

# When a baby or child dies – what happens next?

A guide for parents and carers in Oxford University Hospitals



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We are sorry that your baby/child has died and that you are

having to read this leaflet. We know it is a difficult time for you. Please take care of yourself and use the contents page to read the relevant section that you need at the time.

This guide has been put together by a group of bereaved parents, support organisations and professionals; it is for parents and carers of a child under 18. It will help you understand the next steps and the support that is available.

It is important that there is a review of every child's death to learn as much as possible.

This review is designed to support you and other members of your family in understanding why your baby/child died. It will also try to prevent other children dying from the same cause.

Part 1 of this guide covers the different aspects of the Child Death Review. Part 2 looks at some of the things you can do and where to get more information and support.

This guide includes information about a key worker who can be your point of contact and who can signpost you to sources of support.

"We had no idea what to expect when we lost our child, what would happen and who would be involved. This leaflet will provide an important insight into what might happen next, who you can expect to hear from and who you can talk to for help. We hope this leaflet will answer some of the questions you have and some you may not have thought of and should act as a useful resource to refer to later on." Parent.

#### Your key worker is:

If you are unaware of who your key worker is contact **<u>child.mortality@ouh.nhs.uk</u>** to discuss who this person should be.

Where 'parents and carers' are mentioned this includes the main carers for the child who may not be biological parents, such as carers, same sex partners and any other guardians

## PART 1 A summary of what happens when a baby/child dies

The death of a baby/child is the most difficult thing any family can go through. 'Child death review' or Perinatal Mortality Review are terms used to describe the formal processes that happen after a baby/child dies. There are some elements that take place for every child death, and some that may not be needed depending on the circumstances. Your key worker will be able to tell you about what is happening in relation to your child.

The diagram below sets out the three stages of the overall process and the different parts that may take place. Throughout this guide we refer to the 'review process' to describe this.

There is more information in this guide about each of the sections listed below.

## Soon after your child dies.

- Decisions are made about whether any further investigations may be needed.
- Notifications are made.
- Possible involvement of public authorities eg. Police.

#### Further investigations may begin.

- Coroner's investigation.
- Post mortem examination.
- Joint agency response.
- Patient Safety Incident Response Framework
  / Maternity Newborn Safety Investigations.

The conclusion of the child death review.

- Local discussion about each child's death.
- Once all the investigations have taken place, professionals consider if they can learn anything to try and prevent future deaths.
- Every death can help professionals to learn and improve support and practice.

Throughout the process you should be offered support and information through your key worker.

## **Keeping you informed**

#### The role of your key worker

You should be given a single, named point of contact to act as your key worker throughout the review of your baby/child's death. This is a person who you can ask for information on the child death review process and who can signpost you to sources of support.

Your key worker will usually be a professional from the NHS or a hospice. It might be a nurse or a member of a bereavement support team. If your child had a long-term condition your family may already have an appointed professional, such as a liaison nurse, whom you know and could act as your key worker.

Your key worker should be your **main contact** throughout the review process.

#### Their role is to:

- Be a reliable and readily accessible point of contact for you.
- Help co-ordinate meetings between you and other professionals.
- Clearly communicate information about the child death review process and any investigations that may be necessary.
- Be your voice at meetings between professionals, ensuring that any questions you have are addressed, and feed back to you afterwards.
- Signpost you to appropriate bereavement support.

If you are not sure who your key worker is, or you have not been allocated a key worker, contact a named professional who you do have details for. This may be from a hospital, hospice, police or coroner's office.

#### **Other professionals**

There are other professionals who may also have ongoing contact with you.

If your child's death has been referred to the Coroner, the coroner's officer will take responsibility for the case.

If there is a police investigation, a family liaison officer may be appointed to support you and provide a point of contact.

Other professionals can also provide support and information; they might include your GP, social worker, family support worker, midwife, health visitor, palliative care team, or pastoral support team.

The **Chaplaincy** team are also there to support you or can arrange support by your nominated faith leader. You do not have to have a faith to access this service.

