

Next steps

...a booklet for bereaved parents
and carers for the early days





On behalf of Bristol Royal Hospital for Children, please accept our deepest sympathy.

There is no greater sadness in life than the death of a child. It is a devastating loss and brings an unimaginably painful and difficult time for the parents and the whole family. It can also be a very confusing time.

You most likely have received this booklet soon after the death of your child. Whether their death was sudden or expected, in the midst of your grief it can be difficult to know what to do, who to turn to and what immediate next steps to take.

This booklet has been prepared by staff who have helped to care for bereaved parents, with contributions from parents whose own child has died, and is intended to guide you through the next few days and beyond and to answer some of the questions you may have. We have included some practical strategies to help you navigate the changes you are facing at this difficult time.

We hope this information will be helpful to you, but if it is too hard to read this booklet right now, perhaps you could give it to a family member or friend who is available to help you.



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When your child dies in hospital

Spending time with your child

At the hospital we want to help you do whatever feels right for your family at this most difficult time. Staff will be with you but will make sure that you have privacy and the opportunity to spend time with your child; nothing has to happen in a hurry. You can see, touch and hold your child and say what you want to them. In most circumstances you can help to wash them, comb their hair and dress them in chosen clothing if you wish.

Many parents say that this time of saying goodbye becomes a profound family memory and helps them with their grief. Your needs are highly respected during this time. Let hospital staff know what you and your family's wishes are. It is important that you are supported and given the privacy and flexibility to make this time what you need it to be.

You may wish to have photographs taken, and there will be the option to preserve keepsakes, such as a lock of your child's hair, as well as hand and foot prints. (This will not happen without your consent, but please ask if these are not offered to you). You may feel unsure about this, but many bereaved families describe such mementos and photos as extremely precious in the years to follow.

You may wish to have a short blessing or ceremony for your child at the hospital, even if you are not particularly religious. You can ask for your own faith representative to be called, or the hospital Chaplaincy service is available at all times, day and night. They can be contacted by ward staff or the Bereavement Support Team.

You may be asked at this time whether you plan to have a burial or cremation for your child, so that the correct papers can be prepared. If you are not sure at this stage, you can inform the funeral director of your choice later on.

What happens next?

Your child will be taken to the Rainbow Room on Level 3 of the children's hospital and you may accompany them if you wish. You can spend time alone with your child there in peace and privacy. There are certain situations when someone else is required to be present as well, but if this applies it will be explained to you. Either way, there will be hospital staff always nearby to help and support you.

When it is time, your child will be carefully returned to the mortuary next to the Rainbow Room but a favourite toy, special blanket or other comforting objects can stay with your child all the time.

Can I visit my child again?

If you want to return later or over the following days to see them in the Rainbow Room, perhaps with other family members or friends, you will need to contact the Bereavement Support Team by phone on: **0117 342 7293** (Monday to Friday, 9am to 5pm) to arrange this for you.

Outside these hours, including weekends, please contact the ward staff or telephone **0117 342 1819** to speak with the children's hospital Clinical Site Team Manager to arrange a time. Whilst it is important that you feel able to visit your child in the Rainbow Room at any time, this takes careful planning so, where possible, we would encourage you to visit during the daytime. Your child's body will be kept cool, so when you visit them in the Rainbow Room they may feel very cold.

Whenever you spend time with your child's body you will need to prepare for the separation afterwards which can be an intensely affecting experience. Leaving the hospital without your child can be overwhelmingly emotional for the whole family. Hospital staff will be there to support you but you may also want a close friend or someone else available to help care for you and give practical help, such as with transport home.

If you were still breast feeding your child when they died, you should ask your health visitor, midwife or doctor for advice on how to gradually suppress your milk supply in a natural way. Cold compresses, mild painkillers and expressing small amounts of milk may help until any discomfort is reduced. Otherwise your GP can prescribe medication to stop milk production more quickly.

The Bereavement Support Team will be able to support you through the next few days. They will provide guidance on some of the practical things to be done immediately and they will offer you support over the weeks and months ahead. They will try and meet with you in the hospital or call you in the coming days. You can reach them Monday to Friday by calling 0117 342 7293, or email them at ChildrensBereavementSupportTeam@uhbw.nhs.uk

Keeping you informed

Your Key Worker or 'point of contact'

It is important for you to know that it's okay to ask questions if you don't understand why something is happening, how to do something, or want further information at any time.

You will be given a named person to be your Key Worker throughout the coming days and months. They will be your main point of contact and link back into the hospital during the coming months, especially during the necessary review process of your child's death. This is a person who you can ask for information and who can signpost you to support.

Your Key Worker will usually be a professional from your child's main treating team or from the Bereavement Support Team. If your child had a long-term condition your family might already have an appointed named professional, such as a specialist liaison nurse or social worker who you might know and could act as your Key Worker. What is important is that your Key Worker is someone you have been introduced to and who can support you during the whole process of review of your child's death.

Their role is to:

- Be a reliable and readily accessible person for you to contact
- Help set up meetings between you and other professionals
- Give you clear information on the child death review process and any investigations that might be needed
- Be your voice at professional meetings - ensure that any questions you have are heard, 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 given a Key Worker, please contact a professional who you do have details for - this may be someone from a hospital, hospice, police, coroner's office, or contact the Bereavement Support Team.

Other professionals who may be involved

There are other professionals who might also be in contact with you. Who exactly is involved will depend on how and where your child died.

If your child's death has been referred to a coroner, a **Coroner's Officer** should be in touch with you. You can find more information about the process if a coroner is informed on page 20.

In the case of sudden, unexpected death it is usually necessary for a **Consultant Paediatrician** and the police to visit the child's home. The police are routinely called to every sudden death to investigate its cause. Whilst you might find the involvement of the police very upsetting, you should be assured that the purpose is to find out, if possible, why your baby or child has died. They are required to gather information and have to ask a number of questions that may be distressing, but are necessary and important. The information you provide will be valuable.

A **Police Family Liaison Officer** may be appointed to support you and provide a point of contact throughout their investigation process.

Other professionals can also give you support; they might include your GP, Community Paediatrician, Social Worker, Family Support Worker, Midwife, Health Visitor, Palliative Care Team, Chaplaincy or Pastoral Support Team.

For both expected and unexpected deaths, professionals involved with your child will talk to each other over the days, weeks and months ahead to establish the facts about why your child died.

When all the necessary facts have been gathered, a Child Death Review (CDR) meeting will be held. The purpose of this meeting is for the professionals to review all the information to identify the cause of death and any factors that may have contributed to the death of your child. This may help to prevent future tragedies.

Although you will not attend this meeting, you should be kept involved and informed at all stages of the review into your child's death and support should be available for you. You should have been given a NHS booklet about this process titled 'When a child dies: A guide for parents and carers'. Your Key Worker and/or the Bereavement Support Team will help you with anything you need to understand this process.

Registering the death

The following information may be useful to guide you, or those supporting you, through the necessary steps required to register your child's death.

The process of registering your child's death is highly emotional, but many parents say that it is actually a helpful experience. Still, you might like to ask a family member or friend to go with you for support, or to help with practical tasks such as driving to the registrar's office.

The death should normally be registered **within five calendar days** unless the coroner is investigating the cause of the death.

A Medical Certificate of Cause of Death (MCCD) stating the cause of death will be signed by a hospital doctor who cared for your child. It will be explained to you and put in a special envelope for you to give to the registrar of births, deaths and marriages.

Your child's death usually needs to be registered before their funeral can take place. However if you need the funeral to take place promptly for religious reasons, you can ask the hospital staff for information about arranging urgent registration out of normal office hours.

When you visit a register office, the registrar will see you privately to go through the necessary details. It is very important that the information registered is accurate because the register entry is a legal record and difficult to correct at a later date.

Where can I register the death?

A death is registered in the district where it happened, so your child's death will be officially registered in Bristol.

The registrar's office in Bristol is found in Corn Street at the Old Council House, Corn Street, Bristol BS1 1JG (the entrance is in Broad Street). Register Office opening times are 9am-4pm Mon, Tues, Thurs, Fri and 10am to 4pm Weds. To book an appointment to register a death call 0117 922 2800 or book online bristol.gov.uk/births-deaths-marriages/register-a-death. Phone lines are open: Monday to Friday 8.30am to 6pm.

Registering the death will take about half an hour.

Out of Hours Death Registration Service: If your child needs to be buried within a short time due to cultural or religious reasons, you can call the emergency registrar on **0117 922 2050**.

On Bank Holidays a service is usually available between 9.00am and 10.00am; call the Register Office for details.

Registration by declaration

If it is more convenient, you can register the death 'by declaration' at any other Register Office in England and Wales. You will need to book an appointment and bring the signed Medical Certificate of Cause of Death with you when you attend. At your appointment the registrar will record the necessary details and send your signed declaration to the Bristol Register Office.

