

When a baby or young child dies suddenly and unexpectedly

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We are so sorry that your baby or young child has died. When a baby or child dies suddenly and unexpectedly, the death is a terrible shock and one of the most devastating things that can happen to a family. This booklet is designed for parents who have lost a baby or young child. The Lullaby Trust hopes that it 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.

If you are a professional reading this you may also want to take a look at the advice for professionals on our website www.lullaby.org.uk/professionals/supporting-bereaved-families

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

Introduction

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

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

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

Helpline 0808 802 6868

Mon to Fri 10am – 5pm Sat and Sun 6pm – 10pm

Website www.lullabytrust.org.uk

Terminology

'Sudden unexpected death in infancy' (SUDI) is the term used to describe the sudden and unexpected death of an infant (a child under the age of one year) that is initially unexplained. A term that is often used if a child over one year (and up to 16 years) dies unexpectedly is 'sudden unexpected death in childhood'

Some sudden and unexpected deaths can be explained by the post-mortem examination (a careful internal and external examination of the body performed by a trained specialist). The examination could show, for example, an infection or other illness such as a genetic disorder that could have caused the death. Deaths that are still unexplained after the post mortem are usually registered as 'sudden infant

death syndrome' (SIDS) for babies under a year old. (Deaths of children up to 2 years old are sometimes also recorded as 'sudden infant death syndrome'). SUDC is sometimes used for children over the age of 12 months who die without a known cause. The term 'unascertained' may sometimes be used, which is another way of saying that the cause of death cannot be found

'Cot death' was a term often used in the past to describe the sudden and unexpected death of a baby. It is used less often now, because it suggests that sudden infant death can only happen when a baby or young child is asleep in their own cot or bed, which is not the case.

What happens immediately after a sudden and unexpected death?

At this deeply distressing time, we hope these notes may help to explain some of the procedures, which will have to happen, and the important decisions to be made. You can call The Lullaby Trust, or ask someone to call on your behalf, if it would help to talk things over.

Once your child has been taken to the hospital, a doctor or other health professional must formally confirm that they have died. If they do not know the cause of death, they must inform the Coroner (or the Procurator Fiscal, in Scotland).

The child will be examined carefully and some blood and tissue samples may be taken to try and find the cause of death. You should be offered a keepsake such as a lock of hair, or a hand or foot print. You can ask for this if staff don't mention it to you. A photograph of the whole family can be arranged, and may be important for brothers and sisters as they grow up, or are born afterwards to help them remember their sibling.

Support from the hospital chaplaincy team should be available but you can ask for a minister from your own faith to attend.

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

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







The post-mortem examination

Coroners look into all sudden and unexpected deaths to try and find out why and how the death happened.

You should be given a contact number for the Coroner's office, the Coroner will arrange for your child to be taken to a mortuary. At the mortuary a specialist paediatric pathologist (a type of doctor who is trained to find out how a child has died) will carry out a post mortem examination to try

and find the cause of death.

This may mean your child has to be taken to another city where there is a specialist children's hospital with staff that are trained to carry out the examination. The Coroner does not need your permission for this, but

should explain the process to you. Many families find being separated from their child very difficult, but your child will be treated with great care and respect by the medical staff.

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

Soon after the post mortem examination, the pathologist will write a report on the findings. If more tests are required then this may be an initial report. You should be able to get a full copy of the report if you would like one.

The coroner will get any initial findings. Where possible, with the coroner's approval, you can be given some information about these results. The final post mortem examination report may take several months to be completed, depending on the number and type of tests conducted.

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The post-mortem examination may help the Coroner decide whether an inquest is needed. You may wish to ask a paediatrician (doctor who has special training in looking after children) to go through the report with you, as the report will be written with medical terminology that may be confusing to a person without specialist knowledge in the field. The post-mortem report is often sent directly to you, but you can ask your key worker to check this.

