

The Child Death Review

A guide for parents
and carers



This leaflet is for parents and carers of a child under 18 who has died. It tells you what happens in the child death review.

Introduction

The death of any child is a tragedy. It is vital that all child deaths are carefully reviewed. This is so that we can learn as much as possible, to try to prevent future deaths, and to support families and all those affected by these tragedies.

If you have any unanswered questions about the review of your child's death after reading this leaflet you should contact the following person:

Keeping you informed

You should be kept informed at all stages of the review into your child's death. There may also be times when professionals need to ask you questions.

Expected deaths

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

Local health care staff or others such as hospice or hospital staff should work with you and your family to support you. It may be necessary for the Coroner to order a post mortem examination.

Otherwise, you should be able to register your child's death quickly and proceed with your family's planned funeral and memorial arrangements.

Unexpected deaths

Unexpected means that the death was not anticipated in the 24 hours before the death or before the event that led to the death. The death may have no obvious cause, such as a 'cot death', or the cause might be clear, such as an accident. The law requires that all sudden and unexpected deaths be reported to the Coroner if the cause is unknown or not a natural cause. A process called 'rapid response' will begin.

Rapid Response

Straight away: Your child is usually transferred to an emergency department. Your child is examined by a paediatrician or other doctor and samples will be taken. You will be asked some questions about what happened to your child by a professional at the hospital and an initial meeting between professionals such as the police and a paediatrician takes place. You should be offered the opportunity to have a memento, such as a lock of hair or hand and foot prints from your child.

Usually within the first week: The pathologist will be asked to carry out a post mortem examination. All professionals involved share information about your child. If your child died at home, particularly if your child was a baby, you will be visited at home by a police officer and a health professional to ask you for detailed information.

If your child died away from home, the police may visit the place of death and may visit you later.

From one week onwards and usually several months later: Background information is gathered if required, for example school health records, maternity notes or other relevant information which may include health records of parents and siblings. A final case discussion takes place between the group of professionals who have been involved and a report is completed. The Coroner decides whether to hold an inquest.

Meetings between professionals

For both expected and unexpected deaths, doctors, nurses and others involved with your child will talk to each other to establish the facts about why your child died. They should also offer support to you. They will consider how the procedures at the time of death and afterwards were managed. Information from you is very important. Please contact the person named at the beginning of this leaflet at any time if you think of anything that might help.

Case discussion

A final meeting between all professionals involved takes place after the post mortem examination results are complete. The purpose of this meeting is 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.

They will consider how professional roles were carried out at the time of death and afterwards. A report of the meeting is sent to the Child Death Overview Panel. Following the meeting someone from the team should meet with you to discuss the conclusions reached and to answer any questions you might have.

The Coroner and the Coroner's Inquest

The Coroner usually arranges for a post mortem examination to take place for unexpected deaths. An inquest is held if the cause of death remains uncertain, or if the cause of death is not thought to be a 'natural cause', such as a road accident.

You may want to ask for the Ministry of Justice leaflet '*Guide to Coroner Services*' which describes in more detail what Coroners and their officers do, and what happens at inquests. It is available at <http://goo.gl/HNOBzc>

An inquest is an inquiry to:

- confirm who has died, when and where; and
- establish the cause of death, in broad terms. It does not involve accusations or blame. If the Coroner decides to hold an inquest you are given details of when and where it will take place. You may be called as a witness, in which case you must attend the inquest. If you are not called as a witness you can choose whether to attend. You can ask questions at the inquest, and you may be asked questions. Other professionals may be present. An inquest is open to the public and journalists may be present.

The Coroners' Court Support Service (CCSS)

The support service is a registered charity whose trained volunteers give emotional support to bereaved families and other witnesses attending an inquest.

For more information visit:

www.coronerscourtsupportservice.org.uk

Post mortem examination and the pathologist

What is a post mortem examination?

