

When a baby or
young child **dies**
suddenly and
unexpectedly

the
lullaby
trust



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Introduction

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

If you are a professional reading this you may also want to take a look at the advice for professionals on our website lullabytrust.org.uk/professionals-hub

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

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

Introduction

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

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

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

Helpline: 0808 802 6868

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

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

Website: lullabytrust.org.uk

Terminology

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

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 a cause of death, for example, an infection or other illness such as a genetic disorder. Deaths that are still unexplained after the post-mortem are usually registered as **‘sudden infant death syndrome’** (SIDS) for babies under a year old (deaths of children up to two years old are sometimes also recorded as ‘sudden infant death syndrome’). Sudden unexplained death in childhood (SUDC) is sometimes used for children, over the age of 12 months, who die without a known cause. The term ‘unascertained’ may sometimes be used. This is another way of saying that the cause of death cannot be found.

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

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

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

From the moment a sudden and unexpected death of a baby or child dies, it triggers an ongoing and established Joint Agency Response. This can last twelve months or even longer, and involves many professionals.



Joint Agency Response

The multi-agency response to the sudden and unexpected death of a baby or young child is known as a Joint Agency Response (JAR). The diagram below shows the steps involved:

Ambulance/police immediate response. Assess risks/concerns; resuscitate if appropriate. Police consider scene security. Address needs of siblings/family.



Child/carer taken to hospital with paediatric facilities; resuscitation continued or decision to stop. Hospital doctor notifies designated on-call professional for child deaths/relevant police investigator. Both attend hospital.



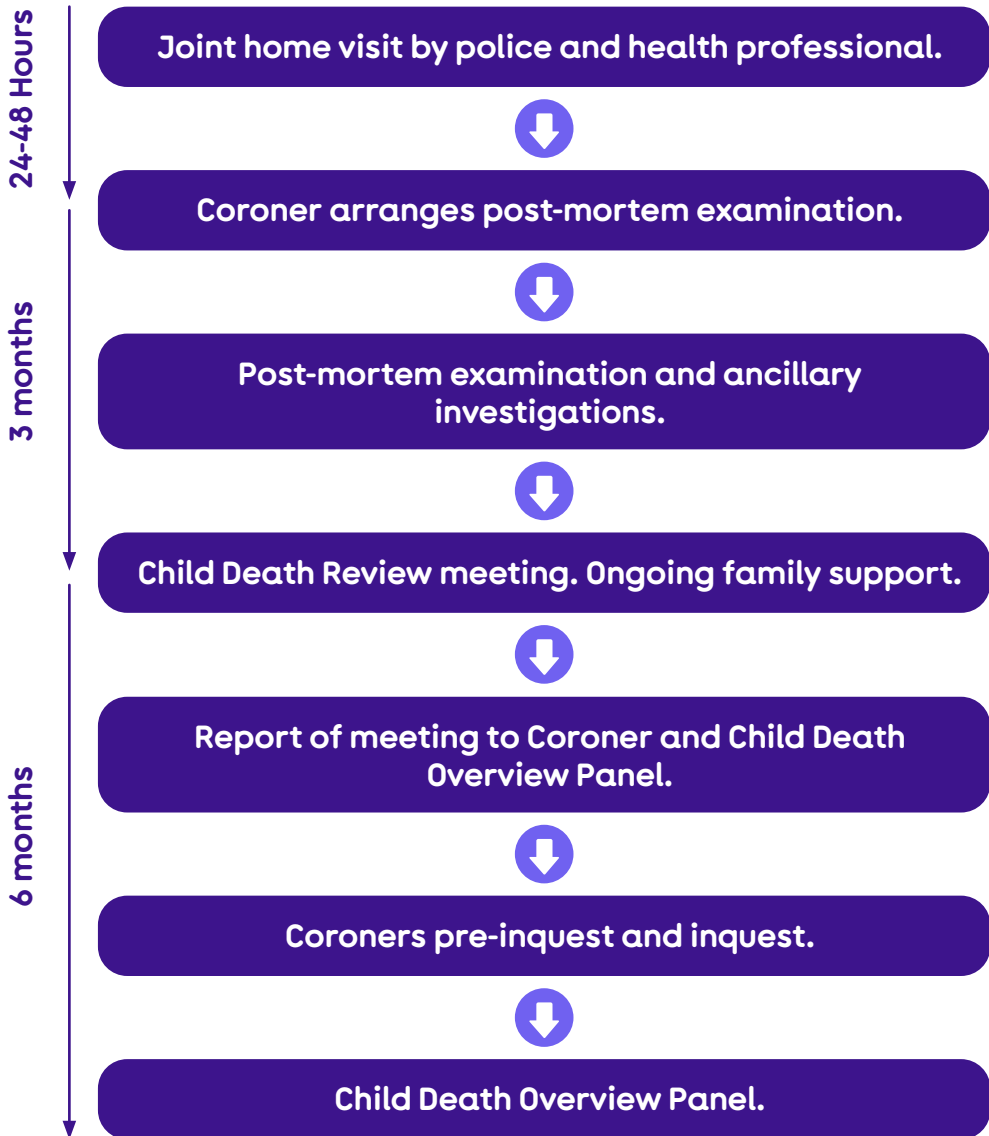
Attending clinician confirms death. Support for family. Planning discussion between lead health professional and attending police officer. Lead health professional and police officer take initial history, examination, and initiates immediate investigations.



