

Information for those who are bereaved when a child or baby dies



We would like to offer you and your family our deepest sympathy following the death of your child.

This booklet has been written with the support of other bereaved parents who have experienced the loss of a baby, child or young person.

We hope that it is helpful in answering some of your questions and guiding you through the many issues you may face.

We are aware that this can be an extremely difficult and confusing time and you may not feel able to read all of the information now, but please take our booklet away with you so that it is available should you need it.

It may not answer all of your questions, so if there is anything else you would like to ask or talk about, please contact us at any time.

Your key worker should be in touch with you over the next few days but you can contact them on the number below or please let them know if you would prefer not to be contacted:

Key worker contact name:
Key worker contact number:
If out of hours please contact the hospital switchboard 01623 622515 who will in turn contact the duty chaplain on call.
The consultant(s) contact for your child is:
Other relevant contacts:

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What happens now?

We realise it is important for you to be given time and support to make choices and decisions that are right for you and your family, particularly in the hours immediately after your child's death. Please discuss with us any thoughts or questions you may have.

Even if you do not follow a particular religious faith, some parents find it helpful to have a brief ceremony or blessing for their child. Staff can call the hospital chaplain for you or contact someone of your choice to arrange this.

You may like to wash and/or dress your child. We may be able to help you create some lasting memories by taking hand and foot prints, a lock of your child's hair and perhaps some photographs. If you are uncertain whether you would like to have these at this time, with your permission, we can place them in your child's notes and you can ask for them later. Please let us know if there is anything else you would like to include.

In most circumstances you will be very welcome to stay with your child for as long, or as little, as feels right for you. However, there will come a time when we will need to move your child from the ward area. We appreciate how hard it must be if you have to leave your child here with us at the hospital, but when you are ready, your child's nurse/midwife will transfer your child to the mortuary into the expert care of the mortuary staff.

If your child has a favourite toy, blanket or comforter, this can stay with them or you can bring it in later.

Your family doctor, midwife and Healthy Family Team will be informed of what has happened so that they are aware you may need their support.

Please tell us if there is anything we can do that may support you.

May I see my child?

You can either see your child here at the hospital or you may choose to wait until they have been transferred to the funeral directors.

There is a bereavement viewing room in the hospital where staff will assist you as much as possible. This is open Monday to Friday from 9am to 4pm and has an appointment system. To arrange an appointment or discuss the possibility of contact outside of these hours, please telephone the Chaplaincy Team on 01623 622515, extension 3047.

It may, in certain emergency circumstances, be possible to see your child outside of these hours by contacting the on-call chaplain via the hospital switchboard on telephone 01623 622515.

It is always important to contact the hospital before coming to see your child in order to make the appropriate arrangements and to avoid an unnecessary wait. The staff are here to help you.

Can I take my child's body home?

There are some circumstances where this is not possible, however, if a post mortem is not required and the doctor has completed the medical certificate of death, this may be possible to arrange.

You could take your child home or to the funeral directors, local hospice (if a room is available) or to another place of your choice. It is best to arrange this through a funeral director who can collect your child from the hospital and give you ongoing advice and support.

There will be paperwork to complete before taking your child home, but the hospital staff will help with this and any other arrangements.

Alternatively, you may prefer to have your child at home the night before or on the day of the funeral.

If you are unsure or have any other questions, please feel free to discuss them with staff at the hospital or the funeral director.

What about organ or tissue donation?

You may have already thought about this or you may have already been asked to consider organ donation, in which case the specialist nurse for organ donation will visit you to discuss this further.

Donations of certain organs such as liver, heart, lungs, kidneys or pancreas will normally only be considered when a patient has been ventilated and dies on the Intensive Care Unit. This means only a small proportion of children will be suitable for this type of donation.

However, some children, who were not ventilated when they died, may still be able to offer invaluable help to others by the donation of tissues.

Many people ask about the possibility of donating organs and tissues to help others. However, it is best if the donation takes place within 24 hours of the death, so please do not hesitate to speak to the nurses or doctors about this and they can arrange for someone to come and discuss this further.

What is the role of the Medical Examiner?

