers and sisters

Parents often feel worried about explaining the death of a sibling to their remaining child(ren). You may feel overwhelmed by your own grief and the difficult task of knowing what to say, especially if you don't have a reason for how or why it happened. Many parents express a desire to try and protect their child(ren).

It is important to tell your child(ren) about the death of their sibling **as soon as possible**. Ideally by you or someone they are close to. Children can pick up on subtle changes in our body language, moods and behaviour, indicating to them that something may be wrong. Children have a greater capacity to understand than adults often expect. Vague explanations and withheld information can be more frightening than the truth as they try to make sense of the bits they know. When not given an explanation, even very young children may feel anxious and insecure and alone in their worries.

Individual children have their own personalities and will **react differently**, just as adults do. Some children may cry, others may carry on as if nothing has happened. All will be affected at some level. It is ok to cry in front of your child. This demonstrates healthy emotional expression. Children will not be frightened by your tears if they know

why you cry. It also gives them permission to do the same.

It is best to begin with a **simple explanation** and then allow children to ask questions when they are ready. Ensure they know they can speak to you when they need to and provide opportunities for this. It is ok not to have all the answers, what is important is to listen to them so that they feel they are supported and included. They may need to repeat the same questions over and over as part of understanding what has happened. It is best to answer in a straightforward way, using simple, age appropriate language.

Some of the things that are said to children, with the best and kindest of intentions, can be misunderstood and lead to confusion and worry, such as:

- **“Gone to sleep”** – can give children the fear that they too may not wake up, and they may be afraid to go to sleep, resulting in anxieties at bedtime.
- **“We have lost your sister/brother”** – can leave a child searching in the hopes of finding them again, like looking for a lost toy.
- **“The doctor has taken him/her away”** – can leave children fearful of visiting a doctor again and may cause the child to feel abandoned or think he or she did something wrong and is no longer loved.

Avoid saying that the child died in hospital as this may create fear that they might die if they need to go into hospital.

Unless your family share a religious faith, which brings comfort, suggesting that a child has ‘gone to heaven’ or ‘to live with God or Jesus’ may be confusing for a young child. A leader from your faith might be able to offer guidance when supporting your children.

Children and young people grieve just as much as adults, but they show it in different ways. Siblings may regress in their behaviour, becoming clingy, reverting to thumb sucking or bedwetting, or complaining of headaches or stomach aches. Some may not speak about their feelings, and others may try to behave well or be helpful. A child may jump in and out of grief. To an adult they may seem ok or uncaring, but this is not the case. It is important to follow their lead. Children, like adults, can experience a wide range of emotions, including sorrow, anger, disbelief, and even guilt. Parents can be surprised to hear that their older toddler or child may worry that their jealous feelings, or a fight over a toy, for example, caused the death. It is important that children are reassured that it wasn’t anybody’s fault that their sibling died.

Try to include siblings in the events and ceremonies which follow the death, as excluding them is likely to leave them feeling anxious, bewildered and alone. Allowing them to see their sibling and say goodbye is usually helpful – their imagination is often much worse than reality.

You may need help in deciding how to prepare your children to attend or participate in the funeral or memorial service.

The Child Bereavement UK website has further information and support around talking to children and animations which explain burial and cremation to children, which they might find helpful:

[childbereavementuk.org/supporting-bereaved-children-and-young-people](http://childbereavementuk.org/supporting-bereaved-children-and-young-people)

[childbereavementuk.org/what-happens-at-a-burial-animation](http://childbereavementuk.org/what-happens-at-a-burial-animation)

[childbereavementuk.org/what-happens-at-a-cremation-animation](http://childbereavementuk.org/what-happens-at-a-cremation-animation)

You can contact Winston's Wish, a charity which offers bereavement support to children, on 08088 020 021  
[winstonswish.org](http://winstonswish.org)



## Ways to help children

- Talk to your children in a straightforward way, giving honest information in simple language.
- Encourage your children to talk and express their feelings, and be honest about your own.
- Listen to your children; it is important for them to be able to talk about their thoughts and feelings without being dismissed.
- Try to welcome their questions. Some questions may be painfully direct, but if the child has asked, it's because they want to know the answer.
- Repeated questions need patient listening and repeated answers (which should remain consistent). Children may ask the same question repeatedly to several adults to check out a puzzling or distressing situation.
- It is alright to say "I don't know" if that is true.
- Share tearful times. Children will not be frightened by your tears if they know why you cry. It gives them permission to do the same.
- Be patient with children when they are angry. It is normal to be angry, and acknowledging the child's feelings rather than telling them 'not to be angry' is best.
- Share memories of their brother or sister by looking at photographs and remembering events. You might like to put together a memory book or box.
- Maintain usual routines as much as possible: bed times, story times, playtimes, walks and meals. If you cannot manage this at first, enlist a relative or other loved and trusted adult to keep the children's routine as consistent as possible.