Initial information sharing and planning meeting.

First 24 Hours

Continued on the next page



Immediate response – straight away

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

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

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

You will be allocated a lead health professional once at the hospital and kept fully informed in an appropriate and private space. Your child will be carefully examined by a paediatrician or another doctor and blood and other tissue samples may be taken. This lead health professional should then tell you that your baby has died and explain what happens next. If they do not know the cause of death, they must inform the **Coroner** (or in Scotland, the Procurator Fiscal).

You will be asked questions about what happened and for information about your baby or child by a professional at the hospital. Initial meetings between different professionals, such as the police and paediatrician, take place.

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

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

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

You should be allocated a keyworker; a single, named point of contact to whom you can turn to for information on the next stage of the child death review process. They can signpost you to sources of support.

Your keyworker can be the ‘voice’ for you. They are often a health professional (but not always) and are often the professional who ‘knows’ you best. Contact details of support organisations and bereavement services should be given to you before they leave the hospital.

The healthcare team will ensure that your baby’s death is notified to the local **Child Health Information System** (CHIS), and that your baby’s/ child’s GP and health visitor are notified of their death.

The **Child Death Overview Panel** (CDOP) administrator will also be informed of the death. These are all crucially important to ensure other professionals are made aware of your baby’s death and do not contact you for other appointments relating to your baby or child, which could be hugely distressing.

Before leaving hospital

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

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

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

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

ukamb.org/donate-milk and
humanmilkfoundation.org/hearts-milk-bank



Early response

- usually in the first week

Home visit

As soon as possible after your baby or child's death, if they died at home, you will be visited at home by a police officer. Their role is to eliminate the possibility that anything unlawful has taken place. You may also be visited by a doctor or nurse to see where the death happened, and to ask you for more detailed information. Sometimes these visits will be made jointly.

If your child died away from home, the police may visit the place of death and may visit you later to ask you further questions. This should be a joint visit with police and a specialist health professional, and the parents will usually be invited to be there.

The Coroner

Where a baby's death was sudden and unexpected, the death will be reported to the Coroner. This means you may not be able to arrange the funeral or register the death for some time. The **Coroner** officially has custody of your baby's body from the point at which they are informed of the death, and will then make decisions about what investigations take place and where and when.

Although in most situations, families will be able to see their baby after death, the Coroner ultimately has control over allowing this to happen. If you have religious or

other requirements that may affect the timing of your child's funeral, please discuss these with hospital staff or your keyworker. They will alert the Coroner who will try to accommodate your wishes, though it may not be possible.

Post-mortem examination

All sudden and unexpected deaths of babies will have a post-mortem examination, which should be undertaken by a specialist paediatric pathologist. This often means your baby will have to travel, sometimes long distances, to a specialist centre. This is clearly upsetting for families, and you should be kept up to date with where your baby has been moved to and when the post-mortem examination is going to take place.

