



Giving babies the
chance of a lifetime

When a baby dies suddenly and unexpectedly


Helpline
0808 802 6868
for families and professionals

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When a baby dies suddenly and unexpectedly



This booklet has been written to help explain what happens after a baby dies, both in terms of practicalities, and the feelings and emotions families may experience. This booklet is produced for all family members and relatives, and the friends, carers and professionals involved with them. You may wish to read this booklet immediately or you may wish to glance at the headings and keep it for later. If you would like more copies, please telephone FSID on 0808 802 6868, or look at the website on www.fsid.org.uk.

‘Cot death’ is a term commonly used to describe a sudden and unexpected infant death 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 postmortem examination revealing, for example, an unrecognised metabolic disorder. Deaths that remain unexplained after postmortem examination are usually registered as ‘sudden infant death syndrome’ (SIDS). Sometimes other terms, such as ‘sudden infant death’, ‘sudden unexpected death in infancy’ (SUDI) or ‘unascertained’ may be used.

What happens immediately after a sudden and unexpected death

The time immediately following the death of a baby is deeply distressing and yet important decisions need to be made. These notes help explain some of the procedures.

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 role of the coroner

The Coroner's duty is to inquire into sudden unexpected deaths to establish the cause and circumstances of the death. This may be through informal inquiries, or an inquest. In either case, the Coroner is likely to arrange for a postmortem examination.

You may want to ask the Coroner's Officer for the leaflet 'When sudden death occurs', which describes what Coroners and their Officers do, and what happens at inquests. You can also call FSID's Helpline (0808 802 6868) for a copy of this leaflet, or to discuss these issues.

The Coroner's Officer, or a uniformed police officer acting for the Coroner, will ask you for information and may ask you to sign a statement.

The police may also visit and take photographs of where your baby died. You may find the necessity for the police presence a shock and upsetting, but they are obliged to gather information on all sudden and unexpected deaths.

A multi-professional joint investigation is recommended, and it may be that a paediatrician will visit you, either with the police, or shortly thereafter.

Such a coordinated response to all sudden deaths of children and young people up to 18 years will be a legal requirement after April 2008. Local Safeguarding Children Boards (LSCBs) will have to put in place procedures to respond rapidly to individual unexpected childhood deaths and to review all childhood deaths in a systematic way.

The Coroner will arrange for your baby to be taken to a mortuary where a specialist paediatric pathologist can carry out a postmortem 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.

Your formal consent should, however, be sought for the retention of any tissue samples (very tiny smears) or organs for future research. You will also be asked by the Coroner's Officer, or person explaining the process to you, for your wishes concerning the retention or disposal of any tissue samples following the postmortem examination.

A postmortem examination is a careful external and internal investigation of the body to try to discover why your baby died. Even if no cause of death is found initially, it is possible that, as medical research advances, further examination of even tiny amounts of retained tissue could eventually provide an answer.

When the postmortem examination is completed, you should be able to organise a funeral for your baby, though the detailed results of the postmortem may not be available for several weeks.

You may be asked whether you prefer 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.

The postmortem 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 postmortem report, for which there may be a fee. You may wish to ask a paediatrician to go through the report with you, when it is available.

Registering your baby's death if there is to be no inquest

You should do this as soon as the registrar for births and deaths for the district in which your baby died has received notification from the Coroner certifying the cause of death. The Coroner's Officer or other official will advise you where and when to register.

The Registrar will provide you with:

- one certified copy of the death certificate (you may buy extra copies of the death certificate for a small fee)
- the documentation (green form) enabling a burial or cremation to take place

- a certificate for the Department of Work and Pensions if you are applying for a funeral loan or payment from the Social Fund.

If there is to be an inquest

An inquest is an inquiry to confirm who has died, when and where, and to establish the cause of death, in broad terms (for example, natural causes). If no medical or other explanation has been found at postmortem, the Coroner will confirm the cause as SIDS or SUDI.

Many parents are 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. Nor does the inquest set out to establish guilt or blame or comment on any person's actions in relation to the death.

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 this latter process may take some time.

You might like to take a family member or a friend to support you at the inquest.

You can ask questions at the inquest and you might like to write down any questions you have before you go. Professionals like a police officer, paediatrician, pathologist or health visitor may be present. An inquest is open to the public, and journalists or other representatives of the media may be there.

You can read more about what happens at inquests in the leaflet 'When sudden death occurs', which you can get either from the Coroner, or from FSID, by calling the Helpline (0808 802 6868).