Once the registration process is completed there, the death certificate and burial or cremation certificates will then be posted to your home address. This is a slower process and can sometimes lead to a delay in the funeral arrangements, so you may find it preferable to register your child's death in Bristol where you'll be given all the documents you need before you leave.

Who can register the death?

The people who are legally allowed to register the death are:

- **Either parent or both**
- **A relative**
- **A person present at the death**
- **An occupier of the place where the death happened, who was aware of the death**
- **The person dealing with the funeral arrangements (but not the funeral director).**

What you will need to give to the registrar

- The Medical Certificate of Cause of Death (given to you at the hospital)
- Date of death and place of death
- Date and place of your child's birth
- Child's full name
- Full name, address and occupation of the mother and / or father
- Child's usual address (the mother's address if your child has never left the hospital)
- Whether your child was in receipt of any benefits - Disability Living Allowance (DLA), etc.
- Whether burial or cremation has been decided upon (it is not essential to have decided at this point).

If the coroner has been informed, you will be advised what to do by the coroner's office.

What the registrar will give you

After the death is registered you will be given:

- A Death Certificate
- A green form. This is a certificate for burial or cremation to enable you to make funeral arrangements. If your child's death was referred to the coroner, other procedures may apply but the coroner's office will advise you.
- Form BD8 (white form) - Certificate of Registration of Death. You will need this form if applying for a funeral expenses claim (see under 'How will I cover funeral expenses?' p.30).

The registrar will provide you with details of the Tell Us Once scheme (p.39) – this allows a variety of government agencies such as social services, the passport office, and

the DWP to be informed about the death at the same time to ensure that any benefits payable in respect of your child, for example Disability Living Allowance, will stop.

There is no charge to register the death and the issue of the two forms is free. You can purchase extra copies of the death certificate at any time. You will need a copy of the death certificate if your child has a bank/building society account that you wish to close, or to surrender any insurance policies held in your child's name.

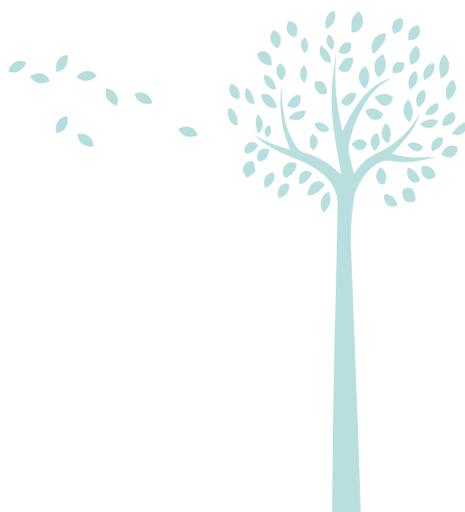
Remember, the Bereavement Support Team are available to provide advice and information if you need help to understand what needs to be done at any stage.

What if my child's birth has not yet been registered?

If you have not yet registered the birth of your child, (which must be done within 42 days of them being born) this can be done at the same time, even if your child was not born in Bristol. You don't need a form from the hospital to register your baby's birth.

If you were married at the time of the birth, either parent can register the birth. If you were not married, it is essential for the mother to be present and both parents need to attend if you wish the father's details to be recorded in the birth entry.

If you're a same-sex couple, please call the Register Office and staff will explain how to register your child. Alternatively you can find more detailed information appropriate to your situation on the GOV.UK website under 'Register a birth'.



Who should be informed about the death of my child?

You will need to inform others about the death of your child. It is important to decide who should be notified immediately, but you do not need to be responsible for informing everyone.

It may help to:

- make a list of who to tell
- ask someone else you trust to let those people know
- find a short phrase you can use to say what's happened so that you can avoid long conversations at this early time
- share only the information you want to share

In the early days after the death you shouldn't feel that you have to personally see or speak to everyone who wants to contact you. Choose who you want to connect with yourself but to avoid added stress you can ask someone to take messages for you or to contact other people on your behalf.

Giving information on social media

It is best to inform family and very close friends of your child's death in person or by telephone, so generally it is wise to wait at least 24 hours before making a more public announcement by posting anything on social media.

There is no right or wrong way to manage social media sites. Do whatever feels right for you and your family, but it's important to remember that you cannot control other people's comments on such sites and beware these may cause you additional distress at such a sensitive time.

If you do decide to post details of the funeral or other relevant information on social media, you may wish to limit who will be able to access these details, so consider your privacy settings. It is sensible not to share anything too personal or give too

many details about the cause of death. Be aware that any photos of your child on social media accounts could be reused without your permission if they are publicly accessible.

Will the press be informed?

There may be public media and press interest in a child's death which can be difficult and confusing to deal with at such a sad time. Our Bereavement Support Team can offer advice on how to manage this. Please call them on **0117 342 7293** if you would like their help and support.

Informing school or nursery

It is important for your child's school or nursery to be informed. The hospital staff or Bereavement Support Team will offer to do this for you if you prefer.

If you have other children who attend school or nursery it is helpful to let the teaching staff there know what has happened as soon as you can so that appropriate arrangements and adjustments can be made to support them during the school day.

Ask your child what they'd like you to tell their school so that they feel involved and have a say. This is especially important with older children. Make sure they know what you've said and to whom.

There are no set rules regarding how much time off school or college bereaved children and teenagers can take. It depends on the individual, the family and the school's policy. Bear in mind that stability and normal routine is important and helps children feel safe, so having too much time off could make it harder for them to manage.

Talking to children about the death

If you have other children you may dread how they will react when you tell them their sibling has died. Every child and teenager is different and will react to the death of their sibling in individual ways. They could be very distressed or may not react much at all. How you explain the death to them depends on your own beliefs and on the age of the child, but they need to be helped to understand that their brother or sister has died and will never come back.

If possible find a quiet, private place to tell them what's happened. Explain key facts simply and honestly and be prepared to repeat the key information again later on, in case they haven't taken it in or have misunderstood.

Children may not have words to express their feelings, but let them talk about what has happened if they want to - it helps them make sense of it. Reassure them that it's okay to talk and much better than keeping their worries to themselves.

If they ask a question you find difficult to answer, you could start by asking what they think. This will give you some idea of what they know and then you can build your answer on their understanding of what's happened. You can also correct anything that's not quite accurate. Be honest about what you don't know, and say that when you find out you will tell them.

They will take time to process what they've been told. Answer their questions as best you can, but you may find they repeat the same questions over and over again. Try to answer only the question and avoid giving extra detail they may not want or need.

Be consistent. Talk about death with them in simple language that suits their individual age and experience, but always use direct words like "dead" and "died."

Euphemisms and explanations such as 'she went to sleep', or 'we lost him' might seem more gentle but could be confusing and make your child frightened to go to sleep or worried that you might go away and not come back.

Many parents find it helpful to explain death as part of life, using examples from nature, such as how plants grow, bloom and die, how the seasons change, or how animals can get ill or so badly hurt or injured they can no longer stay alive. Story books are available that might help you talk to a young child and explain what happens when someone dies. (There are some reading suggestions at the end of this booklet.)

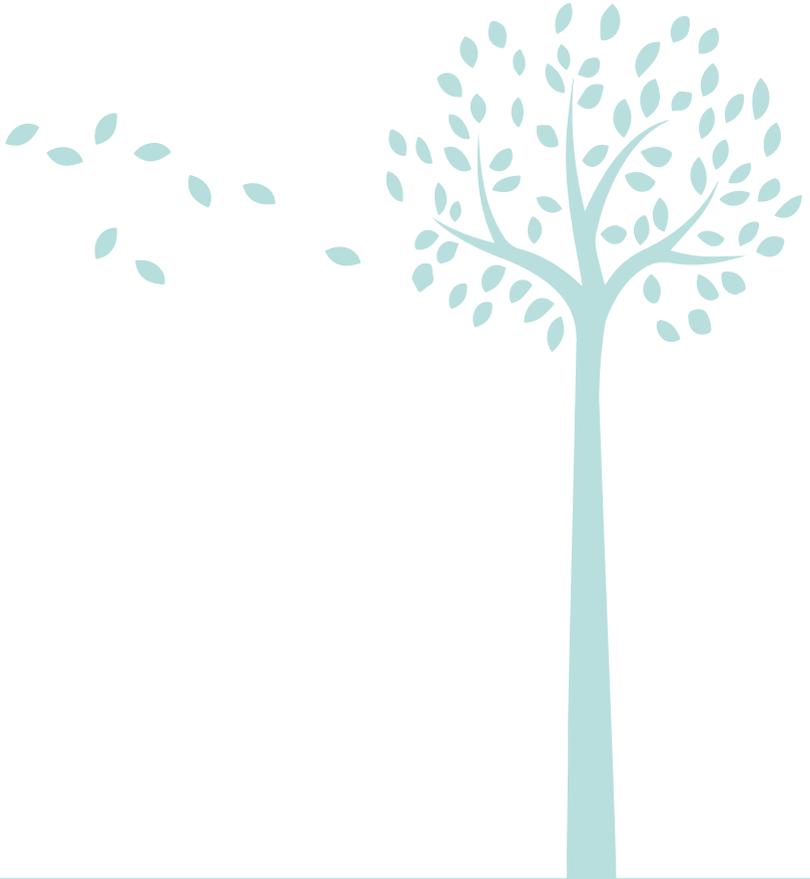
Don't be afraid to cry in front of your children - seeing your tears can be helpful and gives them permission to cry too. If your child seems worried that you're crying, explain to them that crying can help relieve the pressure of sadness and make you feel better.