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

You may wish to discuss possible options with your chosen funeral director, and take time to consider what would be most meaningful for you and your family. If you have religious or other requirements that may affect the timing of your child's funeral, please discuss these with hospital staff. They will alert the coroner who will try to accommodate your wishes, though it may not be possible.

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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 examination is complete, you will be asked what you would like to happen to 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 dispose of them;
- or to have them returned to you.

Some parents have found great comfort in knowing their child's tissues might help research, or that future medical advances may give more answers. It is very rare for whole organs to be kept for additional tests, but should this need to happen the reasons will be explained to you.

Even if at first no cause of death is found, it is possible that in the future as medical research advances, a tissue sample taken from your child could be looked at again, with your consent, and an answer may eventually be found.

Care of your child after the post mortem examination

You may have been able to hold your child 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 can choose how and where you wish to care for your child before the funeral.

Many families choose to visit their child at the hospital or funeral parlour. Others choose to have their child at home for a few hours or days before the funeral, which for some families is a chance to say 'goodbye' in familiar and loving surroundings. Some families choose to invite a

representative from their faith, to say a prayer or give a blessing.

Ask the healthcare professional or funeral director about any ways in which your child's appearance may have changed, or about any visible signs of the post mortem examination (usually only visible if you choose to undress your child), if they don't offer this information.

Your child 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 child's death

If there is no inquest, the Coroner will send a pink form to the local registrar stating your child's cause of death. If no cause was found, this will read as 'SIDS' or 'sudden unexplained death in childhood' or 'unascertained'. You can then formally register his or her death which, legally, must be done within five days (though this 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 child's birth certificate with you. If your baby died before you were able to register their birth then you can do this at the same time, or you can make two separate appointments.

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 allows a burial or cremation to take place.
- A certificate for the Department of Work and Pensions if you are applying for a funeral payment.

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Choosing a funeral director

Arranging a service with a sympathetic funeral director can be a big help. You can choose any funeral director; it doesn't have to be the one who took your child to the mortuary. The advice of a representative of your faith 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**

Funeral arrangements

It is up to you and your family how you wish to commemorate and celebrate your child's life. You will be offered different choices, some options include the following:

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

It is very difficult at such a time to ask all the questions and take in all the information you need to consider. It can help to have another close family member or friend with you when you are making these decisions.

Costs

Whilst there should be no charges for the burial or cremation of any child there are still costs you may have to pay.

It is a good idea to ask for a written estimate or quote before making arrangements. You will not be charged for the basics, such as a coffin and the necessary services of the funeral director, but you will usually still need to pay for any 'extras' such as flowers or a car for relatives. A fee for the person conducting the funeral service would usually still have to be paid.

If you are on a low income or in receipt of certain benefits, you may be eligible for a Funeral Payment to help pay for funeral costs. At present a Form SF200 has to be completed (downloaded from www.gov.uk/funeral-payments) or you can phone the special helpline on 0345 606 0265 to make a claim and for advice. Your funeral director may also be able to advise you.

Burial or cremation

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

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

Ashes

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

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.

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

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

Other children

It can be helpful to involve brothers and sisters in the funeral, whatever their age. Give them a choice about whether or not to be there, and talk to them about what will happen so they are prepared. A member of your family or a friend could be asked to help care for them at the funeral.

It's generally best to give children simple, straightforward explanations about what is happening. It is also important to let the school know about the death of a pupil's brother or sister, so staff can provide support and be aware of any emotional or behavioural changes. There is more information on supporting brothers and sisters on page 28-30.

Memorials

Many places of worship and some hospitals and funeral directors have a Book of Remembrance, in which you may wish to enter your child's name. If you would like to have a headstone or memorial plaque, you can seek advice from your funeral director and ask for estimates of cost. There are regulations on the types of memorial stones allowed in cemeteries and some churches have their own regulations.