A post-mortem examination is a careful external and internal investigation of the body to try to discover the cause of death. A cause of death, or possible factor contributing to the death, is found in approximately half of the post-mortems performed. When the post-mortem examination does not reveal a cause of death, then it is likely that a diagnosis 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. The Coroner will receive any initial findings. Where possible, you can be given some information about these results, with the Coroner's approval. The final post-mortem examination report may take several months to be completed, depending on the number and type of tests conducted.

You should be able to get a full copy of the report if you would like one.

The post-mortem examination may help the Coroner decide whether an inquest is needed. A paediatrician will be able to go through the report with you, if this would feel helpful. The report will be written with medical terminology that may be confusing to a person without specialist knowledge in the field. Please ask your keyworker, GP, health visitor, or midwife, to contact the attending paediatrician, on your behalf, to arrange this. The post-mortem report is often sent directly to you, but you can ask your keyworker to check this.

Performing a post-mortem examination is complex and it can take several months for all tests to be completed. You may have to make difficult decisions as to whether you wish to have a funeral before all the tissue samples have been returned. Soon after the post-mortem, the pathologist gives an initial report to the Coroner. Where possible, with the Coroner's approval, you can be given some initial feedback on these early results.

You may be asked whether you are planning a burial or cremation, so that the correct papers can be prepared. It can feel difficult to make this decision. If you are not sure you can inform the funeral director of your choice later on.

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

Tissue retention

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

Some parents find great comfort in knowing their child's tissue might help research, or provide more answers from future medical advances. Even when no cause of death is found, advances in medical research open up the possibility that an answer may eventually be found. With your consent, a tissue sample taken from your child could be looked at again using these future advancements.

The Coroner should ensure you are offered the choice about what happens to these tissue samples once the post-mortem examination has taken place. You can ask for the samples to be:

- **Returned to you (the Coroner's Officer will be able to discuss what you could do with the samples).**
- **Kept by the hospital, as part of your child's medical record.**
- **With your consent for use in research, future testing, or other purposes (for example, teaching).**
- **Respectfully disposed of by the hospital.**

In rare circumstances, whole organs may need to be kept for special tests, which may take several days or weeks to complete. If this is the case the Coroner's Officer will discuss the possibilities open to you:

- You may wish to delay the funeral until the organs are able to be returned to your child.
- You may wish to receive them back at a later date.
- You may wish to allow the hospital to keep or respectfully dispose of them.

You may also wish to discuss these choices with the funeral director and the doctor.

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

Whole Genome Sequencing (WGS) for unexpected infant deaths

WGS is now available through the **NHS in England** for babies and children who have died suddenly and unexpectedly where the death is unexplained following full investigation, including a post-mortem examination. These babies will have been given a cause of death such as Sudden Infant Death Syndrome (SIDS), Sudden Unexpected Death in Infancy (SUDI), or unascertained. Sudden Unexplained Death in Childhood (SUDC) may be used if your baby was over 12 months old.

A **DNA sample** will have been taken from your baby as part of the post-mortem examination and saved for later analysis. This sample can be analysed for WGS if you give consent. Paediatricians or specialist nurses should talk

with you about WGS when they discuss the results of the post-mortem examination with you. They may be able to arrange WGS directly or refer you to a clinical genetics specialist. A blood sample will also be needed from parents to help with the analysis, preferably from both parents, but it can be done with just one parent's sample if necessary.

At the post-mortem examination, the pathologist will take several tiny tissue samples as well as the DNA sample. You should have been asked by your Coroner's officer or investigator, specialist nurse or paediatrician what you would like to happen with these samples after the post-mortem report has been completed. It is really important that you request for these samples to be saved, if the samples are destroyed, it will not be possible to do WGS. If you would like information about the tissue samples please see: sudc.org.uk/retention

If your baby died some time ago, it may still be possible to do WGS if tissue samples were saved.

You should discuss this with your GP, or your specialist nurse or paediatrician if you are still in contact with them.