The **Child Mortality team** can be contacted by email on: **<u>child.mortality@ouh.nhs.uk</u>** for any hospital based enquiries.

Please contact the neonatal bereavement team if your baby died on the **neonatal unit** on:

#### Telephone: 01865 223 202

Email: NeonatalBereavementNurses@ouh.nhs.uk

## Soon after your child dies

A number of decisions will be made by professionals, including whether a medical certificate stating a cause of death can be issued and if more investigations are needed. In some circumstances, the police will be involved as standard procedure, and this does not mean that you are under suspicion.

A number of people should be told of your child's death, such as your GP, and the coroner if your child died suddenly and unexpectedly. A health care professional will do this.

In most circumstances you should be given time with your child.

You should be offered the opportunity to have mementoes, such as photos, a lock of hair, or hand and foot prints from your child. It is fine to ask if these are not offered to you. You should also have the opportunity to spend some time with your child, but there are some situations where this cannot happen or when someone else is required to be present as well.

Organ donation/tissue donation may be a possibility and the medical team should have discussed this with you if it was appropriate. You can also ask too.

Your input to the review of your child's death is vital and professionals are expected to discuss this with you.

#### **Medical Certificate of Cause of Death**

(Also see page 23)

The medical certificate is written and sent to registration services soon after your child dies, if:

- The cause of death is understood.
- The death is from natural cause.
- A medical practitioner has been involved in the care of the child.
- There are no major concerns about the care provided to the child who has died.

#### **Role of the Medical Examiner**

Medical Examiners (M.E.) are independent senior medical doctors who come from a variety of medical specialities who review all hospital and community deaths, the quality of care and ensure that the cause of death is recorded accurately. Medical records are reviewed and discussed with the relevant doctors. Where there are concerns, or the death needs investigating further, the M.E Office will refer the case to an appropriate person to undertake this work, such as a Coroner. They are supported in this work by Medical Examiner Officers.(M.E.O).

A Medical Examiner or Medical Examiner's Officer will contact the relative or representative of the person who died and will phone you in the following few days **after** the death. This is routine and there is no cause for concern. They will ask if you have any questions or concerns that you would like to speak to the Medical Examiner about, explain what is written on the Medical Certificate in relation to the cause of your child's death. They can explain any medical language that needs clarifying.

There is further information in Part 2, on page 23 about registering the death.

#### Children with a long-term or life-limiting condition

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

It may still 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 and memorial arrangements.

Information on registering your child's death and planning a funeral can be found in part 2.

#### **Hospice Care**

Depending on the circumstances surrounding your baby/child's death there may be an option for your child to go to your local hospice. Many hospices have a room where you are able to stay with your child at time of death or be transferred there post death.

Please ask your nurse if this is something that you may like to consider. Visits can often be arranged prior. Our local hospice is often involved at end of life when your child is receiving palliative care and support the hospital teams with pain management, symptom management and support for the siblings and family.

#### If your child had a learning disability

All child deaths including those with a learning disability are reviewed through the Child Death Overview Panel (CDOP) process.

There is a list of organisations that offer **bereavement support** and other sources of information in part 2 of this guide.

## **Potential further investigations**

In many deaths, after the immediate decisions and notifications have been made, no further investigations are required, although the doctor might still discuss the benefit of a post mortem examination with you.

However, for some deaths, a number of investigations may be needed which we discuss here. They include:

- A post-mortem examination (see page 12.)
- The coroner's investigation (see page 15).
- A Joint Agency Response (see page 16).
- NHS Patient Safety Incident Response Framework (see page 17).
- Maternity and Newborn Safety Investigations (see page 18).

Which investigations are necessary will vary depending on the individual circumstances of your child's death. Sometimes more than one investigation may take place at the same time.

#### How long will investigations take?

There are recommended timeframes for investigations, but they can become delayed for various reasons. An NHS Patient Safety Incident Response should be completed within one to three months and no longer than 6 months; a Maternity and Newborn Safety Investigation within 6 months, a post mortem examination report should be issued within three months; and a coroner's inquest should be completed within six months. Unfortunately, it may take longer in some circumstances. Your key worker or coroner's officer should know more about the expected timescale. During this time you may wish to get support from one of the organisations listed at the end of this guide.