Care of your baby after the postmortem

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 postmortem 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 good-bye in familiar and loving surroundings. Such an option, for many reasons, may not suit all families, but it is important to consider and discuss the choices available. You may not be offered such a choice pro-actively, as many healthcare professionals are not aware of, or confident about, facilitating different or less usual options.

You may wish to ask family members or anyone of your choice to be with you for support when you visit your baby after the postmortem, or discuss options for his or her care.

Ask the healthcare professional or funeral director arranging for you to visit your baby about any ways in which the baby's appearance may have changed, or about any possibly visible signs of the postmortem 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; not specifically connected with any part of the postmortem examination process). It is helpful to know what to expect, especially if you are going to describe to any brothers or sisters how 'their baby' may look or feel.

You may like to ask your priest, minister or hospital chaplain to accompany you to say a prayer or give a blessing, whether or not your baby has been baptised.

Keepsakes

Photographs can be very helpful, especially one including the whole family. This may be especially of value to brothers and sisters as they grow up, or are subsequently born into the family.

In addition, some people may wish to keep a lock of the baby's hair or a card bearing a hand or foot print, and such keepsakes may well be offered by hospital staff, even before the postmortem.

Funeral arrangements

Choosing a funeral director

You may choose any funeral director, not necessarily the one who took your baby to the mortuary, if this was the case. The advice of a minister, priest or other informed person may help you, and you may also wish to consider alternative forms of non-religious service.

Costs

Because charges vary, ask for a written estimate before completing your arrangements. Some funeral directors provide funerals for babies free of charge. Such a service would include a simple white coffin and all the documentation involved in arranging the funeral.

There may, however, be other costs involved: for example, the cremation, if you have opted for this, or optional extras to the basic service, such as cars for guests, the involvement of a choir, or Order of Service stationery.

If you receive Income Support, Income-based Jobseeker's Allowance, Housing Benefit, Council Tax Benefit, Working Families' Tax Credit, or Disabled Person's Tax Credit, and feel unable to meet the funeral costs, ask your Job Centre Plus (formerly Benefits Agency) for advice about receiving payment for the funeral from the Social Fund before making any funeral arrangements.

There is a maximum payment from the Social Fund to cover some of the cost of the funeral. The amount depends on the average cost of a funeral in your area, and would be unlikely to include the cost of optional extras.

Burial or cremation?

Your priest, minister or funeral director can help you decide whether to have a burial or cremation. Try and give yourself enough time to make the decision.

You could choose:

- a service at your own place of worship, or cemetery chapel, and burial in a churchyard or local cemetery. If you live in a parish where burials still take place in the churchyard, your baby should be entitled to burial there, if you wish. No fee is payable for a churchyard burial of a baby under one year old.
- a service at your own place of worship or at the crematorium, and then a cremation
- to attend the service but not the committal at the crematorium
- a non-religious ceremony. This can be arranged by you, by family or friends or by organisations including The British Humanist Association.
- a service, religious or not, in your own home
- a service of thanksgiving some time after the funeral.

You can discuss the choice of songs, hymns, music, readings and poetry for the ceremony with those responsible for the service.

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.

Clothing

You can choose your baby's clothes for the funeral, or use a gown or shroud supplied by the funeral director. It is not necessary for cosmetics to be used, nor for your baby's body to be embalmed, unless the baby is to be moved to another country, when legal requirements must be followed.

Coffin

A coffin is normally used for burial or cremation. Discuss with your funeral director the type and colour. It is possible to make and supply your own, or commission one made from natural materials, such as wicker. However, you should discuss this with a funeral director or crematorium superintendent.

You may wish to place a favourite toy or other mementoes in the coffin. Although this is always possible for a burial, regulations for cremation may impose limitations.

Transport

You can request a small car rather than a hearse, or carry the coffin in your own or a friend's car.

Bearers

You and your family may wish to carry the coffin, or the funeral director can provide bearers.

Flowers

You may wish to make your own floral arrangements or have cut flowers from the garden. As an alternative, some families like to have flowers only from close relatives, and nominate a charity for friends and family to support instead of providing flowers.

Other children at the funeral

It is helpful to involve brothers and sisters in the funeral, however young they are, so that they can share in the ceremony and say good-bye. A member of your family or a friend could be asked to help care for them at the funeral, and children should be given a simple, straightforward explanation about what is happening.

The ashes

If you choose cremation, it should be possible for the crematorium to provide ashes following the cremation of an infant, though not all can do this. It would be advisable to ask in advance and, if necessary, ask them to provide details of another 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 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. You can also choose to delay any final decision concerning the ashes. Some families choose to keep the ashes at home with them.