Children may feel shock, numbness, sadness, guilt, anxiety and fear after their sibling has died. They might have physical symptoms such as headaches or stomach aches, or may regress in their development, like going back to bedwetting or thumb-sucking. It is not uncommon for children to believe that they might have caused the death and

that it happened because they did something naughty, or had bad thoughts. Reassure them with facts and explain that any thoughts they may have had did not cause the death to happen.

Bereaved children often feel scared that some other person they love will die, or that perhaps they will die. Their sense of security can be shaken by what's happened. They may become clingy and show separation anxiety for a while. Reassure them that they are loved and will be cared for and safe. Tell them that it's okay to be sad and to cry, but it's also okay to play and have fun.

After the death of your child you too might feel afraid that something else horrible is going to happen. It's understandable if you feel vulnerable and are overprotective of your other children, especially at first.



Does the coroner need to be informed?

The medical team supporting you and your child will have discussed the likely causes of your child's death, but in some circumstances doctors cannot immediately issue a death certificate and they are then obliged to inform the coroner. We understand that families can be concerned about the coronial process and especially whether it will delay the funeral.

Reasons for reporting the death to the coroner

Usually this is because:

- Death has occurred in unusual circumstances
- Doctors are uncertain of the exact cause of death
- Your child has died suddenly and unexpectedly or within 24 hours of hospital admission
- Your child has undergone recent surgery

What happens when the coroner is informed?

If required, the medical staff will contact the coroner following the death of your child.

Once reported to the coroner, a death cannot be registered until the coroner gives permission.

According to the circumstances:

- The coroner may decide not to be involved and will send a form to the registrar confirming that, although he or she was made aware of the death, no further investigation is needed and permission has been given to the doctor to issue a medical certificate stating the cause of death. You can then register the death at the Register Office just as you would have if the doctor had issued the certificate straight away. Once this has been done, the funeral can take place.

- The coroner may decide to be involved by ordering a post-mortem examination and possibly holding an inquest.
- Sometimes the coroner will request a more detailed ‘forensic’ post-mortem examination by a specifically trained pathologist to assist with establishing the cause of death.

Will my child need a post-mortem?

A post-mortem examination (also known as an autopsy) is a careful external and internal investigation of the body to try to discover why your child died.

Post-mortem examinations are usually carried out to find out exactly how or why a baby or child died.

Coroners post-mortem examination

The coroner may decide a post-mortem examination is necessary to find out why your child died. If the coroner orders a post-mortem, a medical certificate of cause of death cannot be issued by the hospital. You will be contacted by the coroner’s officer who will support you and will be able to give you further information and advice.

The telephone number of the Avon Coroner’s Office (covering Bristol, Bath and North East Somerset, North Somerset and South Gloucestershire) is 01275 461920.

If a post-mortem is legally required by the coroner you will not be asked to give consent. However a discussion should take place between you and a professional from the hospital and/or the coroner’s officer covering what you can expect, what will happen, and what your rights are.

Where possible, the coroner will take account of your religious and cultural needs. If you have queries or if you object to the decision to hold a post-mortem examination, or to additional examination of tissue, you should let the coroner’s office know as soon as possible so that your wishes can be considered. The coroner has the authority to make the final decision and if necessary can order a post-mortem even if the family does not agree. This is clearly a very difficult situation and everything will be done to support you and minimise the delay to your funeral arrangements.

You have the right to be represented by a medical practitioner (such as your GP) at the post-mortem examination, although this is not normally necessary and you would have to pay any fee the doctor may charge.

If the coroner decides that a post-mortem examination is unnecessary, but you disagree, you should discuss this with the coroner's office so that your viewpoint is heard. Any concerns you raise about the circumstances of your child's death (such as their medical treatment in hospital) may provide valuable background information for the coroner's inquiries. In all cases, the final decision about a post-mortem examination and any other tests is the responsibility of the coroner. Sometimes you may be advised that your issues would be better addressed by another organisation, usually the hospital's Patient Support and Complaints Team.

What happens when there is a post-mortem?

The medical practitioner who performs a post-mortem examination is called a pathologist. The pathologist will treat your child's body as their patient and perform the examination carefully and respectfully in a room similar to an operating theatre.

If a specialist paediatric pathologist is required for your child's post-mortem, it may need to be done at a hospital in another city. You will be advised by staff if this is the case and kept informed when and where your child is being transferred.

Many families find this separation from their child very difficult, but you can be assured that they will be treated with great care and respect by the pathologist and their assisting team.

The pathologist may need to retain small tissue samples for further examination or for further tests, such as looking at chromosomes or genes and searching for any infections due to bacteria or viruses that may have caused the death.

No organs or tissue will be retained without your knowledge. The coroner's officer will give you the opportunity to discuss your wishes with regard to the retention and disposal of any organ or tissue.

When the post-mortem examination is complete, the pathologist will send a report to the coroner. If a natural cause of death is given at the time, your child's body can be released and the coroner will send a form to the registrar of births and deaths stating

the cause of death as shown by the report. Once the registrar has received this form, you will be notified and can then make an appointment to register your child's death.

In most cases the pathologist will need to carry out further tests. As this will take some time to complete, the coroner may issue an interim death certificate so that your child's body can be released and the funeral can take place. If for any reason this is not possible, the coroner's officer will explain the arrangements to you.

Occasionally, although the coroner can release a body for funeral purposes, it may not be possible to release a particular organ (or organs) immediately because a specialist and lengthy examination is required. Again, the coroner's office will advise you of the various options available to you in this case.

When will I get the results of the post-mortem?

You need to be aware that, depending on the number and type of tests done, it can take many months to get all the necessary results and for the pathologist to complete the final report. Relatives can request a full copy of the post-mortem report from the coroner, but it is a technical document set out in a very medical and matter-of-fact way. Naturally, this may be distressing for families, and you should be prepared for this if you are considering reading the post-mortem report about your child. For this reason, you should be offered a face to face meeting so that the results can be presented and explained to you in person and in terms you can understand.

Will an inquest be necessary?

Once the cause of death is given by the pathologist, the coroner will then decide whether the investigation into your child's death is concluded or whether to hold an inquest.

An **inquest** is held to establish the facts about a death – who died, and when, where and how they died. It does not deal with issues of blame or responsibility for the death, or with issues of criminal or civil liability. The inquest is held as soon as possible but this may be many weeks or months after your child has died.

The coroner's officer will inform you if an inquest is required and will help you understand and prepare for the inquest process. The inquest is usually held in a courtroom which is open to the public and the media. Some families want there to

be press attention, but some do not. You cannot stop the press from reporting about the hearing, but they should be sensitive to grieving families. The involvement of the coroner may delay your child's funeral, but the coroner may issue an order allowing burial or cremation to go ahead before the inquest is completed. The coroner's officer should be able to give you a date after which the funeral can take place.

Hospital post-mortem examination

If a coroner's post-mortem is not required, the hospital doctor may ask your permission to perform a hospital post-mortem. This would not be for legal reasons, but to gain more information and understanding about your child's illness for you and your family, and it may contribute to medical knowledge to help children with similar conditions. You can ask for a hospital post-mortem if it is not offered.

It is entirely your decision as to whether or not you give permission for this type of examination - unlike a coroner's post-mortem, it is not compulsory. You also have the option of choosing a 'limited' post-mortem (limited to certain areas of the body such as the head, chest or abdomen) rather than a full examination. Limited procedures may provide incomplete, but nevertheless valuable, information. The doctor will discuss it with you, explain what is involved and ask you to sign a consent form.

The form clearly states the nature and extent of the post-mortem examination and your explicit permission is required for retention of any organ or tissue for any purpose. After signing the consent form you will be given a period of time (at least 24 hours), clearly stated on the form, to consider your decision. You will be provided with details of someone to contact if you change your mind and nothing will begin until the agreed cooling off period is complete. Once acute grief has subsided, families rarely regret giving permission for a hospital post-mortem, but may come to regret not doing so.

If your child is going to have a hospital post-mortem examination they will be transferred to department of paediatric pathology at St Michael's Hospital where there are the facilities to undertake this procedure. (St Michael's Hospital is approximately 100 metres from Bristol Royal Hospital for Children, at the top of St Michael's Hill). You will be told when your child is being transferred and they will be looked after by the children's mortuary team who are very experienced in caring for babies and children who have died.