#### Accessing your child's records

To understand as much as possible about the circumstance of your child's death, different types of records from health and social care professionals may be accessed. In some circumstances your written consent might be needed, and in other situations there are legal duties to share information. Speak to your key worker if you need more information about data sharing and access to records.

#### What the coroner does

A coroner is someone who looks into certain types of death. Whether a coroner is involved depends whether the death is seen as being 'natural' or not. This is a term used by coroners, and a 'natural' death might include extreme prematurity (when a baby is born very early in pregnancy) or a virus, whereas deaths from causes such as road accidents and suicide would not be seen as 'natural' from a coronial perspective. If the cause of your child's death is not 'natural', or is unknown, or if your child died while they were under state detention (for example under a mental health section), then the law requires that the death is reported to the coroner and the police.

The coroner usually arranges for a post mortem examination to take place for unexpected deaths, which will be carried out by a pathologist. An inquest is held after the post mortem examination if the cause of death remains uncertain, or if the cause of death is not thought to be 'natural'.

The coroner can open an inquest at the start of the process, or can decide to hold an investigation, which means a formal inquest hearing may not need to be held. It can be several months before the inquest or investigation is closed. Further information about inquests is given on page 15 of this guide. You may want to ask your coroner's office for the leaflet **Coroners and Inquests: a guide** which describes in more detail what coroners and their officers do, and what happens at inquests, if one is to be held. It is also available for download from the Ministry of Justice website.

#### Post mortem examination and the role of the pathologist

#### What is a post mortem examination?

A post mortem examination, also known as an autopsy, is an examination of a person after death by a doctor who is a specialist in this, called a pathologist. Post mortem examinations for children should be carried out by a pathologist who specialises in illnesses and conditions that affect babies and children.

#### Can you decide if your child has a post mortem examination?

If your child's death has been referred to the coroner, then you are not able to choose whether a post mortem examination takes place or not. You can, however, make a representation about your wishes which the coroner can then consider.

If a coroner is not involved, then a post mortem examination can only take place with your consent. You should have a full discussion with healthcare staff to decide if this is the right decision for you and your family.

#### A post mortem examination may help to understand why your child died

## Why is a post mortem examination important?

A post mortem examination may **help to understand** why your child died.

A post mortem examination may do the following:

- Find a medical explanation for your child's death.
- Rule out other diseases or problems you may have been worried about.
- Identify other conditions which may be important for your family to be aware of.
- Provide knowledge that might be used to help your family or other children in the future. In some cases, a post mortem examination may not find a cause of death.

#### What happens to your child during post mortem examination?

When a post mortem examination has been ordered or consented to, it takes place as soon as possible, usually within a few days. It may be necessary to move your child to another hospital where a specialist children's pathologist is based. Page **14** 

During the post mortem examination the pathologist examines all the major organs and looks for any signs that might give clues as to the cause of death. The examination is conducted with the same care as if your child were having an operation.

During the post mortem examination a number of small samples need to be taken for specialist testing. These may be called 'blocks and slides'. You will be asked what you would like to happen to these samples once the tests have been completed. You can ask for the samples to either 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, or with your consent for use in research, future testing or other purposes.
- Sensitively disposed of by the hospital.

Some parents have found comfort in knowing their child's tissues might help research, or that future medical advances may give more information. The Human Tissue Authority (HTA) ensures that human tissue is used safely, ethically and with proper consent. They have produced a leaflet which tells you what happens before, during and after the examination – Post-mortem examination: Your choices about organs and tissue.

After the post mortem examination has taken place and where relevant, the coroner has given permission, you can see your child, and decide where you would like your child to be before the funeral. This includes the possibility of some time at home or somewhere else such as a hospice. If it is important to you to have the funeral within 24 hours, everyone involved will do their best to enable this to happen, but the need for a post mortem examination may not make this possible.

