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 such a 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. All local authorities in England have a duty to review the deaths of every child 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 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 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.

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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 consider all child deaths in Norfolk to look at what happened, and importantly to identify potential improvements in services 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 sufficient 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 Child Death Overview Panel and the Norfolk Safeguarding Children Board.

Coroner

The Norfolk Coroner is an independent Judge who has to inquire into all sudden, unexpected or unnatural deaths. If the Coroner decides it is appropriate, an Inquest will be held. 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 (Death Certificate)

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 also known as a Death Certificate. 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 in place to make sure that children are protected from harm and that their welfare is promoted. Any recommendations made by CDOP are passed to the Board. The NSCB has representatives from all the agencies with responsibility for children, including the local NHS, Norfolk County Council Children's Services, police, voluntary sector, etc.

Paediatrician

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

Pathologist

A Pathologist is the specialist doctor 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 caring for 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 act on behalf of the child to establish whether there is any possibility that something unlawful has taken place.

NHS Rapid Response Team

For most sudden or unexpected deaths the Norfolk NHS Rapid Response Team will visit the family home, in conjunction with the Police, to gather additional important information which may cast light on what happened and why. The Rapid Response Team is made up of senior children's nurses, supported by a consultant paediatrician. After the visit, the team consults with colleagues working in health and Children's Services, as well as the police and Coroner's officers, and draws up a report. This report is used to support 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 sufficient information is available. This will include reports from relevant health professionals, children's services and, if necessary, information from the police and the Coroner. Usually, the review will be undertaken a few months after the death of a child.

The Norfolk CDOP has representatives from:

- The NHS, including paediatricians, children's nurses, designated safeguarding team, pathologists, the ambulance service and other health professionals
- Public Health based at Norfolk County Council
- Norfolk County Council Children's Services
- Norfolk Constabulary
- East Anglia's Children's Hospices
- CDOP is supported by the NSCB Business Support Team

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 the 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 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 and is published on the NSCB website. 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.

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.norfolklscb.org

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 an End of Life Care 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 usually issue a medical certificate confirming the cause of death. This certificate is referred to as the Medical Certificate of Cause of Death also known as a Death Certificate. 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, a 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 a Death

Certificate, there are still important unanswered questions relating to the condition or its treatment.

Usually, families are 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 death certificate has been issued, the family can proceed with making funeral arrangements and register the death.

For further information for registering a death, contact the Norfolk Registration Office ☎ 01603 306149.

https://www.norfolk.gov.uk/births-ceremonies-and-deaths/deaths/register-a-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. Children who die as a result of their own actions are also regarded as unexpected deaths.

If the death is readily established as due to natural causes, then the medical team will issue a Death Certificate, confirming the cause of death, and the Coroner will not usually 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 there may 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.

The next section only relates to families where their child's death is being treated as unexpected.

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. The Coroner will usually direct a post-mortem examination to be carried out. These tests, including the post mortem, are done to give the Coroner as much information as possible.

NHS Rapid Response

If appropriate, the NHS 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 NHS Rapid Response Team includes a team of senior nurses and a paediatrician. They have received specific training to help them identify potentially important factors that may have contributed to the death. The main purpose of this visit is to gather information to help the investigation. For most families, the involvement of the Rapid Response Team is very helpful in supporting them at 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 after death has occurred.

Inquests are held when a death is not due to natural causes, or in certain circumstances where death has been due to natural causes but there are concerns that the death was avoidable. Examples include where there has been a lack of medical care or neglect. The purpose of the inquest is to determine the facts, and does not apportion blame to anyone.

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 where possible learn lessons that may prevent future deaths, and *not* to blame any individual.

Your child's funeral can be held once you have permission from the Coroner, which is usually after the inquest opening and does not have to wait until the actual inquest is held. 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.

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's Officer will usually contact the family before the inquest, to introduce themselves and to learn about the person who has died and the family's concerns. At the inquest you will be given the opportunity to ask questions of any witnesses who give live evidence, who will be asked questions by the Coroner initially, after which any other Interested Persons will be given an opportunity to ask 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 will endeavour 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.

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 section only relates to families where their child has had a post mortem.

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.

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 enough information to issue a Death Certificate, 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 you will receive.

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 would 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 death of a child is an overwhelming and traumatising experience for families. Being supported through this difficult time is very important. Support for families can come from several sources:

- Your family, friends and community, including your church or faith group
- Your GP
- Your child's paediatrician and/or other members of the healthcare team
- Norfolk County Council Children's Services
- Local and national charities
- Schools and Nurseries for other children in the family

Counselling may be available through your GP or healthy child practitioner (Health Visitor/School Nurse). There are a number of local and national charities which offer support to bereaved families. The following list is not exhaustive.

Key Local Charities

CRUSE (Norwich Branch)

☎ 01603 219977 🖱 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 one-to-one support for adults.

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 life threatening condition or complex health need.

Nelson's Journey

☎ 01603 431788 🖱 www.nelsonsjourney.org.uk

Nelson's Journey is a registered charity providing a service for children and young people aged 0-17 years inclusive, living in Norfolk, who have experienced the death of a significant person in their life. They offer a range of services including; resources; telephone support; 1:1 sessions; residentials; activity days; NJClubs, family days and training.

National Charities

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.

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 SIDS – Lullaby Trust

☎ 0808 802 6868 www. support@lullabytrust.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.

Notes

Written by Norfolk Safeguarding Children Board
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