The child death review

A guide for parents and carers

Contents

Introduction

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. Local practices may vary a little.

The death of any child is a tragedy. It is vital that all child deaths are carefully reviewed. This is so that we may learn as much as possible from them, to try to prevent future deaths, and to support families.

Some organisations which offer support in bereavement are listed at the end of the leaflet.

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

Your local contact is:

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 the 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 end-of-life 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.

You should be kept informed about the review of your child's death

Unexpected deaths

An unexpected death is often sudden. Unexpected means not expected for example 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 and the police if the cause is unknown or not of a natural cause.

A 'rapid response' will begin.

Rapid response

There are three stages to the rapid response:

1. Immediate response:

Straight away: Your child is usually transferred to an accident and emergency department in hospital. Your child is examined by a paediatrician or other doctor and blood and other samples may be taken. You are asked what happened and for information about your child by a professional at the hospital. Initial meetings between different professionals, such as the police and paediatrician, take 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.

2. Early response:

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. Their role is to eliminate the possibility that anything unlawful has taken place. You may also be visited by a doctor or nurse to see where the death happened, and to ask you for more detailed information. Sometimes these visits will be made jointly. If your child died away from home, the police may visit the place of death and may visit you later to ask you further questions.

3. Later response:

From one week onwards, usually several months later: More background information is gathered if required, for example school health records, maternity notes or other relevant information. 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.

Unexpected child deaths start a rapid response

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.

You may not get feedback from each and every one of these discussions, but you should be kept generally informed about the review and what will happen next. The person keeping you informed should be a professional whom you have met, perhaps someone you knew before your child died, or a police officer. Information from you is very important. Get in touch with your named contact at the beginning of this leaflet at any time if you think of anything that might help.

It is important that all the professionals involved talk to each other to gather as much information as possible about your child's death

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 (see page 12) and should also be sent to the Coroner. 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 fatal road accident.

You may want to ask for the leaflet *Coroners and Inquests: a guide* which describes in more detail what Coroners and their officers do, and what happens at inquests. It is also available at the following web address: www.fsid.org.uk/childdeathreview

Inquests

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.

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.

A post mortem examination makes an important contribution to explaining why your child died

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 then you are not able to choose whether a post mortem examination takes place; the Coroner can order it.

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 decide 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 knowledge that might be used to help your family or other children in the future.

In some cases, a post mortem examination may not find a cause of death.

What happens to your child?

When a post mortem examination has been ordered or consented to, it takes place as soon as possible, usually within a few days. If a specialist children's pathologist is to carry out the post mortem examination then your child may have to be moved to another hospital.

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

Post mortem examination results

Soon after the post mortem, the pathologist gives a initial report to the Coroner. Where possible, with the Coroner's approval, you can be given some initial feedback on these early results. The final post mortem examination report may take several more 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 samples once the tests have been completed. You can ask for the samples to be:

- returned to you (the Coroner's Officer will be able to discuss what you could do with the samples);
- kept by the hospital, as part of your child's medical record, 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 days or weeks to complete. If this is the case the Coroner's Officer will discuss the possibilities open to you:

- you may wish to delay the funeral until the organs are able to be returned to your child;
- you may wish to receive them back at a later date; 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 *Form B*. 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 the funeral at any time but you can only hold it once 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, though it may not always be possible.

Child Death Overview Panel

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. The Child Death Overview Panels are groups of professionals who meet several times a year to review all the child deaths in their area. The Panel is not given the names of any children who died; all the details are dealt with anonymously. 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 produces 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 health;
- local child health and social care services; and
- police.

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

Can you attend the meeting?

Parents are not invited to be part of the Panel but you may be invited to contribute any comments you might have into the review of your child's death. Contact the person named at the start of this leaflet if you would like to do this.

The Child Death Overview Panel must by law review all child deaths to try to prevent future tragedies

Local Safeguarding Children Board

The Board makes 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 Board may decide it is necessary to conduct a more detailed investigation called a Serious Case Review.

The Local Safeguarding Children Board has a wider responsibility for safeguarding and promoting the welfare of all children in their area

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 a 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 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.

Other professionals

The glossary includes descriptions of some of the key professionals who may be involved in the child death review process. A number of others may also be involved, including:

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

All these professionals 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.

Thank you to the professionals and bereaved parents who helped write this leaflet.

Bereavement support

You should be offered support throughout the review into your child's death, and told about local services or organisations which you may find helpful to contact. The following national organisations can also offer support and advice in specific areas:

Bliss

Support, including after bereavement, for the family of a premature baby.
www.bliss.org.uk
0500 618140

Childhood Bereavement Network

Information and advice about local and national services to support bereaved children and young people.
email: cbn@ncb.org.uk
020 7843 6309

Child Death Helpline

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

The Compassionate Friends

Support for bereaved parents and their families.
helpline@tcf.org.uk
Helpline 0845 123 2304

Foundation for the Study of Infant Deaths (FSID)

Support and advice for anyone following the sudden death of an infant.
www.fsid.org.uk
0808 802 6868 (freephone helpline)

Sand Rose Project

Provides breaks for bereaved families.
www.sandrose.org.uk
info@sandrose.org.uk
0845 6076357

SANDS

Supporting anyone affected by the death of a baby.
www.uk-sands.org
020 7436 5881 (helpline)

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