WGS may lead to useful information for around 1 in 10 SIDS families; but for most families it will not lead to an exact cause of death being identified. For further information on WGS please see:

youtu.be/sn3_FlEbe0U?si=DRvadEii0is4jQXN

The contact information for your local NHS Genetic Services team can be found here: geneticalliance.org.uk/support-and-information/genetic-services-and-testing/nhs-genetic-services-in-the-uk/

Care of your child after the post-mortem examination

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

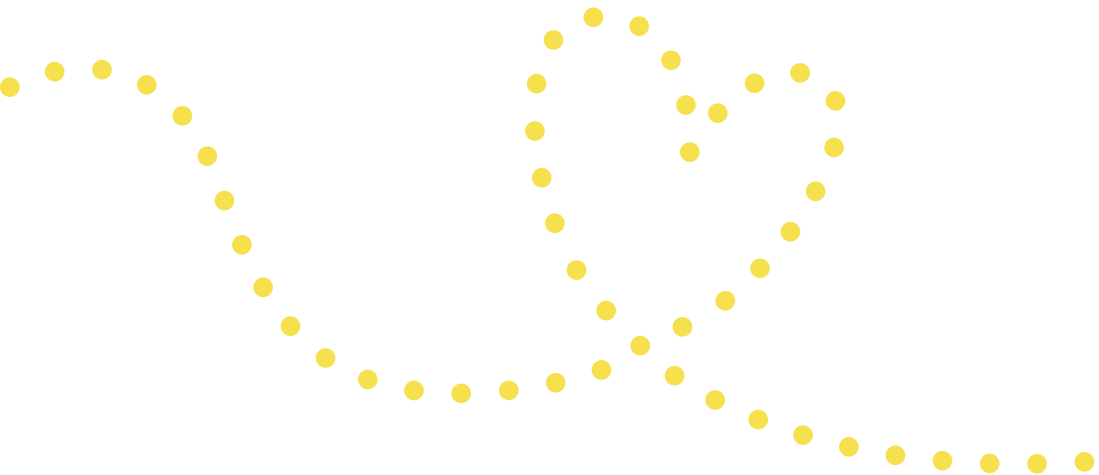
Many families choose to visit their child at the hospital or funeral home. Others choose to bring their child home for a few hours, or days, before the funeral. Some families find it comforting to say 'goodbye' in familiar and loving surroundings. Some families choose to invite a representative from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

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

Some families find comfort in making new and lasting memories in these moments. Singing your child's favourite song, or sharing meaningful stories might bring your family comfort. There are inkless kits to take hand and foot prints without damaging your child's skin. You may want to ask your funeral director if this is possible to be done before the funeral, if this hasn't been done already. You might also want to keep a lock of your child's hair if they had some.

Registration of death

Your baby's death will not be able to be registered formally until the **Coronial Process** has been completed, which can take up to six months or sometimes even longer. However, an interim death certificate will be given to allow a funeral to take place once the initial post-mortem examination has been completed.



Expected deaths

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

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

It may be necessary for the Coroner to order a post-mortem examination. Otherwise, you should be able to register your child's death quickly and proceed with your family's planned funeral.

For further information on what happens when a child dies:

www.lullabytrust.org.uk/wp-content/uploads/parent-leaflet-child-death-review.pdf

Choosing a funeral director

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

Funeral arrangements

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

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

Burial or cremation

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

You can discuss the choice of songs, hymns, music, readings and poetry for the ceremony with family, friends and those helping with the service. These

decisions can feel very upsetting to make, so try to give yourself enough time to make the choices that are right for you.

Ashes

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

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.

Costs

The **Children's Funeral Fund for England (and Northern Ireland)** can help to pay for some of the costs of a funeral for a child under 18 or a baby stillborn after the 24th week of pregnancy.

It is not means-tested: what you earn or how much you have in savings will not affect what you get.

What the fund covers:

The Children's Funeral Fund can help pay for the:

- **Burial fees.**
- **Cremation fees, including the cost of a doctor's certificate.**
- **Coffin, shroud or casket (up to a cost of £300).**

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 might be able to apply for **Funeral Expenses Payment** to cover them.