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

You may want to keep your own memory box or a memory book, containing items that help you and family members commemorate your child's life. Creating your own boxes can be a special activity for your family, or you can buy boxes, which are available in various designs

from several charities, such as Winston's Wish (info@winstonswish.org.uk)

and Child Bereavement UK (childbereavementuk.org)

You may also like to create your own special memorial page in tribute to your child. It's simple, quick and free to set up a tribute page via our website at lullabytrust.org.uk/tribute

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



The inquest

Many sudden infant or child deaths will have an inquest. An inquest is an inquiry to confirm who has died, when, where, and to further establish the cause of death. The inquest does not set out to accuse, blame, or comment on anyone's actions. It happens in a coroner's court, which can feel scary. Sometime this just means a room within the building, with the coroner leading.

If the coroner decides to hold an inquest you will be told the date, time and place. Often inquests can happen quite some time after a death so the coroner may issue an order allowing burial or cremation before the inquest is completed.

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

If no medical or other explanation has been found through the post-mortem examination, the coroner will confirm the cause of death as SIDS or sudden unexplained death in childhood. 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 child died, but sadly this is very often not the case.

You may find it helpful to talk with The Coroners' Courts Support Service (CCSS). CCSS is 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 inquest and explain what will happen. To find out if this service is available in your area visit www. coronerscourtssupportservice.org.uk or phone 0203 667 7884.

Inquests are open to the public, so if you wish you can 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 do not have to speak to the media. In fact you do not have to attend at all if you don't want to, unless you are called as a witness. You may find it useful to speak to the Independent Press Standards Organisation (IPSO) to understand what the press are allowed to report on during an inquest and what to expect www.ipso.co.uk

The Child Death Review

All child deaths (up to the age of 18 years) are reviewed by specialist Child Death Review Panels. These regional panels play no part in the investigation of the cause of an individual child's death but they look at all deaths to see if there are any lessons or patterns that could help improve care and prevent children dying in the future. Once the investigation has finished, the CDOP will see a summary of the events before and after the death of every child in their area. It can take some time for the CDOPs to meet. You

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should have a key worker to support you through this process.

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The CDOP makes recommendations and reports about the lessons learned to those responsible at a local level. They do not produce reports about the death of individual children but each CDOP produces an annual report, which is a public document. Anyone can read the annual report; importantly it does not contain any details that could identify an individual child or their family.

Can you be involved in the child death overview panel?

Parents and carers are not invited to be part of the panel but you may be invited to contribute any comments you might have into the review of your child's death. Although individual deaths are not reported on, you may be given some feedback if there is specific learning that is identified or a recommendation suggested at the meeting that is relevant to your child's death.

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Other practical things to think about

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

You will need to tell your Child Benefit Office about your child's death. Child Benefit payments will usually carry on for 8 weeks after a child's death and you may still be able to claim Child Benefit if your child died before you made a claim. You're entitled to up to 8 weeks of Child Benefit if you claim within 3 months of the death. You can do this either online through the direct.gov.uk website or by contacting the Child Benefit Office.

Your child's GP should have been notified of your child's death very quickly, but some families contact them directly as well. You could ask your GP to add a flag on you and your family's records about your child's death so that you do not have to explain what happened at each visit.

There may be other places that have your child's details such as dentists and opticians that you will need to inform at some point. If you joined any baby or child groups, such as supermarket 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 child's expected progress. The Mailing Preference Service can help with this; you can register online at www.mpsonline.org.uk

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

If you have been employed, and your child died under 1 year of age 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 though your child has died. Talk to your employer about what they can offer you or check your contract.

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

There are other benefits that you are still entitled to if your child died under 1 year of age, such as free dental care and prescriptions.

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 anyone can go through.

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

It can be a turbulent time, although there may be periods of calm. Intense emotions, which had seemed to fade, can return. You may feel confused or find it difficult to make decisions, or concentrate for any length of time. Even if you can sleep you may still feel exhausted. Grieving people can sometimes fear they are going mad. Many parents say that their child is always on their mind, that they experience aching arms, and hear their child cry. 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 child recently. These feelings of guilt and blame are normal, very common, and will lessen with time. Talk to someone if you feel able to. Someone outside of the family can talk through those questions and thoughts.

