When a baby dies suddenly & unexpectedly
Introduction

We are so sorry to learn that your baby son or daughter has died. It is a tragedy that leaves families shocked, devastated and lost. The Lullaby Trust hopes that this booklet can help explain what you might experience now and in the future, both in terms of practicalities, and the complex thoughts and feelings of grief and loss.

Along the way, you will find bereaved parents who have shared their experiences. Although no baby was ever like your own, and no two losses are ever the same, the contributing parents hope their words may be of some help to you in the isolating experience of grief. You may wish to read this booklet immediately or you may wish to glance at the headings and keep it for later. Be sure to take your own time. It could also be helpful to share this booklet with others to try to help them understand what you may be feeling.

We extend our deepest sympathies to anyone affected by the death of a child. If you would like more copies of the booklet, please contact us.

Helpline
0808 802 6868
Mon to Fri
10am - 5pm
Sat and Sun
6pm - 10pm

Website
www.lullabytrust.org.uk
When a baby dies suddenly and unexpectedly

‘Sudden Infant Death’ is the term used to describe the sudden and unexpected death of a baby or toddler that is initially unexplained. The usual medical term is ‘sudden unexpected death in infancy’ (SUDI). Some sudden and unexpected infant deaths can be explained by the post-mortem examination revealing, for example, an unforeseen infection or metabolic disorder. Deaths that remain unexplained after the post-mortem are usually registered as ‘sudden infant death syndrome’ (SIDS). Sometimes other terms such as SUDI or ‘unascertained’ may be used. ‘Cot death’ was a term commonly used in the past to describe the sudden and unexpected death of an infant. It has largely been abandoned, due to its misleading suggestions that sudden infant death can only occur when a baby is asleep in their own cot, which we know to be untrue.

What happens immediately after a sudden and unexpected death

We understand how deeply distressing the time immediately following the death of a baby is. We hope these notes may help explain some of the procedures, as there are some important decisions to be made. Always feel free to call The Lullaby Trust Helpline if you feel we can be of some support over the coming time.

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Once your baby has been taken to the hospital, a doctor or other health professional must confirm formally that your baby has died. If they do not know the cause
of death, they must inform the Coroner (or the Procurator Fiscal, in Scotland). The hospital staff may take some blood and tissue samples and they should also offer you a keepsake of your baby such as a lock of hair, or a hand or foot print. It is ok to ask for this if they don’t raise it with you. A photograph of the whole family can be arranged, and may be especially of value to brothers and sisters as they grow up, or are subsequently born into the family.

Going home without your baby can be extremely difficult for parents, so take your time to leave the hospital, and try to have a loved one or friend to go home with.

The post-mortem examination

Coroners inquire into all sudden and unexpected deaths to establish the cause and circumstances of the death. The Coroner will arrange for your baby to be taken to a mortuary where a specialist paediatric pathologist can carry out a post mortem examination. This may involve your baby being taken to another city where a specialist children’s hospital can offer such a facility. The Coroner does not require your permission for this, but should explain the process to you. Many families find this separation from their baby very difficult, but your baby will receive respectful care from a specialist paediatric pathologist.

A post-mortem examination is a careful external and internal investigation of the body to try to discover why your baby died. Approximately half of cases the reason for your baby dying may be found during the post mortem. Even if no cause of death is found initially, it is possible that, as medical research advances, further examination of even small amounts of retained tissue could eventually provide an answer.
The post-mortem examination may help the Coroner decide whether an inquest is necessary. You, or a doctor acting on your behalf, are entitled to ask the Coroner for a copy of the pathologist’s post mortem report. You may wish to ask a paediatrician to go through the report with you. You can request your own copy of the report but you may be asked to pay a fee for this.

When the post-mortem examination is completed, you should be able to organise a funeral for your baby, though the detailed results of the post mortem may not be available for several weeks. You may be asked whether you plan a burial or cremation, so that the correct documentation can be prepared. If you are not sure at this stage, you can inform the funeral director of your choice later on.

Tissue retention

As part of the post-mortem examination, the pathologist will take small samples of tissues (smaller than a postage stamp), which are then put into slides. These may need to be kept for a while longer for testing. Once the post-mortem tests are complete, you must be asked what you would like to be done with the samples. There are three options: for the tissues to be kept so they could be tested in the future or used for research; to allow the hospital to respectfully dispose of them; or have them returned to you. Some parents have found great comfort in knowing their baby’s tissues might help research, or that future medical advances may give more answers, so do make sure someone explains the options to you carefully.