You can phone the helpline on **0800 7310 469** to make a claim and for advice.

Other children

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

It's generally best to give children **simple, straightforward explanations** about what is happening. It is also important to let the school know about the death of a pupil's brother or sister, so staff can provide support and be aware of any emotional or behavioural changes. There is more information on supporting brothers and sisters on pages on page 48 onwards.

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

www.childbereavementuk.org/what-happens-at-a-burial-animation

www.childbereavementuk.org/what-happens-at-a-cremation-animation

Memorials

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

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

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

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

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

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

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



The 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. It can be helpful to write these down before you go. Professionals may be present, for example: a police officer, paediatrician, pathologist or health visitor.

If the post-mortem examination found no medical or other explanation, the Coroner will confirm the cause of death as SIDS or sudden unexplained death in childhood. Often the 'risk factors' for SIDS may be discussed during the inquest. 'Risk factors' are often present. They are things which may increase risk in some cases, for reasons that no one fully understands yet. It is important to understand that any discussion does not necessarily imply that these risk factors caused the death to occur. 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 coronerscourtsupportservice.org.uk or phone **0300 111 2141**.

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 are reviewed by specialist Child Death Overview Panels (CDOPs), and this includes unexpected infant deaths. CDOPs review the death of every child in England who dies before their 18th birthday. In Wales the process is called the **Procedural Response** to Unexpected Deaths in Childhood (PRUDIC) and this only applies to unexpected deaths.

The aim of these reviews is to identify learning to prevent future deaths and improve support to families. This process works alongside all the other elements of the investigation into a baby's death. You should be informed

that the child death review process is taking place and be informed how you can input into it should you wish. Recently, the national guidance for the child death review was updated to state that parents should be able to contribute to the child death review.

Other practical things to think about

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

You will need to tell your Child Benefit Office about your child's death. Child Benefit payments will usually carry on for 8 weeks after a child's death. You may still be able to claim Child Benefit if your child died before you made a claim. You are 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 about your child's death on your and your family's records. The flag will remove the need to explain what happened at each visit.

There may be other organisations, such as the dentists or opticians, that have your child's details. They will also need to be informed at some point. If you joined any baby or child groups, such as supermarket clubs or online clubs, you may want to tell them that you don't want to receive any more information. Otherwise they may

continue to send offers and information relating to your child's expected progress. The Mailing Preference Service can help with this; you can register online at 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 was less than one year old when they died, you should still be entitled to statutory **maternity or paternity leave** and pay. It may be that you do not have to return to work for a year after your baby was born, although some of this leave may be unpaid. Your employer may offer applicable extra maternity benefits, even though your child has died. Talk to your employer about what they can offer you or check your contract.

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

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



Grieving

0808 802 6868

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

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

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

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

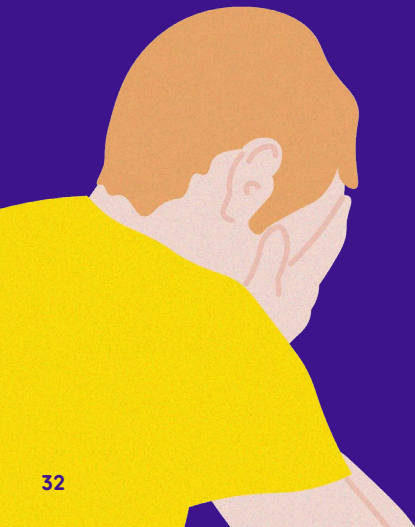
Parents often go over and over in their minds everything they did or did not do, which they worry could have caused the death. They sometimes blame themselves or each other, or feel angry with the doctor, health visitor or

anyone who had seen the child recently. These feelings of guilt and blame are normal, very common, and will lessen with time. Talk to someone if you feel able to. Someone outside of the family can talk through those questions and thoughts.

