

“There is no footprint
too small to leave an
imprint on this world”

Anon



North West & North Wales
Paediatric Transport Service

NWTS is a collaborative initiative by the
Royal Manchester and the
Alder Hey Children's Hospitals

Information Booklet to help guide Parents, Families and Carers when a Child dies



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When your child has died suddenly it seems like all meaning has been drained from your life.

No-one can tell you how you should feel as everyone acts and feels differently. You may feel numb or in denial, or wonder how someone can feel so much pain and survive, there are a whole successions of feelings.

It is important to be gentle and kind to yourself. Over time the intensity of emotions will lessen. It may be hard to believe but one day you will think about the good memories of how your child lived rather than the bad memories of how your child died. You will even be able to laugh and smile again some day—as hard to believe as that may seem.

At NWTS we offer our condolences and hope that this booklet has helped in providing information on the practicalities following the death of your child.

Winston's Wish

🌐 www.winstonswish.org.uk

☎ 0845-203-0405

Winston's wish is a charity for bereaved children; ie brothers and sisters or friends of a child who has died. They can provide professional help before, during and after bereavement to help a child/young person better understand the nature of loss and offer practical support and guidance that many need in order to cope throughout the grieving process.

Registrar Numbers

- Manchester 0161-234-5555
- Liverpool 0151-236-3004

Coroner's Numbers

- Manchester 0161-830-4222
- Liverpool 0151-225-5770

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hen a child dies it is a very sad and distressing time. It can be very bewildering facing what you have to do and the decisions you have to make.

This booklet (produced in collaboration between NWTs and the bereavement services at both Royal Manchester Children's Hospital and Alder Hey Children's Hospital) is designed to provide a guide on what has to be done during the first few days following your child's death.

The loss of a child is a devastating experience and can be hard to cope with and accept. No-one will be able to tell you how you should feel as everyone, even within a family, acts and feels differently. It is not just one feeling, but a whole succession of feelings, which takes time to get through and which should not be hurried.

Doctors, Nurses, Chaplains and Bereavement Care Services wish to do all they can at this difficult time by offering whatever practical help and support you might need. You will find contact details for some of these at the back of this booklet.

Immediately after Death

You and your family will be able to spend time with your child, if you wish to do so.

When you feel ready to leave the hospital your child will be taken to the bereavement suite.

Capturing Memories

At the time of their child's death, some parents want to avoid anything that reminds them of their child because it is so painful. However, almost all parents are grateful to have mementos of their child.

Mementos, such as foot and hand prints, photographs, and perhaps a lock of hair (taken with your permission) provide a tangible acknowledgement of your child's life – however short – and may help provide a focus for your grief.

May I see my Child Again?

You may come and spend time with your child while they are at the hospital.

Your child's body will be kept cool, so when you visit them in the Bereavement Suite they may feel very cold.

If your child has died unexpectedly you may need to be accompanied by a representative from the Coroner's Office. This may be a Coroner's Liaison Officer or a Police Officer.

If you would like to spend some time with your child, please telephone the Ward and a nurse will arrange a time with you.

Roadpeace

☆ www.roadpeace.org

☎ 0845-4500355

National charity for road crash victims and families. Members include those who have been bereaved or injured in road crashes.

The Lullaby Trust (Sudden Infant Death Syndrome)

☆ www.lullabytrust.org.uk/

☎ 0808-8026868

Specially trained advisors / bereaved parents offering support to parents and families whose child has died quickly or unexpectedly.

The Youth Bereavement Service (CRUSE)

☆ www.rd4u.org.uk

☎ 0808 808 1677

☆ www.crusecare.org.uk

☎ 0844 477 9400

A website and helpline for children and young people aged between 12 and 18 years who have been bereaved.

Compassionate Friends

🌐 www.tcf.org.uk

☎ 0845-123-2304

Charitable organisation of bereaved parents, siblings and grandparents dedicated to the care of others who are bereaved. Offer support directly to the bereaved families and indirectly by providing training to improve understanding and good practice amongst professionals concerned with the death of a child.

CRY

🌐 www.c-r-y.org.uk

☎ 01737-363222

CRY offers support to those who have lost a young person, through a network of bereaved families and counselling.

National Meningitis Trust

🌐 www.meningitis-trust.org/

☎ 0808-80-10-388 - 24 hours

Offer emotional, practical and financial support to help families whose child has died following meningitis/meningococcal disease.

Taking Your Child Home

One way in which some families choose to say goodbye to their child who has died is to have their child at home for a time before the funeral. In most circumstances this should be possible, even when a post-mortem examination has been performed.

You can only take your child home immediately after death if the Medical Certificate of Cause of Death has been issued.