It is very rare for whole organs to be kept for additional tests, but should this happen this will be explained to you.
Care of your baby after the post mortem

You may have been able to hold your baby at home or in the hospital before he or she was taken to the mortuary. After the post mortem examination, and once the death certificate is issued, you may choose how and where you wish to care for your baby before the funeral.

Many families choose to visit their baby at the hospital or funeral director’s premises. Others choose to have their baby at home for a few hours or days before the funeral, which can be a helpful opportunity, for some families, to say goodbye in familiar and loving surroundings. You may like to invite a representative from your faith to say a prayer or give a blessing. Ask the healthcare professional or funeral director about any ways in which your baby’s appearance may have changed, or about any visible signs of the post mortem examination (usually only visible if you choose to undress your baby).

Your baby may feel different to touch and hold as a result of natural changes after death. It is helpful to know what to expect, so if necessary you can describe to any other children how their brother or sister may look or feel.

Registering your baby’s death

If no inquest is needed, the Coroner will send a pink form to the local registrar stating the cause of death of your baby. You can then formally register his or her death which, legally, must be done within five days (though can be extended under certain circumstances). The Coroner’s Officer or other official will advise you where and when to register. You will need to take your baby’s birth certificate with you, and register your baby’s birth if you have not already done so.
The Registrar will provide you with:

- One certified copy of the Death Certificate (you may buy extra copies for a small fee).
- A green form, which enables a burial or cremation to take place.
- A certificate for the Department of Work and Pensions if you are applying for a funeral payment.

Funeral arrangements

It is up to you and your family how you wish to honour your baby’s life. Some services that you may like to consider include the following:

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

Arranging a service with a sympathetic funeral director can be a big help. You may choose any funeral director, not necessarily the one who took your baby to the mortuary, if this were the case. The advice of a representative of your faith or other informed person may help you, and you may also 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 0845 230 1343.

Costs

Charges can vary, so ask for a written estimate before completing your arrangements. Some funeral directors provide funerals for babies free of charge (this means covering the basic costs such as a coffin and transport). If you are on a low income, you may be eligible for a Funeral Payment from the Social Fund.

For more information, see www.gov.uk/funeral-payments or speak with your Funeral Director.

Burial or cremation services

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 be upsetting to make, so be sure to give yourself enough time to make the choices that are right for you.
The ashes

If you choose a cremation, it should be possible for the crematorium to provide ashes following the cremation, though not all can do this. It would be advisable to ask in advance and, if necessary, ask for details of another crematorium that can.

You can choose to have the ashes:

• Placed in the crematorium garden of remembrance
• Placed in another crematorium, or a favourite place with the land owner’s permission
• Buried in a local churchyard, cemetery, or any other meaningful place
• Scattered at a special place of your choice.

If you wish to arrange for the committal of the ashes on the same day as the cremation this should be possible if the cremation is held in the morning. Some families choose to keep the ashes at home with them. Again this may be a very difficult decision, so take as much time as you need in making it.

Other children

It can be helpful to involve brothers and sisters in the funeral, however young they are, so that they can share in the ceremony and say goodbye. A member of your family or a friend could be asked to help care for them at the funeral, and it’s generally best to give children simple, straightforward explanation about what is happening. It is also important to let the school know about the funeral and death of their baby brother or sister, so they can provide support and monitor any emotional or behavioural changes.
Memorials

Many places of worship and some hospitals have a Book of Remembrance in which you may wish to have your baby’s name inscribed. If you wish to have a headstone or memorial plaque, seek advice from your funeral director and ask for estimates. There are regulations concerning the types of memorial stones allowed in cemeteries.

You may like to plant a tree or bush or have some other form of permanent memorial to your baby. You could consider planting it in a large pot, so that you can take it with you if you move home.

You may want to keep your own memory box or a memory book, containing items that help you and family members commemorate your baby’s life. If you have other children, drawing pictures of the whole family together and framing them can be a special tribute you can all see every day.

You may also like to include a memorial to your baby on The Lullaby Trust’s website, www.lullabytrust.org.uk. You can leave a poem, photograph or just a few words about your baby, which other parents and visitors to the site will be able to see.

The inquest

An inquest is an inquiry to confirm who has died, when and where, and to further establish the cause of death. The inquest is a medical inquiry and does not set out to establish guilt or blame, or comment on any person’s actions in relation to the death. The majority of sudden infant deaths will have an inquest.