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

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

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



Grieving

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

If you believe you may be experiencing the ongoing symptoms of trauma following the death of your baby or child The Lullaby Trust has a resource that may be supportive: <https://www.lullabytrust.org.uk/wp-content/uploads/Trauma-Resource.pdf>

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. Feelings such as worry and guilt can feel overwhelming, but rest assured they are common and normal parts of grief. One mum described feeling this way:

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

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

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

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

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

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

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

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

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

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

Another parent told The Lullaby Trust:

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

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

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

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

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

"How is your partner?",

and people may forget to say

"How are you?"

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

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

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

One mum told The Lullaby Trust:

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

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

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

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

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

If you are on your own

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

One mum told The Lullaby Trust:

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

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

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

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

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

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

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

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

Helpline: 0808 802 6868

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

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

Website: lullabytrust.org.uk



If a twin or multiple dies

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

Although it is extremely rare for siblings to die, your doctor or the hospital may suggest that your surviving child(ren) go into hospital for tests. 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. [lullabytrust.org.uk/bereavement-support/find-support/having-another-baby/](https://www.lullabytrust.org.uk/bereavement-support/find-support/having-another-baby/).

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

You may find it useful to visit Twins Trust Bereavement website: twinstrust.org/bereavement.html who offer bereavement support groups and resources.
Or Footprints Baby Loss, Twin and Triplet support: www.footprintsbabyloss.org

If your child was over one

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

Some facts

The vast majority of SIDS deaths happen when babies are less than six months old; with the highest number happening at 1-3 months old. Parents naturally expect that after six months they may begin to feel less anxious about 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 small number of young children die suddenly and unexpectedly, in a manner which appears to be similar to SIDS, but is

usually referred to as sudden and unexpected death in childhood.

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

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

Special issues in deaths of children

over one

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

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

If you find talking to friends and family too difficult, you can speak to The Lullaby Trust who has a bereavement helpline. The Lullaby Trust can put you in touch with a volunteer befriender, who is a bereaved parent themselves. Befrienders have proved to be a great

comfort to many parents. You may find it helpful to talk openly to someone who understands your situation. If you are struggling to cope, you can also speak to your doctor who can help.

Helpline: 0808 802 6868

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

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

Website: lullabytrust.org.uk

The investigation

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

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

The paediatric pathology

investigation

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 (a type of doctor who is trained to find out how a child has died).

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

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 SUDC (sudden unexplained death in childhood). They feel it acknowledges 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.

Within The Lullaby Trust, parents who have lost a child over one are available as trained Befrienders to offer

personal support via telephone and email to all families who have experienced the unexplained death of a child. 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'. You will make your own decisions about what

helps you to cope and carry on. You may find support in doing this from friends and relatives and perhaps in discussion with a Lullaby Trust support adviser. It is almost always a good idea to talk things over when you feel especially low, or if you feel tempted to use alcohol, medication, or drugs to numb your grief temporarily.

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

One mum said:

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

Returning to work

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

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

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

explain the change in circumstances when they return.

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

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

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

You may find this resource for employers helpful:

www.lullabytrust.org.uk/wp-content/uploads/Bereavement-support-in-the-Workplace.pdf



The brothers and sisters

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

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

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

It is best to begin with a **simple explanation** and then allow children to ask questions when they are ready. Ensure they know they can speak to you when they need to and provide opportunities for this. It is ok not to have all the answers, what is important is to listen to them so that they feel they are supported and included. They

may need to repeat the same questions over and over as part of understanding what has happened. It is best to answer in a straightforward way, using simple, age appropriate language.

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

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

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

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

Children and young people grieve just as much as adults, but they show it in different ways. Siblings may regress in their behaviour, becoming clingy, reverting to thumb

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

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

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

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

www.childbereavementuk.org/supporting-bereaved-children-and-young-people

www.childbereavementuk.org/what-happens-at-a-burial-animation

www.childbereavementuk.org/what-happens-at-a-cremation-animation

You can contact Winston's Wish, a charity which offers bereavement support to children, on 08088 020 021 www.winstonswish.org



Ways to help children

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

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

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

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



Fathers

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

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

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

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

What helps?