- Keep the children at home, rather than sending them away to relatives or friends, if at all possible.
- Talk to their playgroup/nursery leader or school teacher and explain what has happened. Discuss with them how they will handle the news, and support your child(ren) in the school or nursery.

**It is important for your child(ren) to express their feelings, and, if very young, they may do this through their toys and through play. If your child's reactions worry or puzzle you, do consider talking things over with a support adviser at The Lullaby Trust. You may wish to talk to your GP, health visitor or child's teacher.**

**For ideas on supporting your child's ongoing memories and a list of books which may be helpful, please see The Lullaby Trusts webpage on supporting brothers and sisters: [lullabytrust.org.uk/bereavement-support/supporting-brothers-and-sisters](http://lullabytrust.org.uk/bereavement-support/supporting-brothers-and-sisters)**



## Fathers

When a baby dies much of the focus of support may be on the mother or birth parent, but of course fathers and partners also have an important relationship with the baby or young child that has died so will also be grieving.

From early pregnancy onwards, a lot of parents will daydream about what their babies will be like and imagine them at different life stages: as a child growing up, taking their first steps, playing with siblings, starting school, even them starting their own family. They may also think about the things they want to do together, like teaching them to ride a bike. So, grief will be not just for the young baby or child but for the whole life you imagined with them.

Others might find that they don't feel a connection to the baby until after it's born, and this can affect how they deal with a loss.

How grief gets expressed will **vary a lot** according to how you were brought up to deal with emotions, the society you live in, and the culture you are part of. There is no right or wrong way through grief, but it's important to find something that works for you.

## What helps?

What we do know is that generally it helps to try to find a balance between being immersed in grief and focussing on adjusting to life without your baby and thinking of the future. It also helps to find a way to keep a sense of the bond or connection with your child.

If you are comfortable speaking, it can be good to talk or message with others who understand what you are going through. Some groups base support around an activity like going away for a trip or playing sport. Others might have online support via Facebook or provide peer-to-peer support. You might like to take on a challenge that could be linked to fundraising for a cause that's important to you, in your child's memory.

By having support for yourself or an outlet to vent emotions, many people find they can be more supportive of partners and can cope better with life.

The Lullaby Trust have befrienders who you can speak with. Our befrienders also answer our freephone support line **0808 802 6868**, 6:00pm - 10:00pm on weekends and public holidays.

## Your relationship

Many couples worry about the effect of the bereavement on their relationship and worry it might cause a breakup, but there is no evidence to suggest this is more likely to happen.

You may find that you feel brought closer together by the sadness that you share and may not want support outside the couple. Sometimes partners have very different ways of coping with grief or be out of sync with each other in terms of having a good or bad day and this can cause misunderstandings and tension.

One partner may want to be kept busy and find distraction whilst the other wants to retreat and be with their feelings. One of you might really need support at a moment when the other just hasn't got the resources to give this.

It can lead to feeling the other person doesn't care. So, it is important to listen to each other and keep channels of communication open and to get outside help if things seem to be getting worse between you.

In western culture there can be a pressure for fathers/partners to be the one who provides support and strength for the mother/birth parent and they may feel this means not showing how they feel. This can be misunderstood as being uncaring and lead to distance between couples. It can also mean that people around you don't know how you are really feeling, so may assume you are ok when you're not.

There can be a real strength in realising you need help and finding what's right for you. If you are better resourced, you may find you can be more supportive of your partner and can cope better with life.

When you go through a traumatic loss it can make you both question a lot of things in your life and want to re-evaluate things. It is important to keep talking about this together and not make major decisions in haste.

## LGBTQ+ parents

As a non-birthing mother or partner you have had to face the loss of your child whilst perhaps not always being acknowledged as a parent by health professionals and having your role misunderstood. Your feelings may be just as intense as your partner who gave birth.