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

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

If your child's death was unexpected and has been referred to a Coroner it is the Coroner's decision whether a post mortem examination takes place. If a Coroner is not involved, then a post mortem examination can only take place with parental consent. You should have a full discussion with health care staff to consider if this is the right decision for you and your family. You can request your own representation at the post mortem and the Coroner can provide more information about this.

Why is a post mortem examination important?

A post mortem examination may do the following:

- find a medical explanation for your child's death;
- rule out other diseases or problems that you may have been worried about;
- identify other conditions which may be important for your family to be aware of; and
- provide information that might be used to help your family or other children in the future.

Sometimes, a post mortem examination may not find a cause of death.

What happens to your child?

A post mortem examination takes place as soon as possible, usually within a few days. If a specialist children's pathologist is to carry out the examination then your child may have to be moved to another hospital. The pathologist examines all the major organs and looks for anything that might give clues as to the cause of death. The examination is conducted with the same care as if your child were having an operation. Very small samples of tissue are taken and tested. After the post mortem examination has taken place, and the Coroner has given permission, you can see and hold your child, and decide where you would like your child to be before the funeral. This includes the possibility of some time at home. If your family would like this, you can discuss it with hospital/hospice staff.

Post mortem examination results

Soon after the post mortem, the pathologist gives an initial report to the Coroner. Where possible, with the Coroner's approval, you can be given some details of these early results. The final post mortem examination report will usually take some months to be completed depending on the number and type of tests conducted.

Tissue retention

During the post mortem examination a number of small tissue samples need to be taken for specialist testing. You will be asked what you would like to happen to these once the tests have been completed. You can ask for them to be:

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

Whole organs

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

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

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

When can you register your child's death?

You can register your child's death as soon as you receive the medical certificate from a hospital doctor or when the Coroner has issued a form confirming a natural death. If there is to be an inquest, the Coroner

registers the death at the conclusion of the inquest. Once the death is registered you will be able to obtain a death certificate.

When can you have your child's funeral?

You can start to think about funeral arrangements at any time but you can only hold it when you have the death certificate or appropriate form from the Coroner. You may wish to discuss possible choices with your chosen funeral director, and take time to consider the type of service most meaningful for you and your family. If you have religious or other requirements that may affect the timing of your child's funeral please discuss these with hospital staff. They will alert the Coroner who will try to accommodate your wishes, although it may not always be possible.

What is a Child Death Overview Panel?

The death of all children under the age of 18 must be reviewed by a Child Death Overview Panel on behalf of the Local Safeguarding Children Board. Child Death Overview Panels are groups of professionals who meet several times a year to review all the child deaths in their area. The main purpose is to learn how to prevent future deaths. The Panels make recommendations and report on the lessons learned to the Local Safeguarding Children Board. The Board produce an annual report which is a public document. Anyone can read the report, but it contains no details that could identify an individual child or their family.

Who is on the Panel?

The Panel has representatives from:

- public and child health;
- social care services
- police

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

Can you attend the meeting?

Family members are not invited to attend the panel meetings but you may ask for any information to be considered at the meeting. Contact the person named at the start of this leaflet if you would like to do this.

Staffordshire Safeguarding Children Board / Stoke on Trent Safeguarding Children Board

Local Safeguarding Children Boards make sure any recommendations made by the Panel are sent to those with responsibility for taking them forward. In a small number of child deaths, the Boards may decide that it is necessary to conduct a more detailed investigation called a Serious Case Review.

Other professionals

There are some key professionals who may be involved in the child death review process including:

- accident and emergency staff
- ambulance staff
- general practitioner (GP)
- health visitor
- hospice staff
- local authority representatives
- midwife
- school nurse
- social worker
- teacher

All of these professionals may know your child in different ways and are able to offer different information to build the fullest picture possible of the circumstances leading to, and at the time of, your child's death.