Memorials

Most crematoria, some churches and other 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 churchyards and cemeteries.

You may like to plant a tree or bush or have some other form of permanent memorial.

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.

You may also like to include a memorial to your baby on FSID's website (www.fsid.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. If you do not have access to the internet, then FSID can send you a print-out of your baby's page.

Financial arrangements

These practicalities are very hard to face but there are some important things to know:

- It will be necessary to inform your Child Benefit office about your baby's death, and benefit payments will need to be cancelled.
- Savings accounts or insurance policies in your baby's name will need to be closed.
- All mothers are entitled to free dental treatment and free prescriptions for one year following the birth of a baby, even if the baby dies.

Grieving



When someone we love dies, we experience overwhelming feelings of loss and sorrow which we call grief.

Grief can be an intense, lonely and personal experience. There is no right or wrong way to grieve and there is no set time or process for grieving.

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 has seen the baby recently. These feelings of guilt and blame are normal, and virtually universal, though almost never justified, and lessen with time.

Anger, almost always experienced, can be ventilated in a number of ways which many parents have found helpful, such as crying and shouting in an outdoor open space, strenuous exercise or 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 staff on FSID's Helpline (0808 802 6868) to talk through the way you feel, as well as staying in touch with your local healthcare professionals or other trusted supporters.

Common feelings

Most mothers and fathers 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 FSID, 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 also 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 FSID:

"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 mothers and fathers 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 FSID:

“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 (or not) 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, usually over a few months, 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 FSID:

“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. If you have no one to talk to, you may find it helpful to keep a journal or write letters. One mum told FSID:

“I wrote letters to Michael all the time. I still have those letters and although I don’t write them any more, 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 at home 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 CONI scheme (see page 24) 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 FSID:

“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 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.

It may be useful to remember that 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 this leave may be unpaid. Your employer may offer extra maternity benefits that still apply even if your baby has died.

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 trusted friends and relatives and perhaps discussion with an FSID befriender or advisor, 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, perhaps even tempted to use drink or non-prescription 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

Parents are often anxious about how their 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 gentlest of intentions, can have different implications and are best avoided, such as:

- “*Gone to heaven, gone to God*” – children may think they can also follow or visit.
- “*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.

Each child will have their own way of working through their grief and should be allowed 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 which is too young to know what is happening. A young child may not understand, but needs information.

As with adults, there can be 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 the child is reassured that it wasn't anybody's fault that the baby died.

Siblings may regress in their behaviour, becoming clingy, reverting to thumb sucking or 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 FSID's Helpline Advisors on 0808 802 6868.

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. 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 an FSID Helpline Advisor on 0808 802 6868.

Grandparents and other family members

The death of a baby affects everyone in the family. Some grandparents have told FSID that they feel a double sense of pain: grief for the baby who has died, and distress for their adult 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 sick or infirm, relative continues to survive, may cause great hurt in the heat of the moment.

The situation may be further exacerbated in a 'reconstituted' family, where biological grandparents and step-grandparents are all shocked and grieving.

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 own children or future ones. Suddenly everything seems uncertain. One aunt told FSID:

"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? You can ask the parents how they feel.

One relative wrote to FSID 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 who were there to listen.

The FSID Helpline is there for anyone in a family affected by the sudden and unexpected death of a baby on 0808 802 6868.

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 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 FSID 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 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 FSID:

“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 FSID:

“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.”

If you are a nanny, the death of a baby in your care can mean the loss of your job and sometimes your home and your circle of contacts. 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 telephone FSID’s Helpline for support on 0808 802 6868.

Questions families ask

What does ‘cot death’ mean?

Cot death is a term commonly used to describe a sudden and unexpected infant death that is initially unexplained. The usual medical term is ‘sudden unexpected death in infancy’ (SUDI). Cot deaths that remain unexplained after postmortem examination are usually registered as ‘sudden infant death syndrome’ (SIDS). Sometimes other terms like ‘sudden infant death’, ‘sudden unexpected death in infancy’ (SUDI) or ‘unascertained’ may be used.

What causes cot death?

A thorough postmortem examination will reveal a specific cause of death in less than half of all cot deaths. Causes may include an accident, infection, congenital abnormality or metabolic disorder. Evidence of a mild infection may be found in some babies which may be mentioned on the death certificate. It is puzzling that some babies die with a mild infection while others recover. For the cases that remain unexplained, researchers think there are likely to be undiscovered causes. For many, it is likely that a combination of factors affect a baby at a vulnerable stage of development.