As a couple, you may have had to go through a lot of procedures in order to have your baby which may make it extra hard and financially challenging to be able to consider having another baby.

For resources for **LGBTQ+ parents** see our website:  
[lullabytrust.org.uk/bereavement-support/find-support/  
bereaved-dads-partners-co-parents/](http://lullabytrust.org.uk/bereavement-support/find-support/bereaved-dads-partners-co-parents/)

For resources for **bereaved Dads** see our website:  
[lullabytrust.org.uk/bereavement-support/find-support/  
bereaved-dads-partners-co-parents/](http://lullabytrust.org.uk/bereavement-support/find-support/bereaved-dads-partners-co-parents/)

## Grandparents and other family members

The death of a baby or young child affects **everyone** in the family. Some grandparents have told The Lullaby Trust that they feel a double sense of pain: grief for the baby who has died and distress for their son or daughter's grief. They can struggle to find ways to help without interfering, and often do not feel entitled to express their own grief and instead focus on trying to support their child and remaining grandchildren.

The anger everyone in the family feels about the death is often directed at those closest and is easily misunderstood. Tensions between the generations over differing childcare practices and even spoken-aloud thoughts about the unfairness of a healthy baby dying when a much older, even unwell, relative continues to survive. This may cause great hurt in the heat of the moment.

A very deep sense of loss will be felt by those who live far away from the grandchild and may not have been able to see and hold him or her much before the death. These considerations apply to other relatives as well. If it was a niece or nephew who died, feelings of loss may

be complicated by fears for their own children or future ones. Suddenly everything seems uncertain.

One aunt told The Lullaby Trust:

**"It could just as easily have happened to one of my own children, I cannot imagine what it would have been like."**

A sister or sister-in-law may be pregnant or have a child of a similar age, which may cause pain and even jealousy. It may take a great deal of emotional effort to see nieces and nephews, and join in family celebrations.

If you can, try to let family members know the extent that you feel able to join in the activities and celebrations of their children. Also, how you would like your child's name and life to be spoken of and remembered. Relatives are often very unsure, and risk unwittingly isolating their bereaved family member rather than 'upset' them. They will more than likely feel glad to receive your direction.

## **If someone else's baby or young child dies in your care**

It is a terrible shock if someone else's child dies in your care, whether in your nursery, in foster care or while you were caring for the child in the parents' home.

You will have been the person who had to handle the crisis, perhaps attempting resuscitation and contacting the emergency services. If you work in a nursery, you may have to simultaneously calm the other staff and children.

The police will have interviewed you, and you may feel as

if your professionalism has been called into question. The situation may have been made more difficult when the child's parents arrived and you were not able to talk to them properly while the police still had questions for you.

The exact causes of SIDS and sudden unexplained death in childhood are not known, but you may worry that the death could have been prevented. Even when you are sure you have done nothing wrong and could not have acted differently, feelings of guilt can be strong.

While the death may have occurred in your care and you may have been very fond of the child, carers are rarely involved in the events that take place afterwards, which can help people come to terms with a death. You may not get the chance to say good bye to the child, grieve with the family, or go to the funeral.

Even though the child who died wasn't your own, you are likely to be experiencing shock and grief.

One nursery owner told The Lullaby Trust:

**“Many people asked why I was grieving as the child wasn't mine. Those comments really hurt and still do. I feel very isolated as there was no one that I could talk to who had been through a similar experience. I wouldn't want anyone else to feel the pain and isolation I felt nearly ten years ago. There is a need to talk to someone who understands.”**

The death of a child may change the relationship between parent and carer, and while some friendships can be strengthened, some parents may not want to see the carer again. While experiencing your own grief and

trying to accept the bereaved parents' actions, you may find it helpful to talk to an understanding person. You can talk to someone at The Lullaby Trust, where we have a helpline especially for people affected by the sudden and unexpected death of a baby or a small child.

## Finding support

Talking about your child's death can be a great help. Many people turn to close relatives and friends for comfort and you can also talk with your GP, health visitor or the midwife who knew your child.

If your child has died you may feel that no one can help with any of your feelings, but emotional support in the short term may help you to keep going.