Bereavement Support in Staffordshire and Stoke on Trent

Where to get advice and information:

Child Bereavement UK

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

Confidential support and guidance to anyone who has been affected by the death of a child or who is caring for a bereaved child.

www.childbereavementuk.org.uk

Telephone: 0800 02 888 40

Email: support@childbereavementuk.org

Children of Jannah

A UK registered charity founded in 2011 to support Muslim bereaved parents and families following the devastation of the death of a child. Support and information line: 0161 480 5156

www.childrenofjannah.com

A Child of Mine

Help for Bereaved Parents

07803 751229 Office hours: Monday - Friday 9am - 5pm. Out of hours leave a message and your call will be returned as soon as possible.

www.achildofmine.co.uk

Donna Louise Hospice

Offers a network of specialist care and support to children and young people who have life limiting or life threatening illnesses, and their families; includes bereavement support 01782 654440

info@donnalouisetrust.org

Dove

Bereavement counselling and support
01782 683 155

The Lullaby Trust (formerly FSID)

Offers confidential support to family, friends and carers affected by the sudden and unexpected death of a baby or toddler:

0808 802 6868,

support@lullabytrust.org.uk and

www.lullabytrust.org.uk

Calls to the Helpline are free from all landlines and most mobile phone networks.

The Helpline is open:

Monday – Friday 10am-5pm, Weekends and public holidays 6pm–10pm (answered by trained befrienders, all with personal experience of bereavement)

Winston's Wish

The largest charity provider of support to bereaved children, young people and their families in the UK. 08452 03 04 05

www.winstonswish.org.uk

CLIC Sargent

Helping children and young people with cancer. 0300 330 0803

www.clicsargent.org.uk

Child Death Helpline

A freephone service offering support for anyone affected by the death of a child.

0800 282 986

www.childdeathhelpline.org.uk

SANDS

Stillbirth and Neonatal Death organisation supporting anyone affected by the death of a baby. 02074365881

www.uk-sands.org.uk

BLISS

Information, support and counselling for families with babies “*born too small, too soon, too sick*”. 0500 618 140

www.bliss.org.uk

CRUSE Bereavement Care

www.rd4u.org.uk

Bereavement support for young people, after the death of someone close to them.

FREE helpline: 0808 808 1677 (Monday - Friday 9:30 am – 5:00 pm)

Helpline 0844 477 9400 www.cruse.org.uk

Samaritans

Available 24 hours a day to provide confidential emotional support. 08457 909090 (UK) www.samaritans.org

Saying Goodbye

National Remembrance Services

0845 293 8027

www.sayinggoodbye.org

Staffordshire and Stoke on Trent Safeguarding Children Boards

staffsscb.org.uk and safeguardingchildren.stoke.gov.uk

Child Death Overview Panel 01785 232724

The contents of this leaflet is taken from the booklet “*The Child Death Review, a guide for parents and carers*” produced by The Lullaby Trust.

GLOSSARY

Child Death Overview Panel

A Group of professionals who consider all child deaths in a given area to look for possible patterns and potential improvements in services to prevent future deaths.

Coroner

A Coroner is an independent judicial officer who inquires into all sudden, unexpected or unnatural deaths.

Inquest

The Coroner's inquiry to confirm who has died, when and where, and to decide if a cause of death can be established.

Local Safeguarding Children Board

A local body which agrees how relevant organisations will work together to safeguard children and promote their welfare.

Paediatrician

A doctor who specialises in treating children. The paediatrician (or other doctor depending on the age of your child) is usually one of your key contacts. He or she is involved from the time

your child dies and throughout the review. If a post mortem examination has taken place the doctor should go through the results with you.

Pathologist

A doctor who conducts the post mortem examination (also known as an autopsy).

Police

The police must by law be involved in the review of any unexpected death or where there are other circumstances that might need further investigation. Their role is to eliminate the possibility that anything unlawful has taken place. The police may lead the investigation in the initial stages of most cases and will always do so if suspicious circumstances cannot be ruled out at that stage.

Rapid Response

The series of procedures that automatically begin when a child dies unexpectedly.

Serious Case Review

A detailed review of a child who died where there are serious concerns about the cause of death.

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