Vomit or blood-tinged froth is sometimes found around the mouth or on the bedding. This happens during or after death and is not the cause of death. The skin can become discoloured by blotchy marks after death but this is normal and may disappear, as may the stiffness that occurs when anyone dies.

Did our baby suffer?

No; it seems that babies die peacefully in their sleep without pain or distress.

Did our baby suffocate?

When babies are found dead in their parents’ bed or with their faces covered, it is sometimes thought they have died from suffocation. It is not known how often suffocation is the whole explanation for the baby’s death.

Are our other children at risk?

It is very rare for babies over the age of a year to die suddenly and unexpectedly. This is not catching, and neither you nor your older children are at risk, or a danger to others. If your baby is one of twins, triplets or more, the other babies may be admitted to hospital for observation.

Finding support



Talking about all that happened and going over the details can be of great help. Many people turn to their 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 reassurance or even some medication in the short term may help you to keep going.

How FSID can help

Helpline (0808 802 6868)

FSID 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 advisors staff the Helpline, and your call will be answered personally (9am-11pm, Monday to Friday and 6-11pm on weekends and Bank Holidays). The information you give will be kept confidential.

A phonecard is available for bereaved families to telephone the Helpline free of charge.

Befrienders

Advisors on FSID's Helpline can put you in touch with a parent 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.

There are other organisations that may also be able to offer advice and support. Call the Helpline on 0808 802 6868 to be put in touch, or to discuss the possibility of a Befriender.

Giving support



Just being there can be more important than spoken words.

- Allow the distressed person to express whatever he or she is feeling, even if these feelings seem intense and frightening. Try not to 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 dead 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 danger to themselves or others.
- Don't be nervous about taking FSID's 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 tragedy 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. Gradually, as months and then years go by, the extreme pain eases, and hope comes back into the parents' lives.
- 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 timing. It may be helpful to discuss future children with a doctor or paediatrician. No baby can replace another for each is a unique 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 FSID:

“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 feelings and moods, 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.

Care of the Next Infant

FSID's Care of the Next Infant (CONI) programme is available to support 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.

The scheme is available through hospitals and community health centres.

To find out if there is a CONI scheme in your area, telephone FSID's Helpline on 0808 802 6868.

The scheme may also be available for members of the extended family; in that case known as 'CONI Plus'.

Publications and further reading

FSID produces a number of publications with information about sudden death in infancy and related issues and research.

You can telephone the Helpline on 0808 802 6868 to request copies of publications of interest, or look on the website at www.fsid.org.uk, and download copies for yourself, if you have the facility.

Books for siblings

“Where’s Jess?” and “Sam’s Story” (£5 each) are two books suitable for young children, which can be purchased from FSID. Advice can also be given about appropriate publishers’ lists, which offer an extensive choice of material for children of all ages.

Bereavement

“When my baby died...” Thirty parents tell their stories: A booklet written by parents about what happened when their baby died. This booklet is free on request to bereaved parents; it costs £3.50 for anyone else to purchase.

CONI

This four-page leaflet for health professionals and bereaved parents details FSID’s Care of the Next Infant support programme. Free.

FSID News

Parents and professionals can receive FSID’s annual magazine, published in September each year, detailing research findings and issues related to sudden infant death. If you would like to subscribe to FSID News, please let us know your email or postal address, by phoning 020 7802 3200 (general enquiries) or emailing office@fsid.org.uk. You can also sign up to receive our monthly e-newsletter by visiting www.fsid.org.uk

Factfiles

Factfile 1: Cot death - Facts, Figures and Definitions: This publication for the public and health professionals examines cot death definitions, statistics and risk factors. £0.25

Factfile 2: Research background for the advice to reduce the risk of cot death Explains the research that formed the basis for the advice on sleeping position and other baby care practices. Written primarily for health professionals and researchers, but may be of interest to others. £0.25

Giving babies the chance of a lifetime

This leaflet outlines FSID's activities, aims and objectives. Free.

Guidelines for professionals on responding to sudden infant deaths

Guidelines are available for paediatricians, A&E staff, GPs, health visitors and midwives. £1 each

Recommendations for a joint agency protocol for the management of sudden unexpected deaths in infancy. £1.

Notes



The Foundation for the Study of Infant Deaths (FSID)

***aims to prevent sudden infant death and promote
baby health. We carry out our aims by:***

- ***funding research***
- ***supporting families whose baby has died***
- ***disseminating information about sudden infant death
and safe infant care***
- ***and working with professionals to improve
investigations when a baby dies.***

The Foundation for the Study of Infant Deaths

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