## How The Lullaby Trust can help

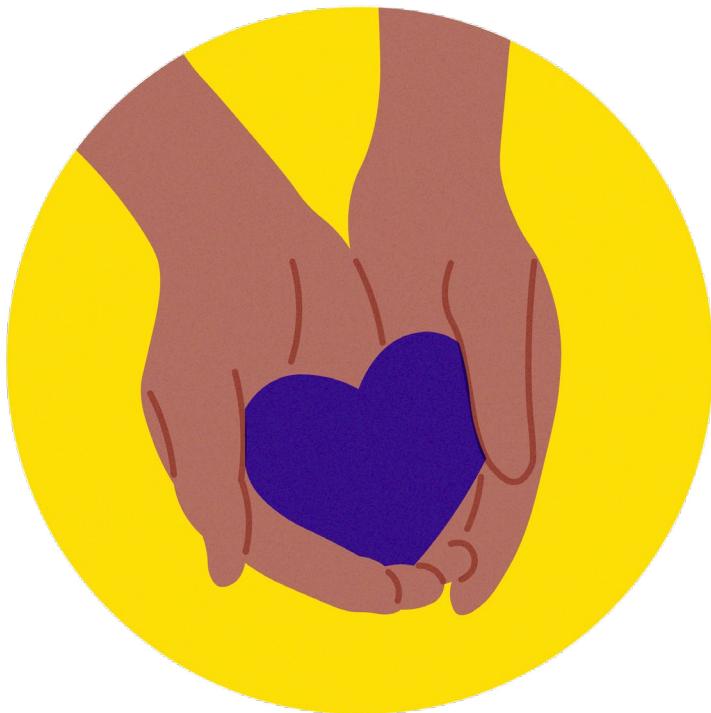
The Lullaby Trust offers a Helpline for bereaved families, carers and professionals involved with bereaved families and anyone concerned about or affected by the death of a baby or young child. Specially trained advisers staff the Helpline, and your call will be answered personally. The information you give will be kept confidential.

**0808 802 6868**

**Mon to Fri 10:00am - 2:00pm,**

**Sat and Sun 6:00pm - 10:00pm**

or email **[support@lullabytrust.org.uk](mailto:support@lullabytrust.org.uk)**



## Befrienders

**Befriending is a listening support service that we offer to bereaved family members. Befrienders are themselves bereaved parents, grandparents and other relatives, who offer personal support, which is arranged via the Helpline. Every bereaved family member who contacts our bereavement support service will be offered the chance to be put in contact with a befriendeer.**

- We know how isolating it can feel to be bereaved by sudden infant death, and sometimes speaking to someone who has been through something similar can be a comfort. We aim to put you in contact with a befriendeer within a few days.
- We will try to match you to a befriendeer based on similar personal circumstances, where possible. However, all of our befrienders are ready to listen and support you. The befriendeer can contact you by phone or email and can stay in contact for as long as you both agree to. All our befrienders have been bereaved for over four years, and most for many more. They have all been given training on how to be a listening support.
- If you are interested in talking with one of our Befrienders, please contact us by calling **0808 802 6868** between 10:00am - 2:00pm or email **support@lullabytrust.org.uk**.



## Counselling

Losing a child is an extremely difficult event in anyone's life. Grief following the unexpected death of your child is an intense and enduring experience. How we grieve is a very personal thing and can be coloured by events in our past. The loss can bring up a wide range of emotions including guilt and anger. If you are finding things especially difficult or require more in-depth support, you may want to access **bereavement counselling or therapeutic support**, in addition to support from The Lullaby Trust.

Not everyone will need or want professional counselling. You may find that the support of family and friends or talking to other parents who have been through a similar loss is enough for you. It is important to get the support that is right for you. Some people benefit from speaking openly to a counsellor about their feelings to gain support and help ease the grieving process and resolve any remaining issues they may have.

Counselling allows you to have a safe, confidential space to talk and explore your feelings with a neutral person outside your circle of family and friends. Some counsellors and therapists are also trained in specialist therapies to help cope with traumatic loss and PTSD (Post Traumatic Stress Disorder).

**You might want to consider seeing a professional counsellor or therapist if:**

- You feel isolated socially.
- You have a previous history of depression and anxiety.

- You have additional life stresses going on, illness or relationship difficulties, for example.
- It is difficult talking about your feelings with family members and friends.
- You are experiencing continued intrusive thoughts or flashbacks related to the death.
- You are experiencing lasting sleep problems.
- You feel unable to talk about your experience, are avoiding people and places that remind you of what's happened.
- You feel constantly very anxious.
- You feel very irritable with others.
- You are having thoughts that there is no point to life or you feel you may harm yourself.
- You feel continually unable to function and carry out day-to-day activities.