If no medical or other explanation has been found through the post-mortem examination, the Coroner will confirm the cause as SIDS or SUDI. Many parents tell us they feel disappointed with this outcome, as they hoped that the inquest would provide a ‘proper reason’ to explain why their baby died, but this is very often not the case.
If the Coroner decides to hold an inquest you will be told the date, time and place. The Coroner may issue an order allowing burial or cremation before the inquest is completed, as often inquests can take some time.

Inquests are open to the public, so you might like to take a family member or a friend to support you at the inquest. Sometimes the media can be present at an inquest, which can come as a shock. You are not obliged to speak to the media. You do not have to attend, unless you are called as a witness.

You can ask questions at the inquest and you might like to write down these down before you go. Professionals like a police officer, paediatrician, pathologist or health visitor may be present.

You may find it helpful to talk with The Coroner's Courts Support Service (CCSS). They are a registered charity whose trained volunteers give emotional and practical support to bereaved families and other witnesses attending an inquest. They can take you to the Court before the proceedings start and explain how an inquest is conducted. To find out in which Coroners’ Courts the service is available visit www.coronerscourtssupportservice.org.uk or phone 0207 802 4763.

The Child Death Review

All child deaths are now reviewed by specialist Child Death Review Panels. These Panels look into every child death to try and prevent future deaths and improve support. The process should be explained to you by a professional, but call our Helpline if you have any questions.

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Financial arrangements

Unfortunately there are financial practicalities to attend to during this difficult time. You may like to focus on these after the funeral when some time becomes available to you, and perhaps you could ask a friend or family member to help you.

Here are a few things you need to know:

• It will be necessary to inform your Child Benefit Office about your baby’s death. You can phone the Child Benefit Helpline on 08453 021 444. The Child Benefit Office will let other parts of HM Revenue & Customs (HMRC) know, so you only have to get in touch with HMRC once. You should be eligible for a Child Benefit for 8 weeks after your baby has died. If your baby dies before you’ve claimed Child Benefit, you should still be able to claim.

• If you have been employed, 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 extra maternity benefits that still apply even if your baby has died.

• If you opened a savings account or a Trust Fund for your child, this will need to be closed. Insurance policies in your baby’s name will also need to be cancelled. Contact your local bank or provider, or visit www.gov.uk/child-trust-funds.

• Have a chat with your health visitor about benefits you are still entitled to, such as free dental care and prescriptions.
Other things to consider

If you were breastfeeding your baby when they died, ask your health visitor or GP for advice on managing your milk supply.

If you joined any baby groups, such as supermarket baby clubs or online clubs, you will need to tell them that you don’t want to receive any more information. Otherwise you may continue to be contacted with offers and information about your baby’s expected progress. The Mailing Preference Service can help with this, and you can register online: www.mpsonline.org.uk.

Grieving

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 one can go through. You may also experience the profound effects of shock and trauma due to the sudden nature of the loss. 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, and has no set time or process.

It can be a turbulent time, although there may be periods of calm. Intense emotions, which had seemed to fade, can return. There is confusion and it can be difficult to make decisions, or concentrate for any length of time. Even if you can sleep you may still feel exhausted. Grieving people may fear they are going mad. Many parents say that their baby is always on their mind, that they experience aching arms, and hear the baby cry. Some people have a strong need to continue with routine childcare tasks.
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 baby recently. These feelings of guilt and blame are normal, virtually universal, and will lessen with time.

Anger, almost always experienced, can be expressed in a number of ways which many parents have found helpful, such as crying and shouting in an outdoor open space, or exercise like walking/running/jogging. Religious beliefs may be questioned, and further tragedy of some sort may be feared. Occasionally thoughts of suicide may occur and you may want to contact The Lullaby Trust

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to talk through the way you feel, as well as staying in touch with your local healthcare professionals or other trusted supporters. If you ever feel as if you are at a risk of harming yourself, please consider calling the Samaritans on 08457 90 90 90
Most parents who experience the death of their baby describe the pain as the most intense they have ever experienced. You may wonder if you will be able to tolerate the pain, to survive it, and to be able to feel that life has meaning again.

You may feel as if you are functioning in a fog during the first few weeks after your baby’s death. Some parents describe their experience of the funeral as being an observer or not really being emotionally involved. These reactions are nature’s way of helping you deal with the very early days following the death of your baby.

One mum described how isolated she felt: “After the funeral and people have gone back home, you have to get back to some kind of normality. But many nights can be spent in solitary grief, feeling that you cannot keep bothering people time and time again, just because you feel upset.”