When a child dies their death will be discussed with a Medical Examiner and will have to be considered for referral to HM Coroner. The role of the Medical Examiner's team is:

- To agree the proposed cause of death and the accuracy of the medical certificate of death (MCCD).
- To discuss the cause of death with the next of kin and establish if they have any concerns with the care and/or treatment the patient received.
- To act as a medical advice resource for the local Coroner.

A member of the Medical Examiner's team will try and contact you within 48 hours of your child's death.

Following scrutiny from the Medical Examiner, a decision will be made to either:

 Issue the medical certificate of death OR refer the death to the Coroner for further investigations.

Why was my child's death referred to the Coroner?

The reasons why a death needs to be referred to the Coroner include:

- A death that has been sudden, unexpected or the cause is not known.
- A death that has been caused as a result of an accident or unusual circumstances.
- The person died during an operation or under an anaesthetic.
- Instances where the cause of death is not accepted by the Registrar's Office.

A Coroner's Officer should automatically contact you within two days of receiving the referral to discuss what has happened and advise you of what will happen next.

The outcome of a referral to the Coroner may be:

- A certificate can be issued by a doctor from the hospital.
- An inquest can take place without a post mortem examination.
- A post mortem examination will take place to determine the cause of death.

When the Coroner decides to carry out an inquest or post mortem examination, you will not receive a medical certificate of death at this time, but the Coroner's Office will issue all the paperwork so that a funeral can take place; they will also inform you of the legal processes.

The contact details for the Nottingham Coroner's Office are:

Address:

The Council House Old Market Square Nottingham NG1 2DT

Telephone: 0115 841 5553

Email: Coroners.office@nottinghamcity.gov.uk

Coroner's Office opening hours:

Monday to Friday: 9am-4.30pm, Weekends and Bank Holidays: Closed

A telephone message provides an emergency out of hours contact number.

For further details about the Coroner and their role please see their website pages on: www.nottinghamcity.gov.uk/Coroners



How do I find out about post mortem examinations?

Post mortem examinations are sometimes necessary in order to establish the cause of death and are required by the Coroner.

If the Coroner has requested a post mortem, this becomes a legal obligation and although you can raise any objections that you may have, there is no right to refusal. Your child will need to be moved to another hospital so that a specialist paediatric pathologist can carry out the examination on behalf of the Coroner.

This will be discussed with you, but do not hesitate to contact the Coroner's Office or your key worker. Further advice and information can be obtained from When A Child Dies leaflet (a guide for parents and carers NHS England).

Even if a medical certificate of death is issued, it is still sometimes possible to gain further information about an underlying illness or why a child has died by carrying out a hospital post mortem examination.

If the medical staff believes this would be helpful, they will usually discuss it with you.

Please do not hesitate to approach the doctors and/or nurses/midwives responsible for your child's care if this has not been mentioned but you would like the opportunity to discuss it.

How can I obtain the death certificate?

While the doctors try to write the medical certificate of death as soon as possible after the death has occurred, there are times when this can take a few days.

You will be contacted by a member of the Medical Examiner's team who will inform you of the proposed cause of death, if you are not already aware.

If your child's death has been referred and accepted by the Coroner, the doctor cannot issue the medical certificate of death. Your child's doctor and the Coroners' officer should discuss this with you. The Medical Examiner Team/Bereavement Office will also advise on the registration process.

How do I register my child's death?

Wherever possible your key worker will assist in arranging to register your child's death.

In most circumstances the medical certificate of cause of death will be scanned by either your key worker or chaplaincy team and sent direct to the Customer Services Centre at Nottinghamshire County Council the next working day after completion.

Nottinghamshire City Council Customer Service Centre - telephone: 0300 500 8080.

Further information about registering the death is available on the Nottinghamshire County Council Website www.nottinghamshire.gov.uk (How to register a Death).

If you have not registered the birth of your baby, this can be done at the same time as registering the death; just let the registrar know when you are making the appointment so they can give you a longer appointment time.

To register your child's death, you or a representative will need the medical certificate of the cause of death and the following information:

- The child's full name, home address, date and place of birth.
- The date and place of death.
- The father and mother's names, home addresses, places of birth and occupations.

At registration the death will be formally registered and you will be able to purchase as many original copies of the death certificate you require at this time.

The registrar will issue you with a green form to be given to the funeral director, which will enable the funeral to take place.

NB: There is a charge for all original copies of the death certificate.