If you think you might benefit from counselling you can see more guidance on our website: [lullabytrust.org.uk/bereavement-support/find-support/seeking-bereavement-counselling/](http://lullabytrust.org.uk/bereavement-support/find-support/seeking-bereavement-counselling/)

Or contact us to talk about what help is available.

## Giving support

When someone you care about has suffered such a devastating bereavement it can be difficult to know what to say and how to offer support. It is okay not to know what to say, and just being there for them is important. The bereaved family member will need their friends and family more than ever. Just being there for someone can be more important than spoken words. We have put together some guidance on how to support a loved one who has lost a child.

- Allow the bereaved family member to express whatever he or she is feeling, even if these feelings seem intense and frightening. Try not to use any language that may be judgemental.
- Be available to listen to the bereaved family member talk as much and as often as they wish about the baby or child who died. This can be helpful for them. It may be difficult for you to hear, so make sure you seek support for yourself if you think this would be helpful.
- Bereaved family members often want to talk about their child and be allowed to remember them. Talk freely about the special qualities of the child and do not avoid mentioning the subject.
- Use the child's name.
- If the parent seems comforted by photos and keepsakes, suggest you look together at photographs together.
- Try not to offer 'reassurance' on things you are not completely certain about and which may

indeed remain uncertain. E.g. “I’m sure they’ll find the answer...”, “You’ll feel better by then...”, “Everything will be okay...”. It’s okay just to listen or admit that you don’t know what to say but that you are there to offer support.

- Give special attention to any other children in the family, especially if the parents are too distressed themselves to give them comfort or attend to their individual needs.
- Offer to help with practical matters: telephoning, shopping, cooking and child minding, but avoid the temptation to take control.
- Do not, however, wash any item of clothing or bedding without being asked, as many bereaved family members find great comfort in things that still smell like their child. Unless you are asked, do not pack away the child’s belongings. Never put or throw anything away as this may be regretted later. Usually, parents will deal with the child’s belongings when they are ready for them. This can be an important part of coming to terms with the death.
- Never tell the bereaved family member what he or she should do or how they should feel. Everyone reacts differently to grief and it is important to accept the differences.
- Do not try to find something positive in the bereavement experience. That is something the bereaved family member may or may not want to do themselves at a later stage.
- Your offers of support, especially at first, may be received without obvious gratitude, or even

ungraciously, but try not to let this lead to an end to your contact or friendship. Bereaved family members are often very distressed at losing a valued relationship because neither side knew how to react to such a tragedy at first. If you can remain sensitive to a family's changing needs as their bereavement goes on, and continue to keep in touch and offer practical help, this will be valuable support.

## Having another baby

The decision to have another baby is a very personal one and sometimes you and your partner may not agree about the prospect or the timing. It may be helpful to discuss future children with a doctor or paediatrician.

You may find that having another baby can be a worrying time, with many mixed feelings: happiness and anxiety, overwhelming love, and fear of loving too much. If your child was over a year old, you may already be pregnant again, or have another very young baby.

If you are in a new relationship your new partner may have difficulty understanding your thoughts and feelings, especially if they have not experienced the strength of the bond that exists between a parent and child. It is helpful to talk honestly about such feelings and to try to show patience if they lack understanding at first. It may be helpful to show your new partner this leaflet and other literature on sudden infant death.

Whatever your situation, talk to your midwife, GP or

health visitor about your worries.

The Lullaby Trust's Care of Next Infant (CONI) programme is available to bereaved families when they have another baby in England, Wales and Northern Ireland. Health visitor support and a variety of resources are offered to families. Many are available on the Lullaby Trust website [lullabytrust.org.uk/professionals-hub/care-of-next-infant/coni-resources/](https://lullabytrust.org.uk/professionals-hub/care-of-next-infant/coni-resources/) that you may find helpful.

Despite CONI not currently being available in Scotland, enhanced support from the health visiting service is likely to be offered to you when you have another baby.