What happens after the post-mortem?

Following any type of post-mortem examination, your child's body will usually be returned directly to the care of your chosen funeral director who will arrange to collect them. Your Key Worker should be able to advise you as to when this will happen.

You will be able to see and hold your child again following the post-mortem, usually once they are returned to your funeral director's chapel of rest.

Before your visit you can ask about any ways in which your child's appearance may have changed but any signs of the post-mortem examination are not usually visible once your child is dressed.

You are likely to have many questions after the death of your child. A post-mortem examination may enable medical staff to answer many of your questions, but it may not answer them all. Once the report on the examination is completed, you will be offered a meeting to talk through the findings. Knowing as much as possible about why your child died is important and many parents have told us that having a post-mortem has been helpful to their grieving process and brought them some closure.

We can provide you a leaflet explaining hospital post-mortem examinations – please ask for a copy if you are not given one.



Taking your child home from the hospital

If there is to be no post-mortem examination, most families leave their child temporarily in the care of the children's hospital until they have appointed a funeral director. To contact a funeral director you can ask friends or relatives for their suggestions or search online. Your chosen funeral director will be able to offer advice and help you decide where you would like your child to be until the time of their funeral.

If the coroner's involvement is not required and there is no risk of infection to yourself or others, your child's body can be taken home or to your chosen place of care, or to another location of your choice, such as your local children's hospice (if you have used their service in the past).

Your appointed funeral director can make the arrangements to transport your child to wherever they are being transferred. Alternatively, if you would like to consider transporting your child yourself, please discuss this option with hospital staff or the Bereavement Support Team to get the advice and information you need to support your choice.

There are no legal obstacles or restrictions to using your own transport but, given that this is such a highly emotional time for parents or very close family, we suggest that you ask a friend or someone else to drive the vehicle. It is advisable to place your baby in a Moses basket or to wrap your child in a blanket for the car journey.

You will have been issued a 'Transfer of Care' form to complete and sign. Hospital staff will ask for this to be handed over by whoever collects your child from the Rainbow Room. The Bereavement Support Team will inform you when your child is transferred from our care if you are not collecting them yourselves.

If you opt for your child to be at home before their funeral, it is advisable to notify your GP to make them aware of your situation, and also to speak to your funeral director regarding care of your child's body. Please keep your child in a cool, well-ventilated room, especially during hot weather. If necessary their body can be kept cool with air-conditioning or a cooling pad or blanket which we may be able to help you source, but after two to three days, you should ask your funeral director for further advice.

Can I visit my child at the funeral home?

Whether or not you go to see your child at the funeral directors' before the funeral is a personal decision. Before you visit it is helpful to ask about any changes to expect in the appearance of your child's body. This is especially important so that siblings can be prepared if they wish to see them too.

What happens if I wish to move my child's body out of England and Wales?

You may choose to have your child buried or cremated abroad. The coroner must give permission for a body to be moved out of England or Wales to be buried 'abroad' in Scotland, Northern Ireland, the Isle of Man, the Channel Islands or overseas. This permission has to be obtained at least four clear working days before your child's body is to be moved so that any necessary enquiries may be carried out (although in urgent situations the coroner may be able to give permission sooner).

This procedure applies to all cases where the body is to be moved out of England and Wales, not only when the death was reported to the coroner. The coroner's officer and/or your appointed funeral director can advise you and arrange all the necessary documentation. It is advisable not to book any flights before all the necessary pre-arrangements have been made.

Unless an inquest has been opened, you will need to provide a copy of the death certificate. This means you must register your child's death before you can arrange repatriation abroad. The coroner will also need to see any certificate for burial or cremation already issued. Many countries require signed documents from an appropriate doctor that the deceased was not suffering from any infectious condition that might pose a public health risk.

Repatriation abroad may mean additional costs, for example caskets and embalming have to conform to high specifications, as well as the cost of the flight itself and costs in the destination country. A less expensive alternative is to have cremation in this country followed by repatriation of the ashes/cremated remains.

You don't need permission from the coroner to take cremation ashes out of the country but if you want to move them by air you should contact your airline for advice.

What happens to any equipment my child uses?

You may not automatically be told when any equipment your child used will be taken away, for example, beds or equipment supplied by the NHS.

Parents have spoken about not being given enough time or respect to grieve before it is collected. It is advisable to contact any equipment suppliers and explain your situation and try and negotiate a date or time that is best for you. Or you can ask someone else to do this on your behalf, so you can be prepared as far as possible.



Arranging a funeral for your child

Organising a funeral or memorial service for your child is an unimaginable task. It might feel overwhelming, but making the necessary choices and discussing all the possible alternatives for your child's ceremony can reduce the loss of control and sense of helplessness you may be feeling, and give you some purpose and direction.

There are many options and considerations but you don't have to make every decision alone. Your funeral director and others can help guide you through everything that needs to be done. You should be supported to do what feels best for you and your family to create a service that honours and celebrates your child, and reflects what you want to say about them. It is a time to share their story, your memories and sorrow and an opportunity to say goodbye with family and friends.

There is no need to rush any of the arrangements. The funeral can take place almost immediately if there is a religious requirement for this, but otherwise it does not have to take place within a certain number of days. You can take time to discuss it and get the thoughts and suggestions of your family, friends, faith leaders and others, if that would be helpful.

What kind of funeral can I have for my child?

You can have a religious or non-religious service, a Humanist service, or no service at all. You might have the service in a church and/or a crematorium, or a ceremony in a garden or special place of your choice. There are many options and you should choose what feels right for your child and for you and your family.

It can be helpful and positive for even very young children to be involved in the funeral arrangements. Feeling included can help them in grieving and adjusting to the reality of the death. If children are given the choice whether to attend the funeral it is helpful to prepare them for what they might see and hear, before, during and after the ceremony, so they know what to expect. Attending the funeral gives children a way to say goodbye and show their love for their brother or sister. Even if they are too young to remember the service, when they are older it can be important for them to know they were part of this significant family event along with everyone else. You could ask a trusted adult to be on hand to support your child/children if they attend, just in case you become too overwhelmed, or they change their mind on arrival.

If your children choose not to attend, reassure them that there are other alternatives, such as having a smaller, private family farewell ceremony - or talk with them and get their own ideas of ways they would like to remember their sibling and say goodbye.

How will I cover funeral expenses?

You may be concerned about funeral expenses but there is help available.

The Children's Funeral Fund

The Children's Funeral Fund for England can help to pay for some of the costs of a funeral for a child under 18, as long as the child's burial or cremation takes place in England. The Children's Funeral Fund enables funeral providers to directly claim burial or cremation costs, as well as a contribution (up to £300) towards the cost of a coffin, shroud or casket, so that parents won't have to worry about managing these expenses. The scheme is available regardless of a family's income. If you are using a funeral director you do not need to submit any claims yourself as the funeral director has to make the claim.

If you are not using a funeral director, the burial or cremation provider can claim for the fees of a burial or cremation and the money will be paid directly to them. You can claim for some other funeral expenses online via the GOV.UK website.

Expenses you can claim for are:

- up to £300 towards a coffin, shroud, casket or other covering
- removal of implanted medical devices for a cremation
- completion of necessary cremation certificates
- a container for storing ashes in a columbarium or similar (if the standard one returned to you is unsuitable for this)
- fees charged by a third-party grave digger (where these are not claimed by the burial or cremation provider).

All claims must be made within six months of the funeral.

A separate but similar scheme exists in Wales.

Funeral Expenses Payment

If you have other funeral expenses not covered by the scheme, you might be able to apply for a Funeral Expenses Payment to cover them. You or your partner must be receiving certain benefits to make a Funeral Expenses claim.

You can complete a Funeral Expenses Payment form SF200 online, but the easiest way to make a claim is by phone.

Call **0800 731 0469** and choose option two. Lines are open from 8am to 6pm Monday to Friday except public holidays. Calls are free from landlines and mobiles. You must make the claim within six months of the date of the funeral.

Funeral directors' charges can vary and it is important to know what services you will receive and how much each part will cost. You should ask for estimates and advice on any additional charges. Remember that you do not have to spend a lot of money to show you love your child.

Deciding on burial or cremation for your child

You may already have a preference for cremation or burial, or your child may have expressed their preference. Your faith representative or funeral director can advise you on 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 explain any costs involved.

When thinking about burial

Burials can take place in churchyards, public cemeteries, natural burial grounds and other places, depending upon local regulations. The ceremony preceding the burial is usually in a building but it can be conducted entirely as a service at the graveside. It is useful to know that normally a memorial headstone cannot be laid on a grave for around 6 months after a burial. This is to ensure that the ground has settled and the headstone will be stable.

Some families arrange to read poems or say prayers or have a simple remembrance ceremony at the graveside at the time the headstone is laid.