#### Post mortem examination results

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. If the post mortem examination was ordered by the hospital (rather than a coroner) then you will be contacted with an offer to talk about the results. You should be able to get a full copy of the report if you would like one.

For coroners' post mortem examinations, the coroner will receive 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. The coroner will then decide how to pass the results to you.

#### The coroner's inquest

An inquest is a legal inquiry to:

- Confirm who has died, when and where.
- Establish the cause of death in broad terms.

It does not involve accusations or blame. The coroner may write a report about a specific concern if they feel this might help to prevent future deaths.

If the coroner decides to hold an inquest hearing you will be given details of when and where it will take place. You may be called as a witness, in which case you must attend. If you are not called as a witness you can choose whether or not to attend. You can ask questions at the inquest, and you may be asked questions. Other professionals may be present. An inquest is open to the public and journalists may be present. In some circumstances a jury may be involved.

If an inquest is going to take place, you may wish to find more support from the Coroner's Court Support Service who are listed at the end of this guide.

#### When joint agencies are involved

#### What is a Joint Agency Response?

If your child died **unexpectedly**, or where the cause of death is not immediately clear, health professionals will work together with the police and other agencies to support you and try to understand how and why your child died. This is called a Joint Agency Response (sometimes referred to as a 'rapid response').

A joint agency response is when professionals from different agencies **work together**.

#### When is it required?

A Joint Agency Response is required if your child's death:

- Is or could be due to external causes (such as an accident).
- Is sudden and there is no immediately apparent cause.
- Occurs in custody or where the child was detained under the Mental Health Act.
- Where the initial circumstances raise any suspicions that the death may not have been natural.

The police must be involved in any unexpected death or where there are other circumstances that might need further investigation. This does not mean you are under suspicion; their role is to act on behalf of the coroner and to eliminate the possibility that anything unlawful has taken place.

There are three main stages to the Joint Agency Response:

**1. Immediate response:** Straight away: Your child will usually have been transferred to an accident and emergency department. Initial meetings between different professionals, such as the police and paediatrician, take place, and you will have been asked some questions about what happened.

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- **2. Early response:** Usually within the first week: All professionals involved will share information about your child. If your child died away from home, these professionals may visit the place of death. If your child died at home, particularly if your child was a baby, you will be visited at home. Usually this will be a joint visit by a health professional and a police officer. They will ask questions about what happened before and after your child died and will take a statement.
- **3. Later response:** From one week onwards. This stage may extend over several months: More background information is gathered if required, for example health records, maternity and neonatal notes or other relevant information. The joint agency team will meet together to review the information they have gathered. They will provide information to the coroner for their investigation, and members of the team will visit you to discuss their conclusions.

#### Patient Safety, Incident Response Framework (PSIRF)

PSIRF sets out the NHS's approach to developing and maintaining effective systems and processes for responding to patient safety incidents for the purpose of learning and improving patient safety.

Patient safety Incidents are unintended or unexpected events that could have or did harm one or more patients. An allocated person is identified to provide support and compassionately engage with families and staff, actively involve them and be available throughout the process.

The response time normally takes between one to three months and no longer than 6 months.

For further information see: <u>www.england.nhs.uk/patient-safety</u>

#### **Maternity and Newborn Safety Investigations (MNSI)**

The MNSI investigates patient safety where babies are born following labour after 37 weeks and if the outcome is one of the following:

- Baby dies during labour and before birth (intrapartum stillbirth)
- Baby born alive and dies within the first week (0 to 6 days) of life (early neonatal death)
- Baby born with a potential severe brain injury diagnosed in the first 7 days of life.

It identifies any recurring themes and makes safety recommendations to improve services. It also investigates mothers who die whilst pregnant or within 42 days of the end of their pregnancy.