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

If you are finding it hard to imagine carrying on, have suicidal thoughts or are thinking about harming yourself, it is important that you tell someone about the way you feel. If you can't face talking to your loved ones or friends, you can talk to someone at The Lullaby Trust, where we have a helpline especially for bereaved parents and family members. The Samaritans are open 24 hours a day on 116 123.

0808 802 6868 Mon to Fri 10am – 5pm, Sat and Sun 6pm – 10pm

Grieving

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

You will need to give yourself time to grieve. Be kind to yourself, avoid trying to block your feelings with drugs or alcohol, this only tends to postpone the grieving process.

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

Other common feelings

Most parents who experience the death of their child describe the pain as the most intense they have ever felt. You may wonder if you will be able to tolerate it and survive or be able to feel that life has meaning again.

It can feel as though you are functioning in a fog during the first few weeks after your child's death. Some parents describe their experience of the funeral as of being an observer or not really being emotionally involved.

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 emailed 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 your child while the other may not even want to hear their baby's name spoken.

One mum told The Lullaby Trust:

"He didn't want to talk, that was his way of dealing with it, whereas I wanted to talk about our son 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 our son 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 child. Fathers are often asked "how is your wife?", and people may forget to say "how are you?" Fathers may feel it is their job to discourage looking back, and to encourage facing the future. Men often refuse help, or may not ask for support when it might be helpful.

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

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

In time, couples who can respect each other's different ways of grieving often find that they can begin to talk, share and support each other more easily.

If you are on your own

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

One mum told The Lullaby Trust:

"It is very hard to describe the loneliness which grief brings when you have no partner to share the loss of a beloved child. The burden becomes only yours. You seem to 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."

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. We can put you in touch with a Befriender, who is a bereaved parent to talk about some of the thoughts and feelings you may be struggling with. Please phone The Lullaby Trust to talk to a Befriender directly.

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

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

"I wrote letters to Michael all the time. I still have those letters and although I don't write them anymore, I do sometimes still read them." Even if you are not on your own you may find writing such letters to your child helpful.

You may find it useful to contact Gingerbread, an organisation who offer support to single parents

gingerbread.org.uk 0808 802 0925







Helpline

0808 802 6868

Mon to Fri 10am – 5pm Sat and Sun 6pm – 10pm

Website

www.lullabytrust.org.uk

If a twin or multiple dies

If your child was a twin or multiple, you may feel that you are not able to grieve properly for the one who died. You have the surviving child(ren) that need your love 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 child(ren) are a constant reminder that there should be more.

Your doctor or the hospital may suggest that your surviving child(ren) go into hospital for tests, although it is extremely rare for siblings to die. If your child was under a year old, you may also want to speak to your midwife, health visitor or paediatrician about joining your local Care of Next Infant (CONI) scheme where you can receive extra support and reassurance. www.lullabytrust.org.uk/bereavement-support/howwe-can-support-you/our-care-of-next-infant-scheme/

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

You may find it useful to visit The Twins and Multiple Birth Association (TAMBA) website **tamba.org. uk/bereavement** who also offer bereavement support including support groups and Befrienders specifically to parents who have lost one or both twins, or multiples.



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If your child was over one

This section is intended especially for anyone who has suffered the unexpected death of a baby or child very close to, or over, the age of one year. If you have turned immediately to this section, you may later find some factual information repeated elsewhere in the booklet. The rest of the booklet has been written both for parents who have lost a baby or who have lost a child over one. We hope that you will find all or much of the information helpful.

Some facts

The vast majority of SIDS deaths happen when babies are less than 6 months old; with the highest number happening at 2-4 months old. Parents naturally expect that after 6 months they may begin to feel less anxious about SIDS, and that on their child reaching the first birthday (and the 'official' end of infancy) the possibility of such an event is now past.