If your child's death is reported to the Coroner you will not be able to take them home until the Coroner gives you permission.

If your child died of an infectious disease then it may not be possible to take them home.

If you wish to take your child home yourself, you will need:

1. A letter signed by a hospital Consultant or senior doctor which states where your child died and that the hospital is aware that you are taking your child home.
2. The Medical Certificate of Cause of Death.
3. The Cremation Form (if required)

How do I take my Child Home from Hospital

Deciding how to take your child home can depend on how you feel and if you are able to drive - or perhaps you could ask a relative or friend to drive for you.

Parents of small children may wish to wrap them in a blanket and carry them to the car and travel with them. Taking older children in the car may be more difficult for you to do on your own and you may wish to ask for help with this from your Funeral Director.

The Medical Certificate of Cause of Death

The Medical Certificate of Cause of Death (MCCD) will be signed by a hospital doctor who has cared for your child and states the cause of death. The certificate will be explained to you and then put into a special envelope for you to take to the Registrar of Births Deaths and Marriages.

If it is not possible to give you the MCCD before you leave the hospital, you will be told when and where to collect it.

If your child's death has been referred to the Coroner, an MCCD cannot be issued by the hospital team .

The medical team at the hospital where your child has died will contact your GP and Health Visitor and inform them of your child's death.

A meeting to answer any questions or concerns you may have following your child's death can be arranged with your child's local paediatric consultant and/or the Paediatric Intensive Care Consultant from the NWTs team who was present at your child's death.

Registering the Death

Your child's death needs to be registered within 5 days at the Register Office nearest the hospital where your child died. This can be done by any close member of your family as long as they have all the relevant information and documents; unless the Coroner is investigating the circumstances, in which case there may be some delay.

National Support Groups

Child Death Helpline

✦ www.childdeathhelpline.org.uk
☎ 0800-282986 or 0808-800-6019 from a mobile

A Freephone service for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances however recently or long ago.

Child Bereavement Charity

✦ www.childbereavement.org.uk
☎ 01494-568900

Supports families when a child dies and can offer help and support to a child if they are bereaved by directing families to national and local services.

Child Bereavement Network

✦ www.childhoodbereavementnetwork.org
☎ 0207-8436309

Provides access to information, guidance and support services for bereaved children and young people, their families and carers.

Local Teams Providing Help and Support

Bereavement Care Services

Alder Hey -	0151 252 5117		
Office Hours	-	Mon – Thurs	9 am – 5.00 pm
		Friday	9 am – 4.30 pm

Family Support Centre

Manchester	-	0161 701 8700	
Office Hours	-	Mon – Fri	9 am – 4.30 pm

Alder Centre

Tel:	-	0151 252 5391	
Office Hours	-	Mon – Thurs	9 am – 5.00 pm
	-	Friday	9 am – 4.30 pm

The Alder Centre is run by a small group of health professionals in partnership with bereaved parents offering counselling, support groups and volunteer befriending.

Sometimes a baby can die before a birth has been registered. The birth and death can be registered at the same time.

If your child has been referred to the Coroner, the Coroner's Office will inform the Registrar.

What you need to Register the Death

1. The Medical Certificate of Cause of Death (given to you by hospital doctor on the ward)
2. Child's full name, home address
3. Date and place of birth
4. Parents' full names, home address, and occupations
5. Child's Medical Card (if available)

The Bereavement Team or local spiritual Chaplaincy Team will be able to assist you if needed.

What the Registrar will Give You

The Registrar will give you:

1. A Death Certificate
2. A **Green** form. This is a Certificate of Burial or Cremation and needs to be given to the Funeral Director who is arranging your child's funeral.
3. A **White** form (BD8). You will need to either take or send this to the Department of Social Security when you return any allowance books eg Child Benefit.

Extra copies of the Death Certificate may be purchased from the Registrar .

The Coroner

Coroners are independent, legally trained officers who are legally required to investigate deaths reported to them by doctors. In certain situations, where doctors are unsure about the cause of a child's death, they have to discuss it with a Coroner who will decide if further investigation (which may involve a Post Mortem examination) is needed. If the Coroner orders a Post Mortem, consent from the family will not be asked for. The Coroner aims to establish the medical cause of death; if the cause of death remains in doubt after a Post Mortem, a Coroner's Inquest will be held.

At a Coroner's Inquest, all the information about how a child died will be presented to the Coroner, and he/she and the parents are able to question doctors and nurses about the circumstances. The Coroner will then decide what the cause of death is and issue a Death Certificate.

Reasons the Coroner may request a Post Mortem are:

1. Your child dies very suddenly, unexpectedly or within 24 hours of hospital admission.
2. Death has occurred in unusual circumstances.
3. Doctors are unsure of the cause of death.
4. Your child has recently undergone surgery.