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

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

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

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

Your relationship

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

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

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

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

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

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

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

LGBTQ+ parents

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

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

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

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

Grandparents and other family members

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

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

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

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

One aunt told The Lullaby Trust:

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

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

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

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

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

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

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

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

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

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

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

One nursery owner told The Lullaby Trust:

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

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

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

Finding support

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

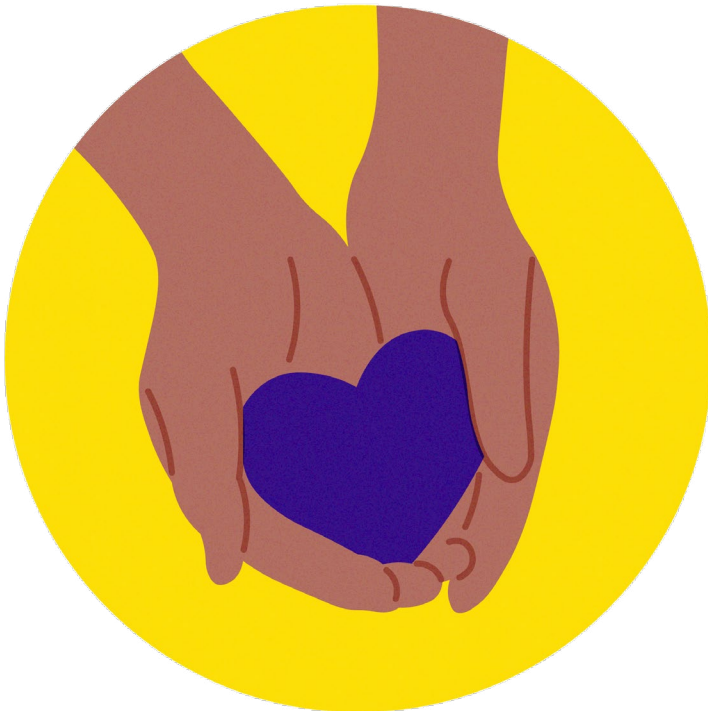
If your child has died you may feel that no one can help with any of your feelings, but emotional support in the short term may help you to keep going.



How The Lullaby Trust can help

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

**0808 802 6868 Mon to Fri 10:00am - 2:00pm,
Sat and Sun 6:00pm - 10:00pm or email
support@lullabytrust.org.uk**



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 you by phone or email and can stay in contact for as long as you both agree to. All our befrienders have been bereaved for over four years, and most for many more. They have all been given training on how to be a listening support.
- If you are interested in talking with one of our Befrienders, please contact us by calling **0808 802 6868** between 10:00am - 2:00pm or email **support@lullabytrust.org.uk**.



Counselling

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

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

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

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

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

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

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

Or contact us to talk about what help is available.

Giving support

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

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

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

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

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

Having another baby

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

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

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

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

Care of the 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 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.

CONI is 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 apnoea 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 scheme in your area, contact the CONI team on 0207 802 3206 or The Lullaby Trust's Helpline.

Publications and Bereavement Resources

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

- Winston's Wish, Living with Bereavement, a leaflet providing support and guidance for the families of bereaved children, and other publications, are free to download. A hard copy can also be ordered, please visit: www.winstonswish.org/supporting-you/publications-resources/

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

- **BLISS**
Support for families of babies born premature or sick. 0808 801 0322 www.bliss.org.uk
- **Twins Trust**
Offer bereavement support groups and resources to parents who have lost one or both twins, or multiples. 0800 138 0509
www.twinstrust.org/bereavement.html
- **Footprints Baby Loss, Twin and Triplet Support**
Provides support to parents and families who experience the death of one or more of their twins or triplets before, during or after birth.
www.footprintsbabyloss.org
- **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.
www.samaritans.org
- **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**

Has further information on sudden deaths of children between 1 and 18 years of age. www.sudc.org.uk info@sudc.org.uk

Bereaved siblings/children

- **Winston's Wish**

Helpline support for children and young people after a death 08452 03 04 05 winstonswish.org