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

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

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

Special issues in deaths of children over one

The shock and sense of isolation can be even more intense for parents who lose an older child, as much of the safer sleep information and advice no longer applies to them. Guilt is a common feeling for all bereaved parents, and parents of children just over the age of one often describe their distress at the impossibility of getting an older child to sleep on their back, or, for example, regret at having begun to use a duvet after a year old.

In a child who was already starting to walk and talk, being irritable, 'naughty', fussy with food or 'a bit off colour' may have been, very reasonably, put down to perfectly ordinary child behaviour. Grieving parents may look back over what happened and see this behaviour as a 'sign' which they failed to take seriously.

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

If you find talking to friends and family too difficult you can speak to The Lullaby Trust who has a bereavement helpline. We also have a Befriender scheme, which allows us to put you in touch with volunteers who are bereaved parents themselves. The scheme has proved a great comfort to many parents as they can talk to someone who has an understanding of their situation and allows them to speak openly. If you are struggling to cope you can speak to your doctor who can help.

Helpline 0808 802 6868

Mon to Fri 10am – 5pm Sat and Sun 6pm – 10pm

or email support@lullabytrust.org.uk

The investigation

Added to this sense of guilt, is the shock of the police getting involved and looking into the circumstances of their child's death. This is a legal requirement after a sudden death at any age, not only the death of a baby or child. Several parents have described feeling 'under suspicion'. This along with the feeling that they 'must be to blame' if their child dies from no obvious cause, means the

shock and grief may be heightened by anxiety and despair.

It is not only parents of children over one year that feel this way but the widespread lack of awareness of sudden unexpected death in childhood even amongst professionals can make these feelings hard to deal with or to talk about.

The paediatric pathology investigation

There is no real difference in the process of investigation of a sudden death of a baby or young child and no difference in the way the post mortem examination is carried out.

In the UK, the post mortem examination should be carried out by a specialist paediatric pathologist.

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

Sometimes if no other cause of death can be found, a pathologist will use the terms SIDS (sudden infant death syndrome). Some parents have said that this is a more well-known term and removes any suggestion of blame or wrong-doing on the part of the parent. Whereas some parents prefer sudden unexplained death in childhood to acknowledge that, though extremely rare, even compared to SIDS, families who experience this tragic event are not alone, but part of a group.

The Lullaby Trust supports all bereaved families including those whose children were over a year old.

The website www.lullabytrust.org.uk contains detailed information about family events, meetings, conferences, publications and research. Some of it may seem to focus more on SIDS simply because sadly there are far greater numbers of SIDS deaths. However, they are also just as relevant for families who have experienced the sudden unexpected death of a child.

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

Another place parents can go for support is SUDC UK. Co-founded by three SUDC bereaved mothers in 2017, it focuses on the 'why' to allow better understanding of the causes and help prevent the sudden unexplained death of children in the future. SUDC UK is dedicated to increasing awareness in the UK, funding crucial research and offers a supportive SUDC community. To contact SUDC UK email info@sudc.org.uk and for more information visit www.sudc.org.uk

Life after your child's death

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

One dad said:

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

People may suggest at some point that you should be 'over it'. This is a meaningless concept for a bereaved parent, so try not to let others suggest that you should be 'moving on'. 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

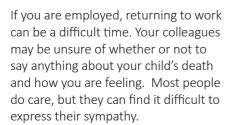
things over when you feel especially low, or if you are tempted to use alcohol, medication or drugs to numb your grief temporarily.

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

One mum said:

"One thing that grief has done for me is to make me wiser and the future brighter. No matter what comes along, you know that you can cope with anything; nothing can ever be as bad again for you. I will always keep my son in my heart and I am glad to have had such an angel share my life."

Returning to work



Some parents have found it helpful to ask their employer or senior colleague (who may be less personally close) to speak to colleagues about what has happened, before a return to work.

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

As a bereaved parent, you will be

entitled to paid leave following the death of your child. This will be two weeks and there will be some flexibility over when you take this. It will be paid at a set amount, which much like a statutory sick pay, may be less than your salary.