A dad wrote to The Lullaby Trust, describing how he felt after his son’s funeral: “After the funeral, part of me felt that I couldn’t carry on. The other part of me was searching for normality – doing routine and mindless things to block out the pain, trying to avoid thinking about what had happened. I returned to work after a week, but I just couldn’t concentrate; I couldn’t see the point.”

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 the baby while the other may not even want to hear the baby’s name spoken.

One mum told The Lullaby Trust: ‘Chris didn’t want to talk, that was his way of dealing with it, whereas I wanted to talk about Jack all the time, to keep his name on people’s lips. I would lie awake at night and there he was, forgetting all his worries, asleep. Losing Jack put an enormous strain on our relationship, but in the end it bonded us together completely. It would take an atomic bomb to split us apart now.’
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 baby. Fathers are often asked “how is your wife?”, and people may forget to say “how are you?”

As another dad told The Lullaby Trust: “My wife was being treated as having lost someone she loved. I was being treated as having lost someone I was responsible for. I felt like shouting ‘I loved him too, you know!’”

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 physical contact may feel a necessary solace for one of you, but 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 baby less intensely) so try to be open and honest about your own needs and feelings, accepting that each person’s response is valid.

In time, couples who can respect each other’s differing ways may find that they can begin to talk, share and support each other more easily.
If you are on your own

For a parent on his or her own the sudden and unexpected death of a baby 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 drive 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.”

If you are on your own, you may feel that you are not receiving the same sympathy that a couple would. Some people may have even suggested that your baby’s death was a blessing in disguise, because it would have been so hard to bring up a child alone.

As one mum put it: ‘My parents regarded my baby as a big problem in our lives. When he died they said it was probably for the best. They felt that this was the solution.”

Many parents turn to their own parents in times of need, but some have no family to support them.

The Lullaby Trust’s befriender programme could be of some support to you, whereby you can be put in touch with 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.

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You may find this helpful straight after your baby has died, or months or even 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 baby helpful.
If a twin dies

If your baby was a twin, you may feel that you are not able to grieve properly for the baby who died. You have the surviving baby who needs your love and continued caring with day-to-day routines, leaving you with little time for your own emotions. Your feelings will also be mixed because your surviving baby is a constant reminder that there should be two.

Your doctor or the hospital may suggest that your surviving baby goes into hospital for tests, although it is extremely rare for both twins to die.

You may also want to speak to your midwife, health visitor or paediatrician about joining your local Care of the Next Infant (CONI) scheme where you can receive extra support and reassurance.

Anniversaries such as birthdays may be especially poignant when a twin has died. It is important, as your surviving child grows, that they know that they had a twin brother or sister. Sharing your memories and photographs may help.

Returning to work

If you are employed, returning to work can be a difficult time. Many of your colleagues will be unsure of whether or not to say anything about your baby’s death and your feelings. Most people do care, but they may find it difficult to express their sympathy.

One parent told The Lullaby Trust: “It was awful going back to work. I was terrified of embarrassing myself by bursting into tears. Everyone else was terrified of me, not knowing what they should be saying or doing.”
Many parents, particularly mothers, are not in work when their baby dies. If parents had decided to leave work or take maternity/paternity leave, they may find it difficult, when they return, to explain the change in circumstances. It may be helpful to ask your employer to tell your colleagues what has happened before you return.

Life after your baby’s death

The death of a baby 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 Patrick’s 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 when you should be moving on. With support from friends and relatives and perhaps discussion with a Lullaby Trust befriender or adviser, you will make your own decisions about what helps you to cope and carry on. It is almost always a good idea to talk things over when you feel especially low, or perhaps tempted to misuse 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.”
The baby’s brothers and sisters

It is common amongst parents to feel worried about how any other children will be affected by the baby’s death. You may be concerned about the difficult task of discussing and explaining the death. It is important to be honest and tell your children what has happened and to answer their questions truthfully. Some of the things that are said to children, with the best and kindest of intentions, can have different implications and are best avoided, 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.

• “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.

Suggesting that a baby has ‘gone to heaven’ or ‘to live with God’ may be confusing for a young child unless the family share a religious faith which they themselves find comforting.

Each child will have their own way of working through their grief and should be encouraged to express their individual feelings. Like you, they will have questions to which there may be no answer, but will need a truthful explanation as far as their age and vocabulary allows. There is no age at which a child is too young to know what is happening. A young child may not understand, but needs information, love and support.

Children, like adults, can suffer a wide range of emotions, including sorrow, anger, disbelief, and even guilt (it is surprising to many parents 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 the baby died.