## Publications and bereavement resources

We have a list of helpful resources including books, podcasts and playlists which you might find helpful:  
[lullabytrust.org.uk/bereavement-support/bereavement-support-resources/](https://lullabytrust.org.uk/bereavement-support/bereavement-support-resources/)



# Glossary

## Procurator Fiscal

A procurator fiscal is a public prosecutor in Scotland responsible for investigating and prosecuting criminal offences and also investigate sudden and unexpected deaths and conduct fatal accident inquiries. They operate independently of the government and police, ensuring impartiality in the legal process.

## COPFS

The Crown Office and Procurator Fiscal Service (COPFS) is Scotland's public prosecution service and death investigation authority and oversees the functions of the Procurator Fiscal.

## Paediatrician

A doctor who specialises in treating children. The paediatrician is usually one of your key contacts.

## Pathologist

A medical doctor who carries out the post-mortem examination.

## Metabolic Disorder

A genetic condition that affects the way the body converts food into energy or fuel. When a baby has a metabolic disorder, the body can't break down the food correctly, which can cause the body to have too much of a particular substance or too little of the ones they need to stay healthy.

## Genetic Disorder

A condition caused by faulty genes which may have been inherited from parents or occurred randomly. Some conditions can be triggered by a combination of genes and environmental factors.

## **Post-mortem Examination**

A detailed medical examination of a body after death, performed by a pathologist. The aim of a post-mortem is to determine the cause of death.

## **Mortuary**

A building or room in which bodies are kept before burial, cremation, or autopsy.



## Other useful contacts

There are other organisations that may also be able to offer advice and support.

### Support following the death of a baby

- **BLISS**

Support for families of babies born premature or sick. [bliss.org.uk](http://bliss.org.uk)

- **Twins Trust**

Offer bereavement support groups and resources to parents who have lost one or both twins, or multiples. 0800 138 0509  
[twinstrust.org/bereavement.html](http://twinstrust.org/bereavement.html)

- **Held in our Hearts**

Held in our Hearts provide counselling and befriending support for family members after the death of a child.

Phone 0131 622 6263 or email  
[info@heldinourhearts.org.uk](mailto:info@heldinourhearts.org.uk)

- **Samaritans**

Free on 116 123 24 hours a day, 365 days a year.  
[samaritans.org](http://samaritans.org)

- **SANDS**

Support for anyone affected by stillbirth, neonatal and other sudden death of a baby. 0808 164 3332  
[uk-sands.org](http://uk-sands.org)

## Support following a child death

- **Child Death Helpline**

Freephone service for all of those affected by the death of a baby or child. 0800 282 986 and 0808 800 6019 [childdeathhelpline.org.uk](http://childdeathhelpline.org.uk)

- **Child Bereavement UK**

The Child Bereavement UK website has further information and support around talking to children: [childbereavementuk.org](http://childbereavementuk.org) or call 0800 02 888 40

- **Together for shorter lives**

Support for families caring for seriously ill children, including bereavement support. 0808 8088 100 [togetherforshortlives.org.uk](http://togetherforshortlives.org.uk)

## Bereaved siblings/children

- **The Child Bereavement UK** website has further detailed information and support around talking to children. 0800 02 888 40

## Loss in pregnancy or birth

- **Action on Pre-eclampsia**

Support for those who have experienced pre-eclampsia, including concerned relatives and health professionals. 01386 761 84801  
[action-on-pre-eclampsia.org.uk](http://action-on-pre-eclampsia.org.uk)

- **Arc**

Offers information and support to parents before, during and after antenatal screening; when they are told their baby has an anomaly; when they are making difficult decisions about continuing with or ending a pregnancy; and when they are coping with complex and painful issues after making a decision, including bereavement.

Helpline: 0845 077 2290 or 0207 713 7486 via mobile [www.arc-uk.org](http://www.arc-uk.org)

- **The Ectopic Pregnancy Trust**

Supporting people who have experienced an early pregnancy complication and the health care professionals who care for them. 020 7733 2653  
[www.ectopic.org.uk](http://www.ectopic.org.uk)