For further information see: www.mnsi.org.uk

## The conclusion of the Child Death Review

#### Review of the death of a baby soon after birth

To improve the quality of the reviews of the deaths of babies who die soon after birth, a tool called the national Perinatal Mortality Review Tool (PMRT) has been developed. The PMRT is designed so that a high quality, standardised review of care of the mother during pregnancy and childbirth, and the care of the baby after birth is carried out. The PMRT is an interactive, web-based tool which guides the review process to ensure that all aspects of care are considered and are reviewed against national guidelines and standards (<u>www.npeu.ox.ac.uk/pmrt/information-for-bereavedparents</u>).

The review is led by the hospital where the baby died and identifiable information is used in the PMRT. The report of the review produced by the PMRT is included in medical records and used as the basis of the discussion at the follow-up meeting with the parents.

#### Local discussions about your child's death

A final meeting will take place between the different professionals who were involved in your child's care both before and after they died. The purpose of this meeting is to review all the information to understand why your child died. The meeting will also identify any learning and consider how professional roles were carried out at the time of your child's death. A report of the meeting is sent to the Child Death Overview Panel (see page 20).

The nature of this meeting, and which professionals are involved, will vary depending on the circumstances of your child's death. It may be referred to as a '**child death review meeting**'. Where a baby dies on the neonatal unit a separate review meeting takes place.

You will be offered a meeting with an appropriate senior member of staff to discuss any findings and answer any questions you have in the weeks and months following your child's death. This could be a consultant paediatrician, neonatologist, obstetrician or senior midwife. Your key worker, the child mortality team or neonatal bereavement team can help to arrange these meetings. This would normally happen around 6- 8 weeks following the death.

Parents and carers are invited to contribute any written comments you might have into the review of your child's death. Please give this to your keyworker or email the child mortality team at **Child.mortality@ouh.nhs.uk** or the neonatal team at **NeonatalBereavementNurses@ouh.nhs.uk** 

We are keen to hear positive comments and areas for improvement. You may also receive a questionnaire to help us improve the care we give to bereaved families.

#### Regional discussions about child deaths – the Child Death Overview Panel

#### What is a Child Death Overview Panel?

This is a multi-agency panel (referred to as a Child Death Overview Panel (CDOP)) that looks at all child deaths in a wider context than the earlier stages of the review, which would have considered your child individually.

The deaths of all children under the age of 18 must be reviewed by a CDOP. There are a number of panels around the country, and your child's death will usually be considered by the panel local to where your child was normally resident. CDOPs are groups of professionals who meet several times a year to review all the child deaths in their area. The panel is not given the names of any children who died or any information that might make the report identifiable; all the details are dealt with anonymously. Their main purpose is to learn from these deaths in order to try and prevent future deaths.

Although the panel will not include the professionals who were involved in your child's death, they will receive a report from the professionals who were involved. 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, but it does not contain any details that could identify an individual child or their family.

#### Who is on the panel?

The Panel has representatives from:

- Public health.
- Local child health.
- Social care services.
- The police.

By law all child deaths should be reviewed to try to **prevent** future deaths where possible.

Other professionals may be invited to give specialist advice where needed.

#### 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.

#### **National Child Mortality Database (NCMD)**

A National Child Mortality Database is currently being developed which will enable detailed analysis and interpretation of the information collected by CDOPs. CDOPs will start to submit information to the database by 2019. Collecting this information will ensure that deaths are learned from, that learning is widely shared, and that actions are taken, locally and nationally, to reduce preventable child deaths in the future.

# If the Child Death Review Process has not been followed

Sometimes the processes that are in place do not happen as they should. This can be difficult for you to question, particularly given that the different elements of this guide will not apply to all deaths.

If you feel you have not been kept informed about what is happening at any point in the review of your child's death, you should first contact your key worker. You could also contact another professional who has been supporting you, or a charity or other organisation who can offer support. If you don't have anyone you can call, please turn to the information and bereavement support sections at the end of this guide.

Your key worker should be your first point of contact.

If you are not sure who your key worker is, or you have not been allocated a key worker, contact a named professional who you do have details for. This may be from a hospital, hospice, police or coroner's office.

## PART 2 Things for you to do

This section covers some of the different things you may need to do. Some of these you will need to do yourself. Where you don't feel able to do them yourself, you may want to think about asking someone to help you.