Siblings may regress in their behaviour, becoming clingy, reverting to thumb sucking, bedwetting, or complaining of headaches or stomach aches.
They may not speak about their feelings and by holding back, and even attempting to be extra good and helpful, may cause adults to assume they are unaffected. This is never the case.

Try to include siblings in the events and ceremonies which follow the death, as exclusion is likely to leave them feeling anxious, bewildered and alone.

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

You may like to talk this over with one of the Lullaby Trust’s Helpline advisers.

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To find out more about supporting siblings, you may like to call Winston’s Wish, a charity which offers bereavement support to children, on 08452 03 04 05 or Child Bereavement UK on 01444 568900.

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**Ways to help children**

**In summary:**

- 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, and do not dismiss their thoughts as superficial, or deny their stated feelings.

- Try and welcome their questions. Some questions may be painfully direct, but if the child has asked, it’s because they want to know the answer, and they can cope with it.
• 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 right 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.

• Share memories of the baby 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 in your home, rather than sending them away to relatives or friends, as far as possible.

• Talk to their playgroup 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 children 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, seek advice from your family doctor or health visitor or perhaps talk things over with a Helpline Adviser at The Lullaby Trust

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or Winston’s Wish
08452 03 04 05
Grandparents and other family members

The death of a baby 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 struggle to find ways to help without interfering, and often do not feel entitled to express their own grief; instead focusing on trying to support 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, 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 before the death. These considerations apply too to other relatives, and 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.”

In addition to this fear, you may be pregnant or have a small child of your own, and wonder how the baby’s parents will feel about seeing your child. Will it be too painful for them to see another baby, will they resent them or be jealous? It is often best to ask the parents how they feel.

One relative wrote to The Lullaby Trust saying: “I fear saying the wrong things or stirring up painful memories that have possibly begun to ease with the passing of time. There seems so little I can do or say and I feel completely helpless.”
While family members may not always feel confident about how to help, bereaved parents often mention their valuable support. Help with the other children or with daily activities and practicalities is nearly always welcomed, and many parents say they were grateful to have family members who were there to listen. The Lullaby Trust Helpline is there for anyone in a family affected by the sudden and unexpected death of a baby.

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A number of bereaved grandparents are available as befrienders to support others whose grandchild has died.

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**If someone else’s baby dies in your care**

It is a terrible shock if someone else’s baby dies in your care, whether in your nursery, in foster care or while you were caring for the baby 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 will have simultaneously had to 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 baby’s parents arrived, and you were not able to talk to them properly while the police still had questions for you.

Some parents have said they felt excluded at this early stage as the police and emergency services had more questions for the carer who was there at the scene, than for the baby’s own.
parents. Carers have told The Lullaby Trust that they wanted to refer and talk to the baby’s parents, but this was not allowed.

Having to speak to the parents will have been traumatic, particularly if they accuse you of causing their baby’s death. While hurtful, this reaction is natural as shocked and grieving parents try to find a reason for their baby’s death. You may well have been reflecting upon your child-minding routines, checking that the baby received good care.

The exact causes of sudden infant death 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 baby, carers are rarely involved in the subsequent procedures, which may help many people come to terms with a death. You may not get the chance to say good bye to the baby, grieve with the family or go to the funeral. Even though the baby 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 baby 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.

One mum told The Lullaby Trust: “It’s been six years now and I still can’t drive past the childminder’s road. I don’t blame her for his death, but I couldn’t meet her to discuss what happened that day.”
Finding support

Talking about the tragedy of your baby’s death can be of great help. Many people turn to close relatives and friends for immediate comfort. You can also talk with your GP, health visitor or the midwife who knew your baby. You should try to do this if you have any physical symptoms or feel very, very low emotionally. If your baby 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 to bereaved families, carers and professionals involved with bereaved families and anyone concerned about or affected by the death of a baby. Specially trained advisers staff the Helpline, and your call will be answered personally. The information you give will be kept confidential.

Helpline: 0808 802 6868
Mon to Fri 10am - 5pm
Sat & Sun 6pm - 10pm
Befrienders

Advisers on The Lullaby Trust’s Helpline can put you in touch with a parent (or grandparent, aunt/uncle or sibling) who has experienced the death of a baby in similar circumstances. Befrienders have been specially prepared to offer this support and may be able to meet with you and your family, if you wish. Alternatively, you could choose to speak on the telephone, or communicate via email.

Referrals

There are other organisations that may also be able to offer advice and support. Call The Lullaby Trust’s Helpline on 0808 802 6868 to be put in touch.

