Information for Families

Following the Death of a Child

Norfolk Safeguarding Children Board

Any child's death is a tragedy and no words can soften your loss. Although the information in this booklet is important, we do understand that it may be difficult for you to read, and we are truly sorry to be giving this to you at this difficult time.

This booklet describes different aspects of the legal processes which may follow the death of any child or young person less than 18 years of age. Local authorities in England have a legal duty to review the deaths of children from their area.

The purpose of this *Child Death Review* is to learn lessons for the future. About 60 children in Norfolk die every year. This is many fewer than even twenty years ago, but if that number is to keep on falling, we need to make things better for children in future.

Looking closely at the death of each child, helps us see where things could be improved or done differently. The Child Death Review does not seek to blame anyone for what has happened; it is all about improving services for children now and in future years.

The review is a confidential process, where a small group of local professionals get together to discuss the facts of an individual case. If you wish, you can contribute to the Child Death Review, by letting us know any information you feel is important, or any unanswered questions you may have.

Once again, we apologise for giving you with this information at such a difficult and sensitive time. However, it is clearly important that families know about the Child Death Review and have the opportunity to contribute to it.

Yours sincerely,

Dr. Nandu Thalange,
Chairman, Norfolk Child Death Overview Panel

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Child Death Review

The **Child Death Review** is held by the Child Death Overview Panel (CDOP) – a group of professionals who look into all deaths of children, from Norfolk. The CDOP looks at what happened, and tries to identify areas for improvements to prevent future deaths. The CDOP also looks at bereavement support for families after the death of a child. The CDOP only completes its review when all available information is available – usually a few months after a child has died.

Children's Services

This is the name given to Norfolk County Council's services for children – principally education and children's social services. Children's Services are a vital part of the Norfolk Safeguarding Children Board and the Child Death Overview Panel.

Coroner

The Norfolk Coroner is an independent Judge who inquires into all sudden, unexpected or unnatural deaths. If the Coroner decides it is appropriate, he will hold an Inquest. Inquests are formal legal hearings, held in the Coroner's Court. The purpose of an Inquest is to decide how the death occurred (not to apportion blame). Whenever a death falls under the Coroner's jurisdiction, the **Coroner's Officer** – an assistant who helps the Coroner – liaises with family to keep them up to date with what is happening.

Expected Death

The term "expected death" refers to deaths from natural causes, in children with serious underlying health problems. This might include a baby receiving neonatal intensive care, a child with severe congenital problems, such as cerebral palsy, or a child with terminal cancer. If the condition is so severe that it may prove fatal, then it is possible to make plans about what will – and will not – be done, in an emergency situation. If a child in this situation dies, then this is an "expected death". By definition, most other deaths are "unexpected". However, most unexpected deaths are still due to natural causes, (e.g. meningitis).

Medical Certificate of Cause of Death (MCCD)

When a child dies, if the cause of death is known, and it was due to natural causes, one of the doctors caring for your child will complete a certificate – the MCCD. This could be your GP or a hospital doctor. If the cause of death was unclear, or was not due to natural causes, then the Coroner is notified.

Norfolk Safeguarding Children Board

The Norfolk Safeguarding Children Board (NSCB) is responsible for the welfare of all children in Norfolk. The **Child Death Overview Panel (CDOP)** is part of the NSCB. This means that any important findings made by the CDOP are passed to the Board. The NSCB has representatives from all the agencies with responsibility for children, including the local NHS, Children's Services, police, charities, etc.

Paediatrician

A paediatrician is a doctor who specialises in treating children. A paediatrician is usually involved after the death of any child, and will normally see families to offer a practical explanation of what has happened, including the results of any tests, and to offer comfort and support.

Pathologist

A Pathologist is the specialist who conducts Post Mortems. A Post Mortem (also known as an autopsy) will usually be ordered by the Coroner for unnatural deaths, or where the cause of death is not known. A Post Mortem may have been held, with your permission, even if not required by the Coroner – usually to help the medical team looking after your child gain a better understanding of what happened.

Police

The police are by law involved in the investigation of any unexpected death on behalf of the Coroner whether or not there are circumstances that might need further investigation. Their role is to establish whether there is any possibility that a crime has taken place.