#### Viewing your child's body in the hospital

It may be possible for you to see your child after they have died, although it may be easier to arrange this through the funeral director. Please check with the bereavement office when they contact you. If your child died in the neonatal unit, please contact the neonatal team.

#### **Registering your child's death**

The Medical Certificate that gives the Cause of Death will be scanned over to the registration services when completed and you will then be informed that this has been done. You can then register your child's death by making an appointment to attend the register office in the county that your child died. If you have not already registered your baby's birth you will also need to do this – there is a requirement to register the birth within 42 days of birth. It is up to you whether you choose to do both during one visit.

If you have been issued with a Medical Certificate of Cause of Death then you must register your child's death, **within five days** of the death. You should have been given information with the certificate about where the death should be registered. If this is not convenient other options are available such as making a declaration more locally; the register office can provide more advice if required. If your child's death has been **referred to the coroner** then **there may be a delay** in your being able to register their death. You can register your child's death as soon as the coroner has issued a form 100A which confirms that the death can be registered. In some cases the coroner may first order a post mortem and where the coroner no longer requires to make any further investigations they will send a Form 100B (called the 'pink form') to the registrar. If there is going to be an inquest, the coroner will report directly to the register office following the inquest who will then register your child's death. Once your child's death has been registered you will be able to obtain a death certificate.

#### Planning your child's funeral

You can start to plan the funeral at any time but you can only hold it once you have the death certificate or appropriate form from the coroner. 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 key worker as soon as possible. They will alert the coroner if a coroner is involved who will try to accommodate your wishes, though it may not be possible.

You may wish to discuss possible choices with your chosen funeral director, and take time to consider what would be the most meaningful for you and your family. The bereavement office will ensure that cremation paperwork is completed in advance of the funeral director coming to collect your child from the Mortuary.

The costs of burials and cremations vary and there are other expenses that you may not have considered, so you should ask for a written estimate before finalising the arrangements. Some funeral providers do not charge.

If you are on a low income, you may be eligible for a 'Funeral Expenses Payment', which your funeral director should be able to help you find more information about.

There is also a charity called the Childrens' Funeral Charity that can help, providing financial assistance, practical advice and guidance, but they would need a referral from a professional who knows your family. For information about creating a headstone in the future, speak to your funeral director. It will cover costs from 24 weeks of pregnancy to under 18 years.

#### Child benefit and other payments

If you have received benefits for your child, either in payments or equipment, these will usually continue for some weeks after your child has died, but the timing differs for different types of benefits. It is up to you to contact the agencies that provide your benefits, and it is a good idea not to delay this or you may be overpaid and have to repay any overpayments.

This can be difficult to do, so it might be a task you ask someone to help you with.

Child benefit is paid for up to eight weeks after a child dies, but you will need to ensure that you have told the child benefit office that your child has died. You can do this either online through the **direct.gov.uk** website or by contacting the child benefit office.

#### Other things to consider

Your child's GP and school or college 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 banks and building societies, local groups, religious organisations, clubs, dentist 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 your child had their own social media accounts, you can either deactivate them, turn them to a 'memorialised' account or leave them as 'live' accounts. To change the accounts you will need to provide proof of your relationship and your child's death certificate to the social media provider.

#### **Support**

The initial days, weeks and months following your child's death are extremely difficult. Whatever your thoughts and feelings, grief is a personal experience and has no set time or process. There is no right or wrong way to grieve.

Returning to employment might not be something you can consider at this stage. Paid leave for bereaved parents will be implemented in the future, but your work may also make their own decision about compassionate leave. 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 and your right to paid leave.

Emotional support is available for you, and your wider family, including any other children you have. The bereavement support organisations listed at the end of this guide are open to you and your family at any point, even if you already have support through a hospital or hospice. Bereavement support is available in a number of different ways, whether you feel most comfortable to call or you would prefer to email, connect online or meet face-to-face.

If you are in need of immediate support at any time, the Samaritans are open at every hour of the day by phoning **116 123**.