Who do I need to tell?

The Tell Us Once Service is a free government service that allows you to report a death when you suffer a bereavement and need to tell central and local government (search **Tell Us Once** (Gov.UK) on the internet or call 0800 085 7308). However, as a parent you may be receiving benefits in respect of your child in your name and it is really important you contact these offices and inform them of your bereavement yourself.

Child Benefit or Child Tax Credit

Your child benefit payments will usually continue for up to eight weeks after your child died. This could help with some of the extra costs that you may face at this difficult time. However, if you do not tell the Child Benefit Office that your child has died, payments will continue after the eight weeks, which could be very distressing as you would then have to pay this back. In summary, you will need to tell the Child Benefit Office as soon as possible if your child, or a child you've been responsible for, has died.

You will need to ring the Child Benefit helpline on: 0300 200 3100. This is open from 8am-6pm Monday to Friday. Offices are closed on Sundays and Bank Holidays. Anyone can do this for you but the person ringing will need to provide the following information:

- Child's name.
- Date of death.
- Contact number of parent or informant.
- Informant's name and relationship to child/parent.
- The full name of the person receiving the child benefit.
- Child benefit number (this can be found on any child benefit letters) or the National Insurance number of the person who receives the child benefit payment.

To inform them online go to:

http://www.hmrc.gov.uk/childbenefit/ keep-up-to-date/changes-to-report/ child-dies.html

To inform them by post:

Child Benefit Office PO Box 1 Newcastle Upon Tyne NE88 1AA

The Child Benefit Office will record this information and also pass it on to other departments within HM Revenue and Customs (HMRC) that need to know such as Child Tax Credit. That way you will only have to contact HMRC once, **but do check that this is possible and that they are able to do this for you.**

If necessary the number for Tax Credit Helpline is: 0345 300 3900.

After informing them, please check that your payments have stopped eight weeks after the child's death. If they are still paying you then please contact them straight away to avoid over-payment.

If your baby has died shortly after birth

Information about the following are available at https://www.moneyadviceservice.org.uk/ en/articles/if-your-baby-has-died-shortly-after-birth:

Maternity pay and leave.

• Maternity allowance.

Child benefit and child tax credit.

• Sure Start maternity grant.

Other benefits and entitlements.

There may be others you need to let know such as:

Carer's Allowance Unit

Telephone: 0800 731 0297 Textphone: 0800 731 0317

Disability Living Allowance (DLA)
 Unit

Telephone: 0800 121 4433 Textphone: 0800 121 4493

Motability

Telephone: 0300 456 4321

Passport Office

Website: www.gov.uk/browse/abroad/ passports

 Local authority offices, council office or any other government departments providing services to your child.

How do I arrange my child's funeral?

Your key worker/chaplaincy team and your funeral directors will be available to discuss arrangements with you.

Give yourselves time to plan your child's funeral as what you choose is so important, including the decision whether your child is to be cremated or buried. It is always advisable that you obtain the death certificate or check with the Coroner before confirming any funeral arrangements.

Choosing a funeral director

Although it is legal and feasible to arrange your child's funeral yourself, most people find it helpful to make contact with a funeral director to discuss the options available. Friends or family may recommend one to you, or you may wish to search on the internet.

Bereaved parents do not have to pay for the full costs of their child's funeral. The funeral director will be able to advise you about additional costs.



The funeral director will need the green certificate given to you by the registrar. The funeral director will contact the hospital and arrange to bring your child to their chapel of rest.

You may prefer to have your child at home with you until the funeral or just prior to the funeral. This can be arranged by the funeral director.

Burial

If you decide on a burial for your child, this can be in a cemetery provided by the council, in your local churchyard or a churchyard of your choice, although some churchyards are now closed.

You could choose a private individual plot or a family plot with an area available for your child or you can opt to bury your child with another family member. Some cemeteries have a specific area for babies and infants at a minimal cost.

Memorial stones can be erected after the grave area has settled. Times can vary from six to 12 months, although most cemeteries provide a small temporary marker.

Natural and woodland burial sites are becoming increasingly popular, providing a natural alternative choice to a traditional cemetery or graveyard.

Cremation

If your child is to be cremated, the funeral director will liaise with the hospital to arrange for the necessary extra papers to be completed. You can plan a service at the venue of your choice followed by a brief service of committal at the crematorium chapel, or just have a service at the crematorium.