When thinking about cremation

If you choose a cremation for your child, usually a 20-30 minute session will be allocated for the service at a crematorium but the funeral director can book two or more sessions if you would prefer a longer ceremony. Alternatively the ceremony part could take place at another venue such a local place of worship, hall, hotel or your home, followed by a short service (called a committal) at the crematorium.

After a cremation you may wish to decide on the final resting place for the ashes but there is no need to make a decision straightaway. The ashes can be kept in an urn and when you are ready you can place them in the crematorium Garden of Remembrance, or a local cemetery or churchyard, or they can be scattered or buried in a favourite place, or kept with you at home.

You may wish to place a small amount of the cremation ashes into a memorial bear or cuddly toy that you can keep close to you. These cuddly toys usually have a concealed opening at the back with a pocket container for the ashes. The idea of taking a small amount of cremated remains and having it made into keepsake jewellery or a beautiful memorial ornament might feel right for some families. Funeral directors can arrange this or you can find details online.

Whether your child is cremated or buried, there are alternative options for permanent memorials, such as a dedication in a Book of Remembrance, or a memorial plaque on a bench, engraved stone or garden ornament.

What sort of coffin will you choose?

A wide range of traditional or alternative coffins and caskets is available for babies and children, including environmentally-friendly options such as seagrass, bamboo, willow or cardboard coffins, simple white coffins, or a range of colourful ones with personalised, themed designs. You can place some favourite possessions, photos or messages in the coffin if you wish, and other children, grandparents or other close family members may also like to do so.

If you want to have the coffin resting at home for a while before the funeral, this can be arranged. There are several options you can consider for transporting your child on the day of the funeral. The funeral director will be able to guide you in terms of cost and practicalities. They could transport your child for you in your choice of vehicle,

or you may wish to take them in your own car. You could consider asking members of the family or friends to be coffin bearers, or may wish to do this yourselves. If you feel it would be too difficult, you could still be alongside to escort the coffin, or hold a connecting cord.

Funeral dress code is a personal choice. Some families ask people to wear brightly coloured clothes as a celebration for the life of their child. You might choose a particular colour theme that was your child's favourite colour, or significant to them in some way.

Considering funeral flowers

People have different ideas when choosing funeral flowers: some want many, others prefer just a few or none. Most florists have specific arrangements for children's funerals and should be able to show you photographs that will help you to choose something meaningful and appropriate. It may help to choose flowers that are easily available, as being able to buy the same kind of flowers on special dates and anniversaries might comfort you in years to come. You may like to dry or press your child's funeral flowers as a keepsake. If you plan on doing this, speak to your florist about which flowers are the best choice for drying/pressing. You could choose to request that floral tributes are from close family only, and suggest that others give a donation in lieu of flowers to a chosen charity.

Deciding what to include in the service

Your funeral director or whoever is taking the service will discuss the detail of what you would like to include, and any videos, music, hymns or special readings you are thinking of incorporating. Your funeral director can show you a range of order of service designs to choose from which can include photographs of your child if you wish. Alternatively you may wish to design and print your own order of service sheets for use on the day, or arrange for them to be done for you.

You can arrange decorations or display mementos to personalise the service and you may like to have candles or incense to create a peaceful and uplifting atmosphere.

Some parents include a guestbook at the funeral, and ask people to write a message to their child. This book can become a treasured memento, containing messages of love for their child.

Considering a eulogy for your child

Writing a eulogy for a child is a sad and difficult task for anyone, but it is good to reflect on special moments in their life and share happy memories, and to focus on their personality and what they enjoyed doing most. You may want to write and read the eulogy for your child yourself, but if you feel that you can't, then ask someone to read your words on your behalf. You may want to invite people who have been important in your child's life to speak or read something – perhaps a godparent, a friend, a teacher. Siblings will sometimes want to read or say something too.

Preserving memories of the funeral

You may wish to have photos taken or even have the entire funeral service recorded. This might sound strange but it could be comforting in the future, especially if your distress on the day makes it difficult for you to have a clear memory of the farewell you arranged for your child. It can be helpful to have a photographic record for your child's siblings too, in particular if they are very young. You may wish to allocate a friend or appropriate person to be responsible for this on the day. If you are unsure about whether you would like photographs or not, remember that if they are taken you do not have to keep them or look at them, but if they are not taken you will not have that opportunity again.

After the funeral service

You may like to end the service by doing something special such as releasing environmentally-friendly balloons for your child, or giving out packs of forget-me-not seeds for people to plant for your child at home.

You may decide that you want to have all your family/friends gather together at your house or another meeting place after the funeral. Alternatively you might prefer to be completely alone, or alone with your immediate family and/or very close friends. There is no right or wrong way to arrange things. Do whatever feels right for you and your family.

After the funeral can be a particularly difficult time and it can be helpful to think ahead about how you will spend the next day. You might want to arrange for someone to be with you and have some kind of plan for what you might do.

Dealing with financial matters and return to work

You are entitled to a certain amount of time off work to deal with the death and to make funeral arrangements. This is often known as compassionate leave, and can be paid or unpaid. If you or your partner works, check your contract and your employer's bereavement policies. This will tell you whether there is a set amount of time granted, and whether any time off is paid or unpaid.

How long parents take off work following their bereavement varies greatly from person to person and job to job. Some jobs, such as operating heavy machinery, need a lot of focus and concentration. If you or other people might be unsafe at work because you're grieving and feeling distracted, you should speak to your line manager.

Whilst you may feel ready to return to work, you may not feel like you can take it all on at once. It may be useful to ask your employer to adopt a more flexible approach to your return - a phased return, reduced hours or, where possible, to have reduced responsibilities.

Bereavement Leave

The Parental Bereavement Leave and Pay Act gives all employed parents the right to two weeks' leave if their child under 18 dies. Employed parents will also be able to claim pay for this period, subject to meeting eligibility criteria. As well as legal parents of the child, foster parents, legal guardians, adopters and individuals who have obtained court orders giving them day to day responsibility for the child, will be entitled to this statutory right.

The Act provides for two weeks of leave to be taken within 56 weeks of the child's death. This extended period of time to take time off allows for the fact that some parents may wish to take time off on or around the first anniversary of the death of the child to assist with their grieving process.

If you or your partner are unfit to work (for example because of depression or stress caused by your bereavement), you may be able to get Employment and Support Allowance on the basis of your health problems.

Above all, always try to communicate regularly with your employer and let them know how you're feeling. Most employers are supportive and will do what they can to help.

Some larger employers have employee assistance programmes which offer helplines and confidential counselling. You can check with your employer to see what support is available.

If your baby has died you'll still qualify for maternity leave and pay. Talk to your employer about what they can offer you or check your contract of employment. You must make your claim within 28 days of your baby's death. If you're self-employed or haven't been with your employer for long enough to qualify for Statutory Maternity Pay, you might be eligible for Maternity Allowance. You will still be entitled to free dental care and prescriptions for one year.

Child Benefit, Child Tax Credits and Guardian's Allowance

Child Benefit payments will usually carry on for eight weeks after a child's death. If you don't tell the Child Benefit Office that they've died until after the eight weeks, they might end up paying you too much and you may be required to pay some money back. You may still be able to claim Child Benefit even if your child died before you made a claim.

When you notify the Child Benefit Office of your bereavement you should also ask them to pass on this information to the Tax Credits Office and Guardian's Allowance office if you also receive either of these benefits. If your tax credits award includes help with childcare costs and these reduce following the death of your child, then make sure you also tell the Tax Credits office about the reduction in these costs.

For further information you can visit the HMRC website or call the Child Benefit Helpline on 0300 200 3100 or you can contact the Child Tax Credit office directly: 0345 300 3900.

The Guardian's Allowance helpline number is 0300 322 9080.

Carer's Allowance

If you or your partner were getting Carer's Allowance for your child, this can also be paid

for the first eight weeks before stopping. Carer's Allowance will only run on for eight weeks if you were already eligible for it when your child died. If it had already stopped (for example, because your child was in residential care) this won't apply. **You need to contact the Carer's Allowance Unit within eight weeks on 0800 731 0297.**

Disability Living Allowance

If you need to contact the Disability Living Allowance (DLA) Unit yourself, (for example if you don't use the Tell Us Once service paperwork provided by your registrar), call **0800 121 4600**.

Motability

If you were using your DLA mobility to lease or buy a car from the Motability Scheme, you will also need to contact them. You will be given the option of either buying the car outright or returning it. **You can call them on 0300 456 4566. If you are getting a road tax exemption, then call 0300 790 6802.**

Income Support

If you were getting Income Support as a carer for your child, at the end of eight weeks you will no longer be treated as a carer and your Income Support may stop. Some parents will be able to carry on getting Income Support on other grounds, for example if you are a lone parent of a child aged under five.