## Where to go for more information

The Child Death Review Process is set out in detail in Child Death Review – operational and statutory guidance for professionals. You may wish to look at this if you would like more detail about the process.

#### Website: www.gov.uk/government/publications/child-deathreview-statutory-and- operational-guidance-england

For further information on elements of the review process described, you may find the following useful:

#### **Coroners Court Support Service**

A voluntary support organisation that provides emotional and practical support to families attending an inquest at a coroner's court.

#### **Post Mortem Examinations**

The NHS provides online information about post mortem examinations and where to get more detailed information.

Website: www.nhs.uk/conditions/Post-mortem

## **Sources of bereavement support**

You should be offered support and signposted to local services and organisations you might find helpful to contact. The following national organisations can also offer support and advice. All these organisations offer bereavement support to families, but we cannot recommend any in particular. You might also want to look at the National Bereavement Alliance which sets standards that some of these organisations work towards.

We ask for your email address and a phone contact so that with your consent we can contact you or to offer support from a charity who may then contact you.

#### **Child Bereavement UK**

Supports families and educates professionals when a baby or child dies or is dying, or when a child is facing bereavement – national provision.

Website: **www.childbereavementuk.org** Email: **enquiries@childbereavementuk.org** Telephone: **0800 02 888 40** 

#### **Child Death Helpline**

For anyone affected by the death of a child of any age from any cause. Website: **www.childdeathhelpline.org.uk** Telephone: **0800 282986** 

#### Seesaw

Seesaw provides grief support for children, young people and their families in Oxfordshire.

Website: www.seesaw.org.uk

#### **Daisys Dream**

Daisys Dream offers support to children and families affected by life threatening illness or bereavement predominantly in Berkshire.

Website: www.daisysdream.org.uk

#### Sudden Unexpected death in childhood

Website: www.sudc.org.uk

#### **Care for the Family – Bereaved Parent Support**

Peer support for any parent whose son or daughter has died at any age, in any circumstance and at any stage in their journey of grieving. Website: **www.cff.org.uk/bps** Email: **bps@cff.org.uk** Telephone: **029 2081 0800** 

#### Bliss

Information and support for families of babies born premature or sick. Website: **www.bliss.org.uk** Email: **hello@bliss.org.uk** Telephone: **0808 801 0322** 

#### **The Compassionate Friends**

Support for bereaved parents and their families. Website: **www.tcf.org.uk** Email: **helpline@tcf.org.uk** Telephone: **0345 123 2304** 

#### The Lullaby Trust

Support for anyone affected by the sudden and unexpected death of a baby or young child. Website: **www.lullabytrust.org.uk** 

Email: support@lullabytrust.org.uk

Telephone: 0808 802 6868

#### Sands

Support for anyone affected by the death of a baby. Website: **www.sands.org.uk** Email: **helpline@sands.org.uk** Telephone: **0808 164 3332** 

#### TAMBA

Support for anyone affected by the death of a multiple. Website: **www.tamba.org.uk** Email: **support-team@tamba.org.uk** Telephone: **0800 138 0509** 

#### Winston's Wish

Support, advice, information and resources for parents/carers and professionals supporting bereaved children and young people. Website: **www.winstonswish.org** Email: **ask@winstonswish.org** Telephone: **0808 802 0021**  Page **31** 

There are also a number of useful organisations who hold information about the many smaller, specialised and local organisations available for bereaved families.

You may be able to find an organisation that focusses on your situation more specifically through one of those listed below, where you can search for bereavement support which is specific to your situation. They also list details of the many other charities that can support you:

#### **The Childhood Bereavement Network**

Website: www.childhoodbereavementnetwork.org.uk

#### A Child of Mine

Website: www.achildofmine.org.uk

#### At A Loss.org

Website: www.ataloss.org

#### **The Good Grief Trust**

Website: www.thegoodgrieftrust.org

## **Sponsorship logos**











At a **Loss**.org Helping the bereaved find **support** 















National Bereavement

### **Further information**

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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