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

You can self-certify sickness absence for the first week, and then you will need to visit your GP for a 'fit note' to continue to take sick leave. Try to contact your work, or ask someone else to, if you need more information about your employer's position.

The brothers and sisters

It is common for parents to feel worried about how any other children will be affected by their sibling's death. You may be concerned about the difficult task of discussing and explaining the death especially when you don't have a reason for how or why it happened.

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 be misunderstood and lead to confusion and complication such as:

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

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

Suggesting that a child has 'gone to heaven' or 'to live with God or Jesus' may be confusing for a young child, unless your family share a religious faith, which you all find comforting.

Children and young people grieve just as much as adults but they show it in different ways. They learn how to grieve by copying the responses of the adults around them, and rely on adults to provide them with what they need to support them in their grief.

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 statement as far as their age and vocabulary allows. There is no age at which a child is too young to be told in the simplest terms what is happening. A young child may not understand, but needs information, often repeated, and 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).

Children have a limited ability to put feelings, thoughts and memories into words and tend to "act out" with behaviours rather than express themselves verbally. Showing your grief will encourage them to express theirs. Their behaviour is your guide as to how they are and this is as true for a very young child as it is for a teenager.

It is important that children are reassured that it wasn't anybody's fault that their sibling 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 excluding them is likely to leave them feeling anxious, bewildered and alone. Allowing them to see their sibling and say goodbye is usually helpful – their imagination is often much worse than reality

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

The Child Bereavement UK website has further information and support around talking to children.

childbereavementuk.org/for-families/support-for-bereaved-children

Or you can contact Winston's Wish, a charity which offers bereavement support to children, on **08088 020 021**

www.winstonswish.org.uk

Helpline

0808 802 6868

Mon to Fri 10am – 5pm Sat and Sun 6pm – 10pm

Ways to help children

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

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



Grandparents and other family members

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

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

A very deep sense of loss will be felt by those who live far away from the grandchild, and may not have been able to see and hold him or her much before the death. These considerations apply 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."

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

Try, if you can, to explain to family members to what extent you feel able to be included in their children's activities and celebrations, and how you would like your child's name and life to be spoken of and remembered. Relatives are often very unsure, and risk unwittingly isolating their bereaved family member rather than 'upset' them.

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

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

You will have been the person who had to handle the crisis, perhaps attempting resuscitation and contacting the emergency services. If you work in a nursery, you 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 child's parents arrived, and you were not able to talk to them properly while the police still had questions for you.

The exact causes of SIDS and sudden unexplained death in childhood are

not known, but you may worry that the death could have been prevented. Even when you are sure you have done nothing wrong, and could not have acted differently, feelings of guilt can be strong.

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

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

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

The death of a child may change the relationship between parent and carer

and, while some friendships can be strengthened, some parents may not want to see the carer again.

While experiencing your own grief and trying to accept the bereaved parents' actions, you may find it helpful to talk to an understanding person.

Finding support

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

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

How The Lullaby Trust can help

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

Helpline 0808 802 6868

Mon to Fri 10am – 5pm Sat and Sun 6pm – 10pm

Befrienders

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

We know how isolating it can feel to be bereaved by sudden infant death, and sometimes speaking to someone who has been through something similar can be a comfort. We aim to put you in contact with a Befriender within a few days.

We will try to match you to a Befriender based on similar personal circumstances, where possible. However, all of our Befrienders are ready to listen and support you. The Befriender can contact by phone or email, and can stay in contact for as long as you both agree to. All our Befrienders have been bereaved for over 4 years, and most for many more. They have all been given training on how to be a listening support.

If you are interested in getting in contact with one of our Befrienders please contact us by calling **0808 802 6868** between 10am and 5pm on working days, or email support@lullabytrust.org.uk

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Counselling

If you are finding things especially difficult or require more in-depth support, you may want to access bereavement counselling or therapeutic support, in addition to support from The Lullaby Trust.