If you child's death has been referred to the Coroner, then a medical Death Certificate will not be issued. If an Inquest is not needed, the Coroner will inform the Registrar (of Births, Deaths and

Useful Contacts

Local Contacts:

Bereavement Team

Name

☎ ?

✉ ?

Spiritual Team

Name

☎ ?

✉ ?

Chaplaincy

Name

☎ ?

✉ ?

The Gift of Organ Donation

Facing the tragedy of a child's death is monumental, but many families have gained comfort through the gift of organ donation, which can give hope to others. This can be a difficult issue to think about, but a number of families have appreciated being given the opportunity to consider this option.

Organ donation will only be considered when death either has occurred (donation after brainstem death—two independent doctors will have carried out tests to confirm brain stem death), or when death is inevitable (donation after circulatory death—doctors will have made the decision to withdraw all life sustaining treatment). When death has been established a Specialist Nurse in Organ Donation can discuss organ donation with you.

Organs will not be taken without discussion with the relatives, even when the person carried a donor card. The decision will always rest with the family.

Following transplant operations, information about the people who receive the organs can be made available to the donor's family. Several families have said that this has been a great comfort and help to them.

The option of donation after death extends beyond organ donation. Tissue such as corneas, skin, bone and heart valves can be donated within a short time after death.

Marriages); the death can be registered and a medical Death Certificate will be issued.

If an Inquest is to take place, the Coroner will normally issue a Burial Order or Cremation Certificate after the Post Mortem has been completed if no concerns are raised.

Following an Inquest, the Coroner will issue a Death Certificate and your Child's death can be registered. If charges are brought against somebody for causing the death of your child, funeral arrangements will be delayed.

Post-Mortem Examination

What is a Post Mortem

A Post Mortem (also known as an Autopsy) is an examination of the body after death. It is carried out by a Consultant Pathologist—a doctor who specialises in identifying the cause of death.

There are three ways in which a Post Mortem may be requested:

1. A Hospital Post Mortem

The consultant who has cared for your child may ask you for permission to carry out a Post Mortem to help them and you understand more about your child's illness or the reason they died. Some parents request a Post Mortem. With this type of Post Mortem you will be asked to sign a consent form.

A doctor will talk to you and explain what will happen. You can agree and give your consent to a full Post Mortem, or a partial

Post Mortem, where the Pathologist will only examine the part of the body you have agreed to.

If you do not wish your child to have a Post Mortem you can refuse. You have 24 hours after giving consent to change your mind.

A Medical Death Certificate can be issued before the results of a Hospital Post Mortem are available.

The full results of a Hospital Post Mortem will be discussed with you by the consultant involved in your child's care.

2. A Coroner's Post Mortem

If your child has died suddenly or as a result of an accident, by law the Coroner must be informed by the doctor looking after your child. The Coroner will then decide if a Post Mortem is required. He has the legal power to make the decision and your permission is not required. The doctor will explain why this is needed.

If a Coroner's Post Mortem is required a Death Certificate will not be issued before you leave the hospital. You will be issued with one later by the Coroner.

If your child's death has been referred to the Coroner, the Funeral Director will be able to talk to the Coroner's Office on your behalf if you wish.

3. Home Office Post Mortem

If your child's death has been referred for a Home Office Post Mortem, the Coroner will advise you when you will be able to

Who you need to Inform

If you feel it is too difficult for you to inform people, maybe you could ask a relative or a friend to do it for you.

- If your child was at school you will need to let school know.
- You will need to inform the Dentist (to avoid check-up appointments being received).
- Child Benefits Office
- Usually the hospital will inform your GP

Grandparents, Other Relatives and Friends

Grandparents, and other family and friends are often a very special part of a child's life.

When a child dies grandparents can feel an immense sadness and grief. They are grieving for their grandchild, and seeing the pain and sadness their child is going through. Grandparents can feel powerless because they cannot make the hurt and sadness better.

Grandparents often want to help you. They may be able to help with arrangements or they may be able to care for other children while you go and make arrangements. Aunts, uncles and cousins who have been close will also feel very sad, and may feel they need and want to help you.

Other People's Reactions

People react differently to grief. Some may be able to talk to you about your child and try to understand. Others might find it very hard and may avoid you altogether because they feel they might say the wrong thing. Friendships may sometimes change too for the same reason.

make arrangements for the funeral. The funeral may be delayed by several weeks in this case.

It can be very difficult for you to contemplate the thought of a Post Mortem examination on your child. Parents usually find it helpful to know as much as possible about why their child has died. A Post Mortem examination may provide families with that valuable information.

Post Mortems take place in a mortuary and are carried out by a pathologist who is a doctor with specialist training.