Rapid Response Team

For the majority of sudden or unexpected deaths, a children's nurse or paediatrician from the **Rapid Response Team** will visit the family home and/or place of death to help the police in their investigation. Their report is given to the **Child Death Overview Panel** to help with the **Child Death Review**.

The Child Death Overview Panel (CDOP)

The CDOP is the committee which carries out the Child Death Review. The review is completed only when all the information is available. This will include reports from relevant health professionals, children's services and, if necessary, information from the police and the Coroner. The review must wait for all inquiries and judicial proceedings to be completed, to ensure the CDOP is fully informed. Usually, this will be a few months after the death of a child. In some circumstances, the review may not be held for up to 3 years or more, if there are on-going inquiries or legal proceedings.

The Norfolk CDOP has representatives from:

- The Norfolk Safeguarding Children Board
- The NHS, including paediatricians, children's nurses, a pathologist, a GP and others
- The Public Health department, based at Norfolk County Council
- Children's Services
- Norfolk Police
- East Anglia's Children's Hospices
- A lay member

In addition, other professionals may be invited to attend, if they can bring additional specialist knowledge to help the CDOP in its discussions on particular cases. Parents can contribute to the Child Death Review by providing information to the panel.

All these professionals bring their own expertise and insights which mean the CDOP is able to discuss all deaths frankly and openly, to ensure that, wherever possible, lessons are learned which may reduce the likelihood of deaths in future. CDOP Meetings are not open to the public.

After the CDOP has reached its conclusions, a confidential letter summarising the main findings is sent to the relevant organisations who were involved in a child's care. If it is relevant, the letter includes a comment on the quality of care provided by the organisation. If necessary, the summary may require improvements or changes to policies, procedures or services

Every year, an Annual Report is submitted to the Norfolk Safeguarding Children Board. This report is a public document, which anyone can read. The report does not identify individuals or families.

Contributing to the Child Death Review

If you have concerns or information you want to tell us about, or any unanswered questions about what happened, please feel free to contact the CDOP Co-ordinator by phone, email or letter. You can also ask the medical team or other professionals who cared for your child to contact us on your behalf. Our contact details are on page 2.

We do not send copies of our conclusions to parents, as the letter may arrive months or years afterwards, and is likely to be a distressing reminder of what happened for most parents.

If you wish to know more about the recommendations made by the panel, we would suggest looking at the Annual Report, which is available on the NSCB web site. www.nscb.norfolk.gov.uk

Expected Deaths

Some children have severe or incurable health problems. Modern medicine can do much to help such children, but sometimes it is clear that death is likely or inevitable, or that further treatment will not improve or prolong life. This might include children with a range of health problems:

- Severe congenital problems such as inoperable congenital heart disease, or certain chromosomal or genetic disorders (e.g. Edwards' syndrome, spinal muscular atrophy)
- Children with advanced or incurable cancer and other life-threatening conditions for which treatment has failed, (e.g. irreversible organ failure of the heart, lungs, liver or kidneys).
- Progressive incurable conditions, where treatment may improve quality and length of life, but which are inevitably fatal. These conditions may commonly go on for many years. (e.g. Batten's disease, muscular dystrophy).
- Irreversible but non-progressive conditions causing severe disability leading to increased risk of complications and the likelihood of premature death (e.g. severe cerebral palsy, multiple disabilities such as following brain or spinal cord injuries).

Care at the End of Life

Whilst children with severe underlying health problems may become seriously ill and die, it is often very difficult to predict how or when this may happen.

However, if it is clear that a child is reaching the end of their life, then a plan can be drawn up with the family. In the intensive care unit, this might be a plan to discontinue active treatment. This plan can specify things that will be done in the event of specific problems, such as pain, or difficulty in breathing. It can also specify what will not be done, in order to reduce suffering to a child from treatment which will not improve or prolong life.

When the time comes, the medical team will issue a medical certificate confirming the cause of death. This certificate is referred to as the MCCD. The Child Death Overview Panel (CDOP) co-ordinator is notified that the death has occurred, and requests information from the relevant professionals, to assist the CDOP in the Child Death Review.

In some cases, the family may be asked whether they would be willing to allow a post-mortem to be held. Medical teams may ask families to consider a post mortem where they feel that, although there is sufficient information to issue an MCCD, there are still important unanswered questions relating to the condition or its treatment.