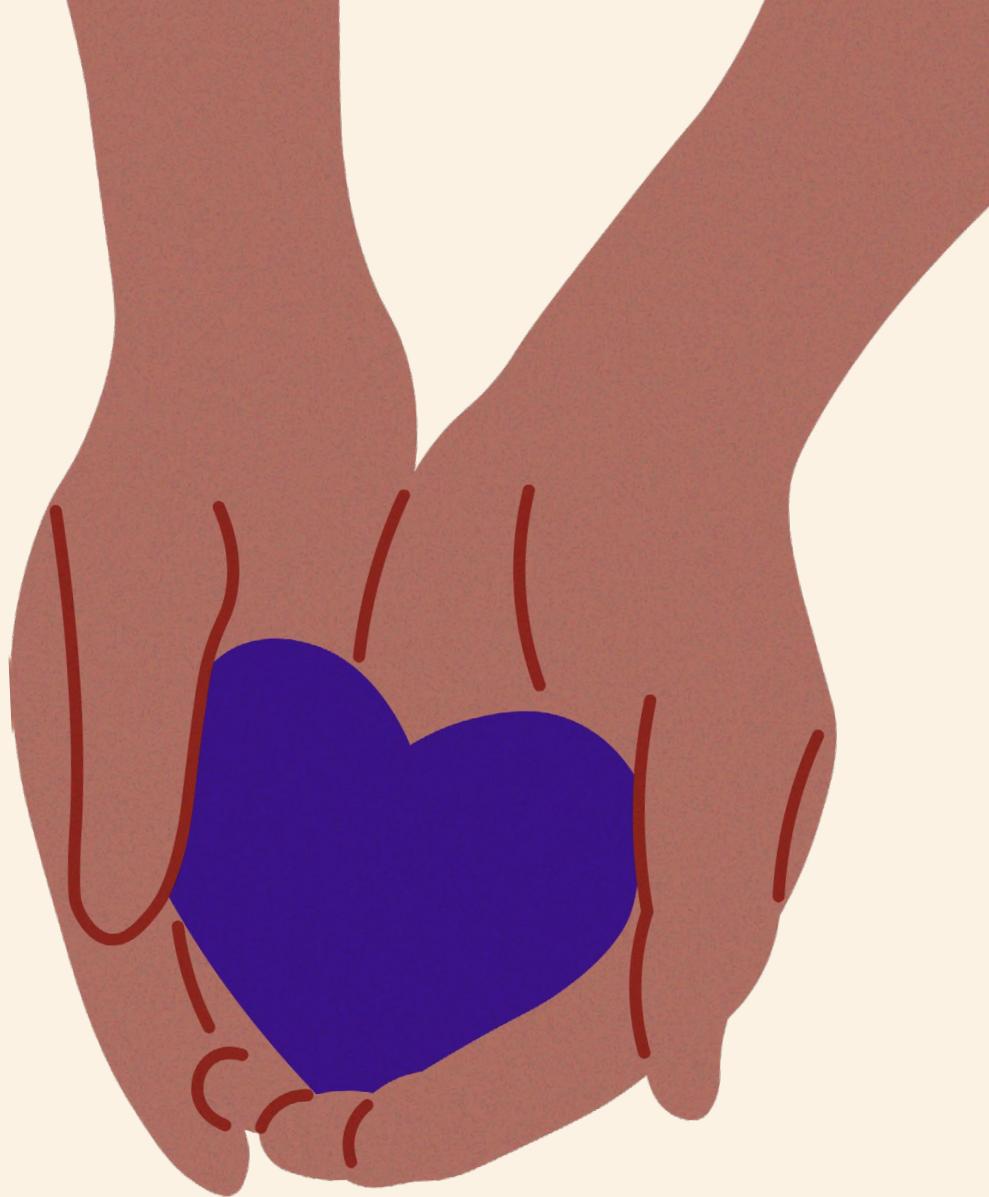
- **Miscarriage Association**

Offers support and information to those affected by miscarriage, ectopic pregnancy or molar pregnancy. 01924 200 799  
[www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)

- **Strep B Support**

Support and Information on families affected by Strep B, including bereavement support.  
[01444 416 176 gbss.org.uk](http://01444 416 176 gbss.org.uk)

## Notes



## For bereavement support:

Call: **0808 802 6868**

Email: **support@lullabytrust.org.uk**

Visit: **lullabytrust.org.uk**

The Lullaby Trust exists to keep babies safe and keep grieving families supported. We offer anyone affected by the sudden or unexpected death of a baby or young child a supportive and confidential space to grieve, however you need us.

My key contact is:

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Their contact number/email is:

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**For every baby.  
For every family.  
Forever.**

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**[lullabytrust.org.uk](http://lullabytrust.org.uk)**  
**[info@lullabytrust.org.uk](mailto:info@lullabytrust.org.uk)**