If you wish to collect your child's ashes you will have to wait at least a day before collecting them from the funeral directors. They will be placed in a casket.

It is your choice what you do with your child's ashes after cremation. There is no rush to decide and there are many different choices available. Some parents choose to scatter or bury the ashes, but you

may require particular permission from the owners of the grounds to do this. If you wish to bury your child's ashes in a churchyard or cemetery you will be asked for the certificate of cremation which should have been given to you at the same time as the ashes.

You could keep the ashes in an urn, casket or other special container as long as you wish. There are many other alternatives such as having them incorporated into jewellery, a paper weight, a teddy or a garden sculpture for example.







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The funeral service

There are many different forms of services, both religious and non-religious, with or without music and readings, etc. You should discuss all the options and possibilities with your funeral director, religious leader or hospital chaplain. You do not have to hold a funeral ceremony in a set place. You may prefer to hold it in your own home. It is really important that you plan the funeral that is right for you and your family.

Help with costs

Since 2019 the Children's Funeral Fund for England can help to pay for some of the costs of a funeral for a child under 18 years or a baby stillborn after the 24th week of pregnancy. If your baby is born before 24 weeks please speak with your bereavement midwife / hospital chaplaincy or the Early pregnancy Assessment Unit for further advice.

The Children's Funeral Fund is not means tested; what you earn or how much you have in savings will not affect what you get.

Your funeral director should claim this on your behalf. The burial or cremation must take place in England. If you are in receipt of certain state benefits then the Social Fund, run by the Benefits Agency, may also be able to help with the costs of the funeral.

Further information and forms can be obtained from your local benefits agency or your funeral director. Some charities associated with particular illnesses or conditions can provide help towards funeral payments.

Please speak to your funeral director or key worker if you would like further information and advice in arranging your child's funeral.

Will I have opportunities to give feedback on my child's care?

Government legislation requires a review of the circumstances of all child deaths up to the age of 18 years, to learn as much as possible.

Child Death Review is a term used to describe all the processes that happen after the death of a child. There are some elements that take place for every child death and some that may not be needed, depending on the circumstances. This review is designed to support you and other members of your family in understanding why your child died. It will also try to prevent other children dying from the same cause.

Your key worker will be able to tell you about what is happening in relation to your child's death.

A national leaflet with more detailed information about the Child Death Review and key worker role is also available, so please ask if they have not been given to you or you can refer to the **NHS England - When a Child Dies** booklet on the internet.

All deaths are screened as part of the Child Death Review process. It is really important that we know what we have done well and where we need to improve our care, so that the best possible care is always given and that lessons are learned if any mistakes are made. Your feedback into these reviews are important, so you will therefore be asked several times if there are any issues or concerns about your child's care that you wish to raise.

These need to be raised so that they can be properly investigated for you and to ensure we learn from what happened and improve the care we offer.

The Medical Examiner's Office or Coroner's Office will ask you if you have any concerns about your child's care. You can also give feedback to your key worker or any member of staff at any time.

You can also contact the Patient Experience Team (PET). PET (incorporating complaints and the patient advice liaison service) provides a confidential advice and information service. The team are dedicated to listening to those that use our services, their carer's and relatives in order to review and improve our services where required. All NHS staff are experienced in helping resolve concerns, however, if they are not able to resolve the problem, PET are here to assist.

You can contact the team on 01623 672222, Monday to Friday between 9am and 5pm.

Alternatively, you can email the team on sfh-tr.PET@nhs.net

Or write to:

The Patient Experience Team King's Mill Hospital Mansfield Road Sutton in Ashfield Nottinghamshire NG17 4II



How can my child be remembered within the hospital?

You may like to enter your child's name into the book of remembrance in the Faith Centre, or we have a memorial cairn in the Faith Centre garden where you may place a stone showing your child's name.

There is an annual Service of Remembrance.

Will I have the opportunity to ask questions of the consultant involved in my child's care?

When your child dies it can be difficult to take everything in and you can be left with questions. It is really important that you feel you have the opportunity to ask your questions.