Whether a post-mortem has been held or not, families are normally offered the opportunity to meet with the consultant who looked after their child to talk through any questions, or concerns the family may have, and to be offered comfort and support.

After the MCCD has been issued, the family can proceed with making funeral arrangements and register the death.

Unexpected Deaths

An unexpected death is often sudden. Usually, there is no obvious cause, such as occurs with 'cot death'. In other situations, the reason may be clear; for example, an acute infection such as meningitis, or death due to an accident.

If the death is obviously due to natural causes, then the medical team will issue an MCCD, confirming the cause of death, and the Coroner will not usually be involved. However, when a death is due to natural causes, but there are concerns about possible failings in care, the Coroner may be involved.

The Child Death Overview Panel (CDOP) co-ordinator is notified that death has occurred, and requests information from the relevant professionals, to assist the CDOP in the Child Death Review.

If the cause of death is not apparent, or death was not due to natural causes, then the Coroner is notified, and a formal investigation begins. This does not mean that anything suspicious has happened, although in rare circumstances this will be a criminal inquiry – for instance if death follows an assault. More commonly, the cause of death is not apparent, and a Sudden Unexpected Death Investigation begins. The purpose of the investigation is to understand what happened and why.

We suggest you skip the next section, unless your child's death is being treated as a Sudden Unexpected Death.

Sudden Unexpected Deaths

Specific tests are carried out as soon as possible after death to help the investigation. This may include tests on blood and other body fluids, and in some circumstances, x-rays. A Coroner's post-mortem examination will also be held. These tests, including the post mortem, are done to give the Coroner as much information as possible.

Rapid Response

If appropriate, the Rapid Response Team will be contacted, and will arrange to visit the family home and/or place of death, usually in conjunction with the police, the same or the next day. The Norfolk

Rapid Response Team includes a paediatrician and children's nurses. They have received specific training to help them identify potentially important factors that may have contributed to what happened. The main purpose of this visit is to gather information to help the investigation, and to provide support to the family. For most families, the involvement of the rapid response team is very helpful in supporting them through a very difficult time.

The report from the rapid response team is given to the pathologist who will do the post mortem examination and to other relevant professionals. The Child Death Overview Panel also receives a copy.

After the post mortem examination, the cause of death may be clear, but in many cases, further specialist tests may be required, which often take several weeks, or even a few months. The Coroner's officer will liaise with the family and relevant health professionals, so they are kept informed of what is happening. In most cases, a paediatrician will be involved. The paediatrician will usually offer to meet the family to discuss the results of tests including the post mortem, (with the Coroner's permission), once these are available. This is normally a few weeks afterwards.

When the results of the post mortem and other tests are available, the Coroner will review all the available information, and decide whether it is sufficient to establish the cause of death. If the death was due to natural causes, the Coroner can issue a certificate – Form B – indicating the cause of death. You can then register your child's death and make funeral arrangements.

If the death was not due to natural causes, or the evidence is unclear, an inquest will be held.

Inquests

If the death was not due to natural causes, an inquest will be heard to determine how the death occurred. In certain circumstances, an inquest may be held when death is due to natural causes, where there are potential issues of neglect. However, the purpose of the inquest is to determine how the death occurred and *not* to blame any individual or organisation.

If the Coroner decides to hold an inquest you will be given details of when and where it will take place. An inquest is open to the public and the press is usually present. An inquest is a formal court hearing. You may be called as a witness, in which case you must attend. If you are not called, you can decide whether or not to attend.

The Coroner will usually meet with the family privately before the inquest, provided this is agreed with all other properly interested people; not to discuss the evidence but to introduce himself and to learn about the person who has died and the family's concerns. You can ask questions at the inquest and you may be asked questions. If you wish, you can have a legal representative at the inquest, but Legal Aid is not normally available for inquests. Although the inquest is a court hearing the Coroner always endeavours to conduct the hearing in a sensitive and compassionate manner.

After the inquest, the Coroner will notify the Registrar of Births Marriages & Deaths of the outcome. The Registrar will then register the death and contact the family in writing, informing them that the death certificate is now available.

Your child's funeral can be held once you have permission from the Coroner. If you have religious or other requirements that may affect the timing of your child's funeral, please discuss these with hospital staff. They will alert the Coroner who will try to accommodate your wishes, though this may not always be possible.