Practical support

- **BACP**

(British Association of Counselling and Psychotherapy) Find a BACP therapist in your local area. 01455 883300 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.coronerscourtsupportservice.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

Loss in pregnancy or birth

- **Action on Pre-eclampsia**

Support for those who have experienced pre-eclampsia, including concerned relatives and health professionals. 01386 761 84801
action-on-pre-eclampsia.org.uk

- **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**

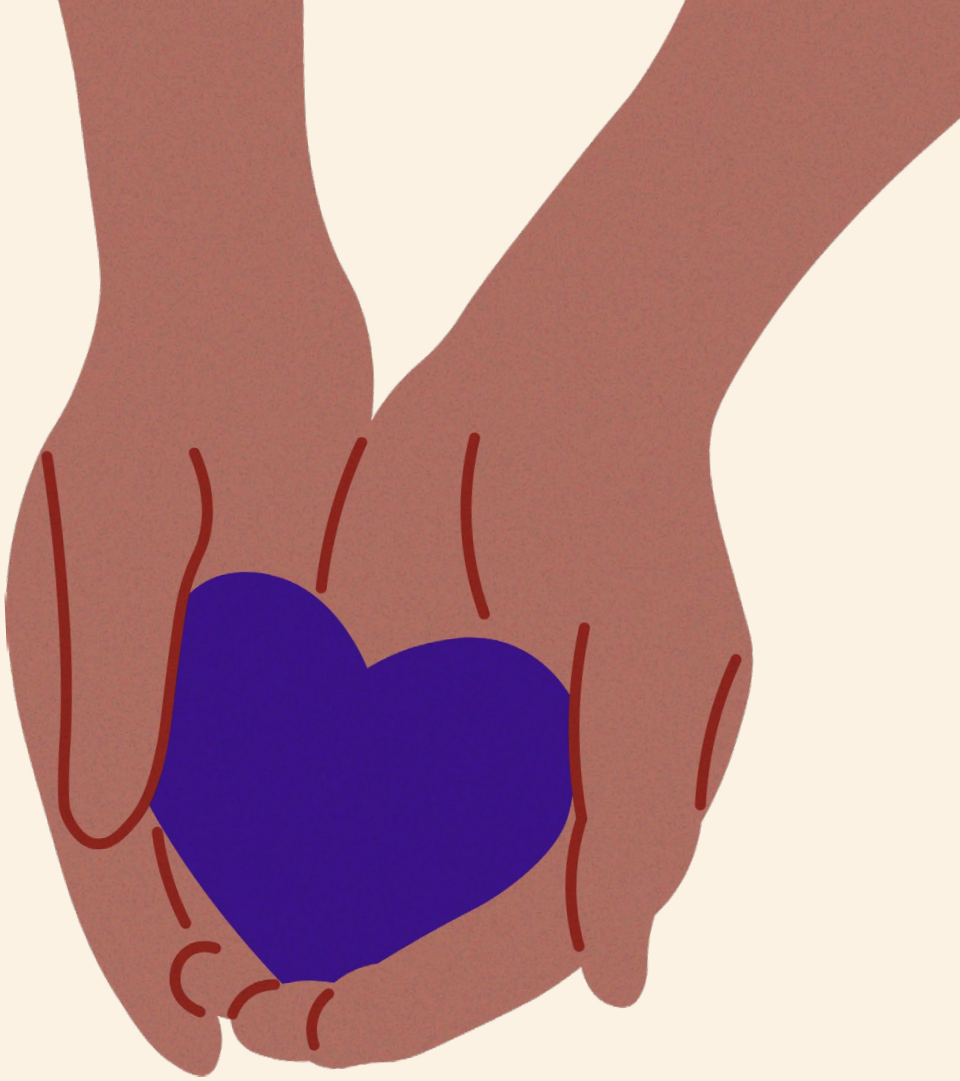
Supporting people who have experienced an early pregnancy complication and the health care professionals who care for them. 020 7733 2653
www.ectopic.org.uk

- **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: **lullabytrust.org.uk**

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

My key worker is:

Their contact number/email is:



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

**lullabytrust.org.uk
info@lullabytrust.org.uk**