If your child's death is not being investigated by the Coroner, about eight weeks after your child's death you may be contacted by letter to invite you to meet with your child's consultant. This will provide an opportunity for you and the consultant to discuss your child's condition, the events around their death and any other particular issues that you may wish to discuss. Sometimes, there are the findings on the post mortem examination and where applicable, results of tests to pass on. However, these can sometimes take six months or more before they are available, so you may wish to delay the appointment until they are available. You may find it helpful if you make a list of questions before the meeting so that you do not forget things.

This appointment is usually held in a room away from the ward area. However, if you feel you cannot return to the hospital, alternative arrangements can be made. If you are unable to attend on the suggested date, or you do not feel ready but would like to meet in the future, please contact your key worker when the time feels right and an appointment can be arranged.

Support for brothers and sisters

Often one of the big worries for parents if they have other children is how the death of their brother or sister will affect them. Just like adults, children and young people will all handle it individually and may well have very different ways of coping.

Instinct is often to protect them from the pain of grief, but children and young people have told us they want honest information and to be involved and included.

Don't be afraid to show your feelings and to grieve together as a family.

Other family members may have the need for additional support and there are a number of services which offer this that they could be signposted to.

If you would like support or information to help with this either now or later then please contact your key worker for advice.

Who can I contact for support?

The death of a child is possibly the most difficult experience that any parent has to face. Nobody can say how you will feel and no two people's experiences will be the same.

However, there may be times when you feel your emotions are totally out of control and although this is quite normal, it can be helpful to talk to someone at this time. Some people can find all the support they need from within their family, others may prefer to talk to someone who isn't directly involved and others a mixture of both.

Some of the support services available in the community are:

• **GP**

- community midwife
- Healthy Family Team

• social worker

community nurse

Counsellors at GP surgeries and counselling centres

Minister, priest or representative from your own faith

Let's Talk Wellbeing

Free helpline: 0300 300 2200

Website: www.nottinghamshirehealthcare.nhs.uk/letstalkwellbeing

Nottinghamshire CRISIS

Free helpline: 0808 196 3779 (this is a 24 hour mental health crisis helpline)

Notts Help Yourself

Website: www.nottshelpyourself.org.uk (enter Bereavement in the keyword section)

Sands (Stillbirth and Neonatal Death charity)

Free national helpline: 0808 164 3332 Website: www.sands.org.uk

Email: Helpline@sands.org.uk

Missing Piece (24 hour support)

Text: 07894 436422 Website: www.missingpiecechildloss.com

Zephyrs Nottingham

Facebook: Zephyrs Nottingham Twitter: Zephyrsnotts

Email: Contact@zephyrsnottingham.org.uk

Children's Bereavement Centre - Newark

Telephone: 01636 551739 Email: info@childrensbereavementcentre.co.uk

Laura Centre (Leicester)

Telephone: 0116 254 4341 (they will direct you to your local area)

Website: www.thelauracentre.org.uk

Tree Tops Hospice

Telephone: 0115 949 6944

A variety of national bereavement support organisations are available, some of which are mentioned below and may have local groups:

Babyloss

Website: www.babyloss.com Email: support@babyloss.com

BLISS

Telephone: 020 7378 1122 Website: www.bliss.org.uk Email: hello@bliss.org.uk

Care for the Family

Telephone: 0292 081 0800

Website: www.careforthefamily.org.uk

Email: mail@cff.org.uk

Cruse Bereavement Care

Free helpline: 0808 808 1677 (local 01623 647645) Website: www.cruse.org.uk

Winston's Wish Family Line Free helpline: 0845 203 0405 /

0808 8020 021

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Email: ask@winstonswish.org

Website: www.winstonswish.org.uk

Child Bereavement UK

Free helpline: 0800 028 8840

Website: www.childbereavementuk.org

The Lullaby Trust

Free helpline: 0808 802 6868 Website: <u>www.lullabytrust.org.uk</u> Email: <u>support@lullabytrust.org.uk</u>

Compassionate Friends

Telephone: 0345 123 2304 Website: <u>www.tcf.org.uk</u> Email: <u>helpline@tcf.org.uk</u>

The Child Death Helpline

Free Helpline: 0800 282 986

Website: www.childdeathhelpline.org.uk

A Child of Mine

Telephone: 01785 283434

Email: hello@achildofmine.org.uk Website: www.achildofmine.org.uk

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