After the inquest and any other enquiries have been completed, the Child Death Overview Panel will be able to proceed with the Child Death Review.

The next pages talk about the Post Mortem. Most children do not have a post mortem, so if it is not relevant to you, we suggest you skip this section.

The Post Mortem

There are two kinds of post mortem examination; a hospital post mortem, and a Coroner's post mortem, which follows sudden, unexpected or unnatural deaths.

A post mortem examination may do the following:

- Find a medical explanation for your child's death;
- Identify other important conditions which may not have been recognised before death
- Provide knowledge that might be used to help your family or other children in the future.

A post mortem needs to takes place as soon as possible; usually within a few days. In certain circumstances, your child may need to be moved to another hospital for the post mortem to be done.

During the post mortem the pathologist examines all the major organs and looks for any 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 and body fluids are taken for microscopic examination and other tests.

After the post mortem examination has taken place 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, or the Coroner's Officer.

The Hospital Post Mortem

For a hospital post-mortem the family is asked whether they would be willing to allow a post-mortem to be held. Medical teams may ask families to consider a post mortem where they feel that, although there is sufficient information to issue an MCCD, there are still important unanswered questions relating to the condition or its treatment. The family is free to refuse the request for a post mortem, and this will not affect the care and support the family receives.

The Coroner's Post Mortem

A Coroners Post Mortem will normally be ordered for any death which is unexplained, unexpected, or not due to natural causes.

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.

Soon after the post mortem, the pathologist gives an initial report to the Coroner. Where possible, with the Coroner's approval, you can be informed about these early results. The final post mortem examination report may take several more weeks to be completed depending on the number and type of tests conducted.

What Happens to Samples Taken at Post Mortem?

During the post mortem 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, for you to make your preferred arrangements
- Kept by the hospital, as part of your child's medical record.
- Used for ethically approved research, (for which your consent would be required), or other purposes such as teaching,
- Disposed of by the hospital

In rare circumstances whole organs may need to be kept, for special tests, which may take several days or weeks to complete. For hospital post mortems, your permission will be needed for any such tests to be done.

In these circumstances, you may wish to consider:

- Delaying the funeral until the organs are able to be returned to your child
- Having the organs returned to you at a later date for you to make your preferred arrangements
- Asking the hospital to keep or dispose of them.

You may wish to discuss these choices with the funeral director and your doctor or paediatrician.

Support for Bereaved Families

The loss of a child is an overwhelming and traumatising experience for families. Being supported through your loss is very important. Support for families can come from several sources:

- Your family and friends, your community, or church or faith group
- Your GP
- Your child's consultant and/or other members of the healthcare team
- NHS Bereavement Services
- Children's Services
- Local and national charities

Counselling may be available through your GP or health visitor. Specialist NHS bereavement services may be available in certain circumstances. However there are a number of local and national charities which offer support to bereaved families. The following list is not exhaustive.

Local Charities

CRUSE (Norwich Branch)

☎ 0333 230 0189 www.norwichcruse.org.uk

CRUSE has a telephone helpline (Monday, Wednesday and Friday mornings, 10am - 12am, and Thursday evenings, 5pm – 7-30pm; leave a message at other times), advice and leaflets and information, and specific support for children and young people.

East Anglia's Children's Hospices (Quidenham)

☎ 01953 888603 www.each.org.uk

Offering support to families following the loss of their child from a long-term medical condition.

Nelson's Journey

☎ 01603 431788 www.nelsonsjourney.org.uk

Offering support to children who have lost a close relative, through their advice and guidance service, support from trained therapists and residential weekends.

Norfolk & Waveney Suicide Bereavement Support Group

☎ 01263 768604 🖱 www.suicidebereavement.co.uk

The group, founded in 1990, supports all who have been bereaved by suicide. All who make contact will be offered a home visit to help better understand their situation. The support group meets fortnightly in Norwich.

Norfolk Stillbirths & Neonatal Deaths

☎ 075 3946 2315 🖱 www.norfolksands.org.uk

Norfolk Sands is run by a group of parents who have all experienced the death of a baby either in pregnancy, during or soon after birth. They run a regular monthly support group.