Employment and Support Allowance (ESA)

If you or your partner are unfit to work (for example because of depression or stress caused by your bereavement), you may be able to get Employment and Support Allowance (ESA) on the basis of your health problems. In order to claim Employment and Support Allowance you will need to get a medical certificate from your GP, known as a 'fit note'. While having a fit note allows your ESA claim to start, within a couple of months the Department for Work and Pensions (DWP) will also put you through their own medical assessment.

If you can't claim Employment and Support Allowance or Income Support and neither you nor your partner are working, then after the eight weeks have passed you will need to consider signing on as available for work and claim Jobseeker's Allowance.

In some postcode areas you can no longer make a new claim for income-related Employment and Support Allowance or income-based Jobseeker's Allowance, and may need to claim Universal Credit instead.

Housing Benefit

Following the death of a child, your Housing Benefit will need to be re-assessed and, depending on your circumstances, you may start to get less help after eight weeks. If the death of your child leads to you being treated as needing fewer bedrooms under the size criteria rules, any cut in your Housing Benefit resulting from you being treated as having a 'spare' bedroom should be delayed for 12 months. However, this only applies so long as you remain in the same property. If you are claiming Housing Benefit, or help with your council tax or rates, then contact your local authority office straight away to avoid being overpaid benefit, which you may have to pay back.

Council Tax

The loss of your child may affect the amount of help you get towards Council Tax. This will depend on your own particular circumstances. Contact the local council office paying you this benefit straight away to avoid being overpaid benefit, which you may have to pay back.

Universal Credit

If you are receiving Universal Credit, then the death of a child will impact on the amount that you receive. However, for a temporary period you continue to receive payments for your child, including any childcare costs, alongside any carer element for looking after them - this is for the remainder of the monthly assessment period in which they passed away, and for the following two months. Depending on your circumstances, the loss of your child may mean that you start to be expected to look for work, as part of continuing to claim Universal Credit. Seek further advice if this applies to you.

Tell Us Once

Tell Us Once is a service that lets you report a death to most government organisations in one go. Unless you use the **Tell Us Once** service, you will also have to notify any other government departments providing services to your child. For example, this might include social services if you receive a package of support.

A registrar will explain the Tell Us Once service when you register the death. They will either:

- complete the Tell Us Once service with you
- give you a unique reference number so you can use the service yourself online or by phone

You must use the service within 28 days of getting your unique reference number. If you cannot register the death because an inquest is underway, you can still ask a registrar for a unique reference number. You'll need to get an interim death certificate from the coroner holding the inquest first.

Child Trust Fund money

If you had opened a bank account or Child Trust Fund for your child, you will need to inform the bank and/or fund provider about your child's death. Any money within the fund will be paid to the next of kin – usually the parent(s). No notification is required.



Living and coping with the loss of your child

It is helpful to remember that grief is a very individual process and you need to allow yourself to grieve in your own way. No one else can tell you how to feel or act. Even two parents of the same child are likely to grieve differently. If your partner doesn't react the same way as you, it doesn't mean that they are hurting any less. How you are affected will be influenced by many factors including your personality and usual coping style, and the circumstances surrounding your child's death.

How can I expect to feel after my child has died?

It is possible you will experience such a broad range of emotions you might think you are losing your mind, but you're not. In other circumstances these emotions might appear to be inappropriate or irrational. However, in this instance they are likely to be a completely normal, appropriate emotional response to the loss of your child.

Common emotional reactions to grief include:

- Shock • Numbness • Intense sadness • Despair • Disbelief • Anguish
- Yearning or longing • Emptiness • Confusion • Anger • Guilt • Worry
- Anxiety • Relief • Helplessness • Self-doubt • Peace.

Common physical reactions to grief include:

- Crying • Panic attacks • Fear • Heart palpitations/chest pain • Headache
- Muscle tension/body aches • Agitation • Upset stomach • Sleeping problems
- Nausea • Loss of appetite • Difficulty concentrating.

If your child's death was sudden and unexpected you may be in a total state of shock with many unanswered questions.

Feeling guilt is one of the most common responses following the loss of a child.

As you try to understand why your child has died, you may feel guilty that you couldn't prevent their death somehow. Parents often mentally replay their actions

prior to the death and wonder if they could have done something differently.

You may blame yourself or others for something they did or did not do. Try to talk through any feelings of self-blame with someone close and listen to reassurance you are given.

You may feel angry after the death of your child – it is a normal and necessary part of grief. If your child's death was accidental, the anger and frustration you feel may be intensified. You might question or doubt your faith or beliefs.

You may feel numb, or as if you're 'on autopilot', struggling to get through each hour, let alone each day. The numbness can be your mind's way of shielding you from the pain. You might feel as though you are running on adrenaline and have difficulty slowing down your thoughts or getting to sleep at night.

Taking care of yourself

Because grief is exhausting and can impact both your physical and emotional health, it is really important to pay attention to self-care.

Try to look after yourself in the following ways:

- Rest when you can
- Eat regularly, even if you don't feel like it
- Get fresh air and exercise
- Avoid using alcohol or drugs to mask the pain of your grief
- Set small goals to get through each day/week/month.

Don't be afraid to ask for help; talk to someone you trust about the way you feel. It is normal to feel sad and depressed, but if you feel as though life without your child is no longer worth living, make an appointment to see your doctor. If at any time you have a plan to harm yourself or are thinking about suicide, ask someone take you to the nearest hospital emergency department (ED) immediately where you can be assessed and where different treatment options will be offered to help you.

As time passes, these emotions and reactions should lessen in their severity. If you aren't feeling any better at all over time you may be experiencing actual depression that may need treatment so you should seek advice from your GP.

What should I expect in the early days?

Coming home and seeing your child's bedroom and toys and possessions again will be very hard. Do whatever feels right for you, but there is no rush to change anything.

If you have spent weeks or months in the hospital with your child, it will take time to adjust to being at home again and to deal with the many changes. If you have other children, looking after them can be emotionally and physically draining, but try and arrange whatever help you need to keep their routines as normal as possible. It will help them feel secure.

In the early days you may be so low that you have the feeling there is no point in getting up to start the day. Try to establish a simple routine, even if you don't feel like it, as this can give structure to your day. You might feel unable to complete even simple tasks, but take small steps. Write a simple daily to-do list and tick off each item as you complete it. If you have difficulty concentrating or find it too difficult or painful to make decisions, consider asking family and friends to support you. People are likely to offer help, so have a think about what practical things they could possibly do and delegate tasks to others whenever you can, such as shopping, preparing cooked meals, help with transport. Ask someone to go out with you on your first outings so they can answer questions instead of you.

Some parents find it helpful to set aside time when they can be alone to grieve for their child so that when their other children are home they can try to focus and give more attention to them. If your other children go to school, there may be time when you can sit quietly and think about your child and talk to them as though he or she were there next to you. You could write down the things you didn't have a chance to say, or play songs or music that reminds you of your child.

What to expect as time goes by

Around four to six weeks after the death of a child, many parents feel as though they are getting worse. This time can be particularly challenging because the reality is starting to set in, and it tends to coincide with family and friends returning to their normal lives and routines.

The feeling of being on an emotional roller-coaster is very common. Grief often follows a wave-like pattern, with many ups and downs. Knowing this will help you

understand why you have bad days and better days. Sometimes large waves of grief can seem to come out of the blue. These are often triggered by situations that you can't control or predict, such as hearing a song on the radio. Finding ways to manage these triggers is the key. You will be aware of reminders everywhere you go and sometimes you may think you hear your child talking or crying. This is the time you may feel particularly helpless and it is important you share your feelings with someone close.

Birthdays, Christmas and anniversaries will be very hard. The 'first' of everything can be especially difficult. Think about how you want to approach these dates. It can be helpful to make a plan and agree how you will remember your child. You might light a candle or plan a special walk. You could create a new tradition to celebrate your child's birthday or to remember them at Christmas. You might choose to support a good cause in their memory.

Finding ways to keep the memory of their child alive is very important for most bereaved parents. You may feel anxious that as time goes on you will forget certain things about your child, but this won't happen, and gradually you will work out ways to maintain an ongoing connection with them.

You could create a memory box to store treasured possessions and special mementos, or create a photo collage, keep a journal of thoughts of your child, or write details of their life and ask friends and family to write down their memories of your child that can be collated into a life story book. You might find a special outdoor place where you can go to think about your child and your relationship.

Your priorities and views may be changed by what has happened but it is wise not to rush any major decisions such as house moves, job moves or career changes soon after your child has died. It is important to have access to friends, neighbours and familiar colleagues at this difficult time.

Grieving for your child is a lifelong journey. Your grief will not go away but gradually you will find you have survived another day, another week, another month, and you will begin to feel stronger. You will learn to live with your loss and find a way forward. It may seem impossible but, with time, most parents find they can begin to experience happiness and find purpose and meaning in life again. Your precious memories will never fade and the love you shared with your child will live on and always be part of you.

How does bereavement affect relationships?