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

Not everyone will need or want professional counselling. You may find that the support of family and friends or talking to other parents who have been through a similar loss is enough for you. It is important that you get the support that is right for you.

Some people benefit from speaking openly to a counsellor about their feelings to gain support and help ease the grieving process and resolve any remaining issues they may have.

If you think you might benefit from counselling you can see more guidance on our website www.lullabytrust.org.uk/bereavement-counselling

Or contact us to talk about what help is available.

Giving Support

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

• Allow the bereaved 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 judgemental.

- Be available to listen to the parents talk as much and as often as they
 wish about the baby or child who died. This can be helpful for them.
 It may be difficult for you to hear, so make sure you seek support for
 yourself if you think this would be helpful.
- Bereaved parents often want to talk about their child and be allowed to remember them. Talk freely about the special qualities of the child and do not avoid mentioning the subject.
- Use the child's name.
- Suggest you look together at photographs, if the parent seems comforted by photos and keepsakes.
- Try not to offer 'reassurance' on things you are not completely certain about, and which may indeed remain uncertain. E.g. "I'm sure they'll find the answer....." "You'll feel better by then...," "Everything will be okay......" It's okay just to listen or admit that you don't know what to say but that you are there to offer support.
- Give special attention to any other children in the family, especially if the parents are too distressed themselves to give them comfort or attend to their individual needs.
- Offer to help with practical matters: telephoning, shopping, cooking and child minding, but avoid the temptation to take control.
- Do not, however, wash any item of clothing or bedding without being asked, as many parents find great comfort from things that still smell like their child. Unless you are asked, do not pack away the child's belongings. Never put or throw anything away as this may be regretted later. Usually parents will deal with the child's belongings when they are ready for them. This can be an important part of coming to terms with the death.
- Never tell the 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.
- Your offers of support, especially at first, may be received without obvious gratitude, or even ungraciously, but try not to let this lead to an end to your contact or friendship. Parents are often very distressed at losing a valued relationship because neither side knew how to react to such a tragedy at first. If you can remain sensitive to a family's changing needs as their bereavement goes on, and continue to keep in touch and offer practical help, this will be valuable support.

Having another baby

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

You may find that having another baby can be a worrying time, with many mixed feelings: happiness and anxiety, overwhelming love and fear of loving too much.

If your child was over a year old, you may already be pregnant again, or have another very young baby.

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

Whatever your situation, contact with the Care of Next Infant (CONI) programme can be a great support.









Care of Next Infant (CONI)

The Lullaby Trust's Care of 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 may be available to the extended families of a child who died of SIDS or 'unexplained SUDI', and to parents of children 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.

It is important to mention that unfortunately the CONI scheme isn't available everywhere and can differ between areas. This depends whether the programme has been commissioned as an element of the local Health Visiting services.

As you can imagine, we'd like CONI to be available absolutely everywhere and we'll continue pushing to gain funding for the programme.

A bereaved mum said of CONI:

"My wonderful, wonderful consultant and midwife team made me aware of the CONI Scheme. This became a lifeline for me. As I neared the end of my pregnancy, the CONI Scheme offered me and my family first aid training in our home and provided an Aproea monitor for our baby to monitor his breathing as they do in hospitals. A sophisticated piece of equipment, which gave me great comfort in the early months."

For more information and to find out if there is a CONI or CONI Plus scheme in your area, contact the CONI team on **0207 802 3206** or The Lullaby Trust's Helpline.

Helpline

0808 802 6868

Mon to Fri 10am – 5pm Sat and Sun 6pm – 10pm

Publications

The Lullaby Trust and other organisations produce information about SUDI/SUDC and related issues and research.

Many of the publications below are free to download or can be ordered online. Please visit www.lullabytrust.org.uk

• Winston's Wish, Living with Bereavement

A leaflet providing support and guidance for the families of bereaved children.

Call 08452 030405 or email info@winstonswish.org.uk

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

Glossary

Coroner A coroner is a doctor or lawyer, or sometimes both who inquiries into all sudden, unexpected or unnatural deaths.