St Peter Mancroft Church

☎ 01603 610443 🖱 www.stpetermancroft.org.uk

The church offers individual bereavement support in your own home.

National Charities

Bereaved Parents' Support

☎ 029 2081 0800 🖱 www.careforthefamily.org.uk/bps

Offering hope and comfort to those who have lost a child of any age and in any circumstance - through telephone befrienders, events, an email newsletter and web resources.

Child Bereavement UK

☎ 01494 568900 🖱 www.childbereavementuk.org

Provides support to families when a child dies or when a child is bereaved of someone important in their lives. Services offered include a Support and Information Line and interactive website with a Families' Forum.

Child Death Helpline

☎ 0800 282986 🖱 www.childdeathhelpline.org.uk

The Child Death Helpline is a Freephone service for anyone affected by the death of a child of any age, including still birth, under any circumstance, no matter how recently or long ago. The helpline is

staffed by trained and professionally supported volunteers who are all bereaved parents, and are open every day throughout the year.

Sand Rose

☎ 0845 607 6357 www.sandrose.org.uk

Sand Rose provides free one or two week breaks in Cornwall to any bereaved family with a particular emphasis on young families. Families must be nominated by a professional who knows you well such as your GP, counsellor, bereavement worker etc. but not a family member.

The Compassionate Friends

☎ 0845 123 2304 www.tcf.org.uk

The Compassionate Friends is an organisation of bereaved parents and their families, offering mutual understanding and support to others after the loss of a child. Helpline hours: daily from 10.00-16.00 and 19.00-22.00.

Winston's Wish

☎ 0845 203 0405 www.winstonswish.org.uk

Winston's Wish supports bereaved children and young people up to the age of 18 through a whole range of activities, including a helpline, group work, residential events and information.

Support after Loss of a Baby

BLISS

☎ 0500 618 140 www.bliss.org.uk/help-for-families/bereavement

BLISS offers a free counselling service for parents of premature and other sick babies, including those who have died, and also a free helpline (Monday to Friday 9am to 9pm).

Foundation for the Study of Infant Deaths (FSID)

☎ 0808 802 6868 www.fsid.org.uk

FSID has a Freephone helpline for parents who have experienced the sudden and unexpected death of their baby. It is answered personally by trained advisors from 10am to 6pm on Monday to Friday and from 6pm to 10pm weekends and bank holidays.

SANDS - Stillbirth & Neonatal Death Charity

☎020 7436 5881 www.uk-sands.org

Support when your baby dies during pregnancy or after birth.

Support after Loss of a Child from Heart Disease

CRY - Cardiac Risk in the Young

☎ 01737 363222 www.c-r-y.org.uk

Cardiac Risk in the Young (CRY) supports those bereaved through sudden cardiac death.

Little Hearts Matter

☎ 0121 455 8982 www.lhm.org.uk

Support for anyone affected by the loss of a child or baby with single ventricle heart disease.

SADS UK - Sudden Arrhythmic Death Syndrome

☎ 01277 811215 www.sadsuk.org

SADS UK provides information and support to individuals and families who have been affected by a sudden cardiac death. SADS UK has qualified counsellors with experience of SADS. The charity holds Retreats for people bereaved through sudden cardiac death, and support is also available to families diagnosed with cardiac conditions of the electrics of the heart.

Support after Loss of a Child in a Road Accident

Brake

☎ 0845 603 8570 www.brake.org.uk/support

Brake is a road safety charity. It runs a helpline for anyone bereaved or seriously injured as a result of a road accident.

RoadPeace

☎ 0845 4500 355 www.roadpeace.org

Offering practical and emotional support to all bereaved or injured through road crashes.

Support after Loss of a Child from Epilepsy

Epilepsy Bereaved

☎ 01235 772850 www.sudep.org

Epilepsy Bereaved provides a contact line providing support and information, as well as working to increase awareness of deaths due to epilepsy, and funding research into prevention.

Support after Loss of a Child from Suicide

Survivors of Bereavement by Suicide

☎ 0844 561 6855 www.uk-sobs.org.uk

Providing help and support to those bereaved by the suicide of a relative or close friend. They provide information, a helpline (9am to 9pm) and other activities.

Notes

Written by Dr Nandu Thalange on behalf of the Norfolk Safeguarding Children Board
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