The death of your child will affect your relationship with others. Your partner, who may be your usual support, may not be able to respond to you in their usual way because they are dealing with their own grief. You may both react very differently but try not to judge the depth or quality of each other's grief. Having opposite ways of coping is normal but can be hard for both of you.

Try to be patient and meet each other halfway. It is important to talk and share your sadness, but you may need some time and space apart from each other to think and to grieve in your own way. Grief can also affect your sexual relationship. Talk openly about your feelings if you can, and remember that simple kinds of touch such as hugging, cuddling and holding can be healing at this time. Both crying and laughing together is important. It's okay to do things that you enjoy without feeling guilty.

Grandparents

Grandparents experience a double kind of grief when a grandchild dies. They will want to support their bereft son or daughter but can feel overwhelmed while sorting out their own feelings. Grandparents can particularly struggle with a sense of guilt that their lives have been fully lived whereas their grandchild's life has ended prematurely. Depending on the distance they live away, they may be able to offer practical help if it is wanted.

However it may actually be later, rather than in the immediate stage that they are able to provide the most comfort and support. They can play a key role in supporting their surviving grandchildren whilst the parents are in the depths of their own grief. Taking them out for a break can give the parents a rest and the children time off from the heightened emotions at home. Some grandparents may feel isolated, alone and powerless to help. Whatever their situation, it is important for them to seek appropriate support for themselves and find their own ways to honour and remember their grandchild.

The Compassionate Friends organisation produces a helpful booklet called 'When our grandchild dies' which is available through the charity's website. (See 'other support organisations' section at the end of this booklet for details.)

Friends

Bereaved parents often find themselves being the supportive one for others. Friends sometimes find it hard to know what to say and some may even avoid you or respond in ways that you find unhelpful. It may be best if you can take the lead and let friends know if you want to be with them, or if you want some time alone. Let them know that it's okay for them to talk about your child, even if you become upset.

As time goes by, try to accept or make dates with friends to do an activity such as exercise, meeting for a coffee or going to see film. Although you may not enjoy these activities at first, they will help create structure in your life.

Seeking support

Grief can be a lonely and isolating experience for anyone, but there is range of support that might help you now and in the future, including:

- Help from family and friends
- Spiritual or religious support
- Consultation with your GP or other healthcare professionals
- Support groups
- Bereavement counselling
- Telephone helplines
- Online groups and information
- Self-help books
- Community groups and organisations.

The children's hospital Bereavement Support Team will discuss the support you might need. They can signpost local services and organisations you might find helpful. You can search for support groups in your particular area by using an internet search engine to search key terms with the name of your community (such as grief and bereavement support, Weston-super-Mare).

At the end of this booklet you will find some contacts and information which may also be useful to you when seeking support.

Returning to the hospital again after your child has died

Many parents find they have unanswered questions or concerns as they think about the period of their child's illness and death. It may help to write these down as they arise so you don't forget them.

It is very important that you have the opportunity to talk over all these questions.

Around six to eight weeks after your child died you should be sent a letter inviting you to meet with the Lead Healthcare Professional and/or the most appropriate person/s to discuss your questions and concerns. The Bereavement Support Team or your Key Worker will consult with you on where the meeting will take place. If you feel it is too difficult for you to return to the children's hospital we can arrange another location, such as a nearby hotel or your own doctor's surgery, depending on your distance from Bristol.

If you are concerned that you have not been offered the opportunity for a meeting, please contact the Bereavement Support Team for advice.

If at any time you would like to revisit the unit or ward where your child was cared for, this can usually be arranged by the Bereavement Support Team.

The Sanctuary (E405) on Level 4 of the children's hospital is open at all times and provides a quiet multi-faith space for you to reflect and remember your child.

Opportunities to remember

It is important that we provide opportunities to reflect, remember and honour the children we have cared for at the children's hospital who have sadly died, and to show families that they remain in our hearts.

The Book Of Remembrance

Bristol Royal Hospital for Children has a Book of Remembrance kept in the Sanctuary (E405) on Level 4 of the hospital. If you would like to have an entry for your child, please contact the Bereavement Support Team who will send you a form to complete. Your entry will be printed in the book and you will be sent a copy of the page. You can come and see the book at any time.

Special Afternoon of Remembrance

In Spring or Autumn we usually host 'A Special Afternoon of Remembrance' when bereaved parents, families and the hospital community come together at a venue in Bristol. After the service there is an informal reception and refreshments are provided.

Service of Light

At Christmas-time we record a 'Service of Light' and send a link via the children's hospital social media pages, warmly inviting you to watch wherever you are and connect with us by lighting a candle in memory of your child. Our wish is that the service unites bereaved parents and families and bring comfort, peace and hope.

In the first year after your child has died you will be contacted directly about these events. In subsequent years you will find details advertised on the children's hospital website and social media pages near to the date, or you can contact the Bereavement Support Team. **Tel: 0117 342 7293** or email: ChildrensBereavementSupportTeam@uhbw.nhs.uk

Wallace & Gromit's Grand Appeal Star Tribute Fund

Creating a unique Star Tribute Fund is a meaningful and rewarding way to remember your child and create a legacy in their name. Once you have created a Star Tribute Fund page online, you can update it as often as you like with photos, videos, memories, and light virtual candles or buy virtual gifts on special days such as on an anniversary, birthdays, and at Christmas time.

The fund named in honour of your child will raise money to benefit babies, children, and their families cared for at Bristol Children's Hospital. You can also choose to support a particular ward or service.

For further information please contact The Grand Appeal www.grandappeal.org.uk
Telephone 0117 927 3888, email: info@grandappeal.org.uk

Hospital information and support

University Hospitals Bristol NHS Foundation Trust

Telephone: 0117 923 0000

Bristol Royal Hospital for Children: Main Reception

Telephone: 0117 342 8460/8461 (Monday - Friday 09:00 till 17:00)

The Bereavement Support Team

Bereavement Support Team, Bristol Royal Hospital for Children

Telephone: 0117 342 7293

Email: ChildrensBereavementSupportTeam@uhbw.nhs.uk

Chaplaincy

Bristol Royal Hospital for Children

Telephone: 0117 342 6799

Email: Chaplaincy@uhbw.nhs.uk

Clinical Site Team (For out of hours visits to the Rainbow Room)

Bristol Royal Hospital for Children

Telephone: 0117 342 1819

Patient LIAISE, dedicated patient and family support service, Bristol Royal Hospital for Children

Telephone: 0117 342 8065

Email: bchinfo@ubht.nhs.uk

Patient Support and Complaints Team, UHBW

Telephone: 0117 342 1050

Email: PSCT@uhbw.nhs.uk

Other support organisations

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:

Samaritans

24 hour service providing emotional support for anyone who's struggling to cope, who needs someone to listen without judgment or pressure, at any time of day or night.

www.samaritans.org

Free helpline: 116 123 Email: jo@samaritans.org

Child Bereavement UK

Supports families, provides information sheets and offers a telephone helpline for anyone affected by the death of a child, or who is caring for a bereaved child.

www.childbereavementuk.org

Phone: 0800 02 888 40 Email: helpline@childbereavementuk.org

Child Death Helpline

For anyone affected by the death of a child of any age from any cause. The helpline is staffed by volunteers, all of them bereaved parents.

www.childdeathhelpline.org.uk

Phone: 0800 282986 (from landlines) / 0800 800 6019 (from mobiles)

Email: contact@childdeathhelpline.org

Winston's Wish

Offers practical support and guidance and a range of helpful and practical publications, resources and information to families, professionals and anyone concerned about a grieving child.

www.winstonswish.org

Phone: 08088 020 021 Email: ask@winstonswish.org

Grief Encounter

Offers personal support and a variety of resources to anyone bereaved.

www.griefencounter.org.uk

Phone: 020 8371 8455 Email: contact@griefencounter.org.uk – general information

Email: ecounselling@griefencounter.org.uk - counselling service via email and skype.

Grieftalk Helpline: 0808 802 0111

Cruse Bereavement Care

Offers support, advice and information to children, young people and adults when someone dies. www.cruse.org.uk

Free National Helpline: 0808 808 1677 Email: helpline@cruse.org.uk

For face-to-face or group support, contact your local Cruse branch.