Giving support

Just being there can be more important than spoken words.

• Allow the distressed bereaved person 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 judgmental.

• Be available to listen to the parents talk as much and as often as they wish about the baby who died. This can be helpful for them.

• Talk freely about the special qualities of the baby and do not avoid mentioning the subject.

• Use the baby’s name.

• Suggest you look together at photographs of the baby, if the parent seems comforted by photos and keepsakes.
• Give special attention to the 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, launder any item of the baby’s clothing or bedding without an explicit request, as many parents find great comfort in articles which retain the baby’s scent.

• Unless you are asked, do not pack away the baby’s belongings. Never put or throw anything away as this may be regretted later. Usually parents will deal with the baby’s belongings when they are ready and this can be, for them, an important part of coming to terms with the death.

• Never tell the grieving person what he or she should do or how they should feel. Everyone reacts differently and it is important to accept the differences.

• Do not try to find something positive in the bereavement experience. That is something the parents may or may not want to do themselves at a later stage.

• If you are not sure how the parents might feel about a particular issue, ask them. You should not assume, or try to guess, their feelings and views. Accept their answer, and do not try to dissuade them from any view or decision which you feel is misguided, unless it poses a danger to themselves or others.

• Don’t be nervous about taking The Lullaby Trust leaflets to the family. The parents and the rest of the family may get some comfort from reading them.

• Keep in touch as the months go by, even just a telephone call now and then. Parents do not get over the death after any set period of time and continue to need the support of their family and friends.
• Anniversaries, traditional and special family days are often more difficult times, and it may be helpful to increase your support. Gradually, as months and then years go by, some parents tell us the pain eases.

• You may never know the value of the support you give but don’t let that stop you from offering it.

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. No baby can replace your son or daughter who died, for each is a special individual with his or her own personality.

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.

One mum told The Lullaby Trust: “The death of Tom shattered all our dreams. I still fear contact with babies and I am frightened of loving our new baby too much.”

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 baby. It is helpful to talk honestly about such feelings and to try to show patience with any initial lack of understanding. It may be helpful to show your new partner this leaflet and other literature on sudden infant death.
The Lullaby Trust’s Care of the Next Infant (CONI) programme is available to support bereaved parents when they have another baby. Using symptom diaries, weighing scales, movement monitors, thermometers, weight charts and regular visits from health visitors, parents can monitor their baby’s progress, helping to ease some of the worries.

CONI Plus is available to the extended families of a baby who died of Sudden Infant Death, and to parents of babies who died suddenly of other causes, or whose baby suffered an apparent life-threatening event. The schemes are available through many hospitals and community health centres. For more information and to find out if there is a CONI or CONI Plus scheme in your area, contact The Lullaby Trust’s Helpline

Helpline: 0808 802 6868
Mon to Fri 10am - 5pm
Sat & Sun 6pm - 10pm

or the CONI Head Office 0114 276 6452 in Sheffield.

Publications

The Lullaby Trust produces a number of publications with information about sudden death in infancy and related issues and research. You can telephone The Lullaby Trust office on 020 7802 3200 to request copies of publications of interest. Many of the publications below are also free to download on our website. Please visit www.lullabytrust.org.uk
• **The Child Death Review**
  A guide for parents and carers through the practical issues surrounding a sudden and unexpected infant death, including the role of the coroner and the post mortem examination.

• **Winston’s Wish, living with bereavement**
  A leaflet providing support and guidance for bereaved children and their families.

• **CONI**
  A brief leaflet for health professionals and bereaved parents details The Lullaby Trust’s Care of the Next Infant support programme.

• **Fundraising**
  You can request a fundraising pack by calling 020 7802 3201 or emailing fundraising@lullabytrust.org.uk

**Glossary**

**Coroner**
A coroner is a doctor or lawyer, or sometimes both. They are a judicial officer who inquires into all sudden, unexpected or unnatural deaths.

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

**Inquest**
The formal inquiry of the Coroner to confirm who has died, the circumstances and decide if a cause of death can be established.

**Pathologist**
A medical doctor who conducts the post mortem examination.

**Metabolic Disorder**
A genetic condition affecting the chemical and physical processes of the human body (the metabolism).
You can find more information about SIDS and risks:

Call: 0808 802 6869
Email: info@lullabytrust.org.uk
Visit: www.lullabytrust.org.uk

The Lullaby Trust provides support to bereaved families, expert advice on safer sleep for babies, and raises awareness on sudden infant death.

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