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

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

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

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

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

Other useful contacts

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

- Support following the death of a baby
- Support following a child death
- Bereaved siblings/children
- Practical support
- Loss in pregnancy or birth

Support following the death of a baby

BLISS

Support for families of babies born premature or sick

0808 801 0322

www.bliss.org.uk

TAMBA

Offers bereavement support including support groups and Befrienders specifically to parents who have lost one or both twins, or multiples.

0800 138 0509

www.tamba.org.uk

Scottish Cot Death Trust

Provides a wide range of support for bereaved families and educates the public and professionals about cot death and how to reduce the risks in Scotland.

0141 357 3946

www.scottishcotdeathtrust.org

Samaritans

Free on **116 123** 24 hours a day, 365 days a year

SANDS

Support for anyone affected by stillbirth, neonatal and other sudden death of a baby

0808 164 3332

www.uk-sands.org

Support following a child death

Child Death Helpline

Freephone service for all of those affected by the death of a baby or child **0800 282 986** and **0808 800 6019** childdeathhelpline.org.uk

Child Bereavement UK

Supports families when a baby or child of any age dies or is dying, or when a child is facing bereavement.

0800 028 8840 childbereavementuk.org

CRUSE

Offers bereavement support after the death of someone close **0808 808 1677**

www.cruse.org.uk

• Together for shorter lives

Support for families caring for seriously ill children, including bereavement support

0808 8088 100

www.togetherforshortlives.org.uk

• 2 Wish upon a Star (Wales)

Support for families after the death of a baby/ child up to 25 years **01443 853125**

support@2wishuponastar.org

SUDC UK

Raises awareness and understanding of sudden unexplained death in childhood

info@sudc.org.uk sudc.org.uk

Bereaved siblings/children

• Winston's Wish Helpline

Support for children and young people after a death

08452 03 04 05

www.winstonswish.org.uk

Practical support

BACP (British Association of Counselling and Psychotherapy)

Find a BACP therapist in your local area.

01455 883300

www.bacp.co.uk/search/Therapists

Child Funeral Charity

Offers financial Support for families to arrange funerals for babies and children under 16. * Only takes referrals from professionals.

01480 276088

www.childfuneralcharity.org.uk

• Coroners Court Support Service

Offers practical and emotional support, whilst you are at the court. If possible, the volunteer will take you into the court before the proceedings start and explain how an Inquest is conducted and the layout of the Court.

0300 111 2141

www.coronerscourtssupportservice.org.uk

IPSO

*

Independent Press Standards Organisation. Can offer advice with the media presence at inquests.

*

0300 123 2220

www.ipso.co.uk

Gingerbread

Offers support to single parents

*

0808 802 0925

gingerbread.org.uk

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Loss in pregnancy or birth

• Action on Pre-eclampsia

Support for those who have experienced pre-eclampsia, concerned relatives and health professionals.

01386 761 84801 action-on-pre-eclampsia.org.uk

• Arc

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

Helpline: 0845 077 2290 or 0207 713 7486 via mobile www.arc-uk.org

• The Ectopic Pregnancy Trust

Supporting people who have experienced an early pregnancy complication and the health care professionals who care for them.

020 7733 2653 www.ectopic.org.uk

• Miscarriage Association

Offers support and information to those affected by miscarriage, ectopic pregnancy or molar pregnancy.

01924 200 799 www.miscarriageassociation.org.uk

• Strep B Support

Support and Information on families affected by Strep B including bereavement support.

01444 416 176 gbss.org.uk







For bereavement support:

Call: **0808 802 6868**

Email: support@lullabytrust.org.uk

Visit: www.lullabytrust.org.uk

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

The Lullaby Trust, 11 Belgrave Road, London, SW1V 1RB Registered charity no. 262191

This booklet is funded by his loving family, in memory of Krishan Kantaria 14/07/11- 17/08/11