Hope Again

The youth website of Cruse Bereavement Care - supports young people with how to cope with grief and feel less alone.

www.hopeagain.org.uk

National Helpline: 0808 808 1677 Email: hopeagain@cruse.org.uk

The Compassionate Friends

A registered charity formed by and for parents whose children have died.
www.tcf.org.uk Helpline 0345 123 2304 Email: helpline@tcf.org.uk

The Lullaby Trust

Support for anyone affected by the sudden and unexpected death of a baby or young child. www.lullabytrust.org.uk
Phone: 0808 802 6868 Email: support@lullabytrust.org.uk

Sands

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

A Child of Mine

Support for anyone affected by the death of a child, offering emotional support, practical information and guidance.
www.achildofmine.org.uk
Phone: 01785 283 434 Telephone helpline: 07803 751229
Email: hello@achildofmine.org.uk

Survivors of Bereavement by Suicide

Exists to meet the needs and break the isolation experienced by those bereaved by suicide. www.uksobs.org
Helpline: 0300 111 5065 Email: Email.support@uksobs.org

Sudden

Online guidance to help ease the suffering of people bereaved by any kind of sudden death. www.sudden.org
Helpline 0800 2600 400 Email: help@sudden.org

The Good Grief Trust

Website run by the bereaved, for the bereaved and exists to help all those suffering grief in the UK. www.thegoodgrieftrust.org
Email: hello@thegoodgrieftrust.org

2Wish Upon A Star

Support for anyone affected by the sudden and unexpected death of a child or young person aged 25 and under in Wales. (The child must be Welsh, have resided in Wales or the death must have occurred in Wales).

www.2wish.org.uk

Phone: 01443 853125 Email: info@2wish.org.uk

Care for the Family

Peer support and resources for any parent whose son or daughter has died at any age, in any circumstance. The charity also runs events, support days and weekends away for bereaved parents.

www.careforthefamily.org.uk

Phone: 029 2081 0800 Email: mail@cff.org.uk

At A Loss.org

Charity signposting to bereavement support services, information, helplines and resources. www.ataloss.org

Children of Jannah

An organisation supporting Muslim parents, providing practical, emotional and spiritual support.

www.childrenofjannah.com

Support and Information Line : 0161 480 5156 Email: info@childrenofjannah.com

The Jewish Bereavement Counselling Service

Bereavement counselling for everyone in the Jewish Community.

www.jbcs.org.uk

Phone: 020 8951 3881 Email: enquiries@jbcs.org.uk

The Harbour

A Bristol based independent charity providing free, professional counselling and psychotherapy for parents following the death of a child through illness.

www.the-harbour.org.uk

Phone: 0117 925 9348

Email: info@the-harbour.org.uk

Information about funeral directors

The National Association of Funeral Directors (NAFD)

The largest professional association of funeral directors with a Code of Practice and Arbitration Scheme.

www.nafd.org.uk

Phone: 0845 230 1343

Natural Death Centre

Charity offering help, support, advice or guidance on green funerals and planning a funeral yourself.

www.naturaldeath.org.uk

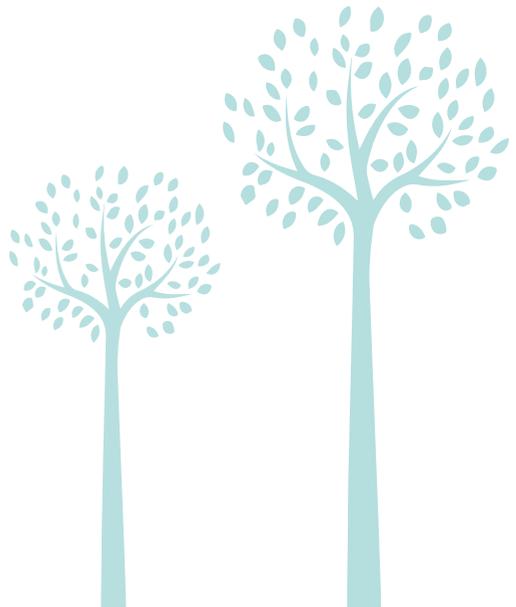
Phone: 01962 712 690

The British Humanist Association

Information and officiants for non-religious funerals.

www.humanism.org.uk

Phone: 020 7324 3060



Helpful books

There are a range of books available for bereaved parents and children. Here is a selection you may find useful. The Bereavement Support Team can recommend others that may be more relevant to your specific situation.

Books for adults

Bereaved Parents and their Continuing Bonds: Love after Death by Catherine Seigal (2017) For bereaved parents, the development of a continuing bond with the child who has died is a key element in their grieving and in how they manage the future.

The Unspeakable Loss: How Do You Live When a Child Dies? by Nisha Zenoff (2017) Written in a Q & A format, charting the long path from shock, trauma, and overwhelming pain, to a life that once again contains joy, love, and laughter.

Grieving Parents: Surviving Loss as a Couple by Nathalie Himmelrich (2014) The loss of a child affects the whole family, especially the parents and their relationship. This book will help you to adjust to life post-loss and emerge as a stronger couple.

Bearing the Unbearable: Love, Loss, and the Heartbreaking Path of Grief by Joanne Cacciatore (2017) The author shares wisdom and advice for dealing with the most painful losses, with the insight that only someone who has experienced deep personal grief can offer.

Ask Me His Name: Learning to live and laugh again after the loss of my baby by Elle Wright (2018) A bereaved mother's story of love and loss.

Books for children

You Will Be Okay: Find Strength, Stay Hopeful and Get to Grips With Grief by Julie Stokes (2021) This honest, comforting and strength-building guide teaches children that there are many things they can do to build strength and resilience in order move forward with life and look toward the future with hope.

Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died by *Diana Crossley (2001)* This book can be used to help children make sense of their experience by reflecting on the different aspects of their grief, whilst finding a balance between remembering and having fun.

The Memory Tree by *Britta Teckentrup (2014)* This gentle story about the loss of a loved one will bring comfort to both children and parents.

Always and Forever by *Alan Durant (2013)* Explains death gently through a charming picture story, giving young children some insight into grief and how to cope with it.

The Invisible String by *Patrice Karst (2018)* This heart-warming picture book for all ages explores questions about the intangible yet unbreakable connections between us. A tool for coping with all kinds of separation anxiety, loss, and grief.

Where are you Lydie? by *Emma Poore (2019)* A special picture book centred around the subject of sibling loss, sensitively written and illustrated for children between 3 and 7 years old.

What on Earth Do You Do When Someone Dies? by *Trevor Romain (2003)* This book answers questions, describes feelings and suggests ways to feel better after a loved one dies.

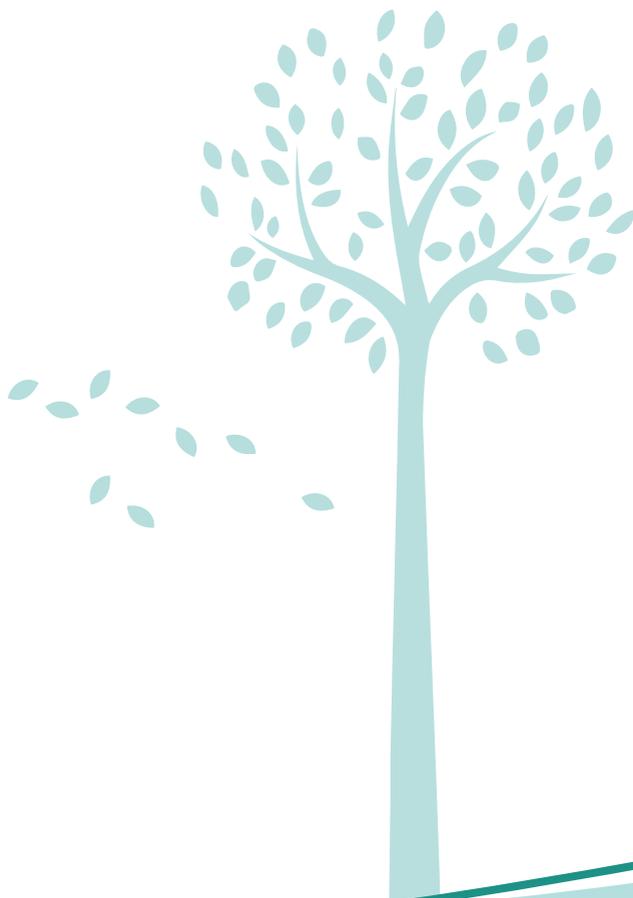
We will meet again in Jannah by *Zamir Hussain (2013)* This activity book helps bereaved Muslim children make sense of their experience following the death of a sibling, offering a way of honouring their memory, celebrating their life, and understanding the Islamic perspective.

The Dragonfly Story: Explaining the death of a loved one to children and families by *Kelly Owen (2018)* This story is often used to help explain death and the concept of heaven to people of all ages.

The Magical Wood by *Mark Lemon (2018)* This is a story about loss, friendship and hope that offers children an opportunity to share the journey of woodland characters finding their way through their grief.

When Dinosaurs Die: A Guide to Understanding Death by Laurie Krasny Brown and Marc Brown (1998) This book provides age-appropriate answers to some of the most-often asked questions and also explores the feelings children may have regarding the death of a loved one and the ways to remember someone who has died.

What Does Dead Mean?: A Book for Young Children to Help Explain Death and Dying by Caroline Jay and Jenni Thomas (2012) A beautifully illustrated book that guides children gently through the questions they often ask about death and dying.



Notes



Notes





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For Children



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NHS Foundation Trust

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