Many parents worry about what will happen to their child at Post Mortem, and whether they will be able to see their child again. There is no reason why you cannot see your child after Post Mortem, and if dressed, the incisions made on your child's body and head will not be visible.

Your child's face, hands and feet will not usually be affected by the examination. The Post Mortem examination will be carried out as soon as possible after consent has been given, usually within 72 hours, and is conducted with respect and dignity. A child may be taken to another hospital so the examination can be carried out by a specialist children's pathologist.

Results are usually available within 2-3 months, and reports are written in detailed medical terms and may be difficult to understand. A meeting can be arranged with one of the consultants (senior doctors) involved in your child's care or your family GP to discuss the Post Mortem results with you

and to help you to understand the results. You will also have an opportunity to ask questions.

A Post Mortem may help to find the cause of death, but it may still leave some questions unanswered and it does not always find a definitive cause of death. It can rule out certain diseases and conditions and provide families and the staff who care for them with valuable information and knowledge for the future.

Mums and Dads

As bereaved parents you will experience lots of different feelings and emotions, which may be very strong and unusual for you. These are normal and all parents experience them.

Many parents experience feelings of sadness, numbness, shock, disbelief, anger, guilt, frustration, worry, fear, confusion, powerlessness, being lost, loneliness, emptiness, or sometimes a sense of relief. These feelings may get mixed up and some parents feel as if they are going mad.

Some parents feel they need to talk over events time and time again, and find this difficult as other people seem to be getting on with their lives again.

Partners can grieve very differently and it can be difficult when one parent wants to talk about their feelings and the other parent is not able to express how they feel. Talking to a friend or relative can be helpful, or you may want to talk to somebody in confidence.

Brothers and Sisters

Brothers and sisters are also grieving and will be very sad. It will depend on the age of your other children and their understanding, but it is best to be honest with them and to answer their questions as much as you can.

You may feel you want to protect them from the overwhelming sense of grief and sadness after the death of their brother or sister, but they will miss them too, and it will help them now and when they are older if they are involved and know what is happening.

The Headstone

If you would like a headstone on your child's grave you will need to contact a stone mason. It is usually at least 6 months after the funeral before a headstone can be erected, as the ground has to settle. A headstone usually takes 10-12 weeks to complete; a stone mason will discuss the choices you have regarding the headstone and the inscription you would like on it.

The cost of the headstone will vary depending on the stone you choose. Some stone masons will let you pay in instalments. You will not be able to claim this money back even if you are in receipt of benefits, but there are some charities that may be able to help.

The Funeral

It is possible to make the funeral arrangements yourself, though most parents usually ask a Funeral Director.

Arranging a funeral for their child is something for which few parents are prepared. Although this can be painful and distressing, it is an important step in the process of saying goodbye to a child who has died.

It can be helpful to take a few days to decide what is right for you as a family. You can choose to have a burial or cremation, a religious or non-religious service, in a Church, at the graveside, in your home, or anywhere appropriate of your choice. There is no requirement for a religious minister to be involved. When a child dies in hospital, the hospital can help or make the arrangements for you if you feel unable to do this yourself (please see contact information later in this leaflet). Usually, though, parents who have had time to think will choose to arrange the cremation or burial themselves.

Not only are you likely to be feeling shocked and numb following the death of your child, but also you may be unaware of what is possible of the choices that are open to you. The Bereavement or Spiritual/Chaplaincy team at your local hospital or Bereavement Care Services at Alder Hey or Family Support Centre at Royal Manchester Children's Hospital will be able to help. Funeral Directors, should you appoint them, can also help you make these arrangements.

If there are other children in the family, it can help them if they are included in discussions about the funeral. Perhaps they might like to contribute a favourite song or poem or reading. Children feel more

involved if they are offered the chance to attend the funeral or a special goodbye. It can help to talk to them about what happens at a funeral. Parents have found it a good idea to ask another adult who is close to the children to help support them if they do choose to come to the funeral.

The funeral is the family's opportunity to say their last goodbye to their child, and as such it is important that families are able to do things in whatever way feels appropriate to them, to their customs, culture and beliefs.

A Funeral Director

Parents often choose to contact a Funeral Director quite soon after their child has died. This is because the Funeral Director will be able to give help and advice with all the practical and legal requirements. It may be helpful to ask a friend or relative to phone several Funeral Directors in your area to ask what they provide and get an estimated cost.

There is no set cost for a funeral, and the cost may vary. Many Funeral Directors charge a very nominal amount for a child's funeral. The cost may increase if you ask for anything special. The fees that have to be paid are cemetery and crematorium fees.

If you are on certain benefits, then you may be able to claim some of the cost back. The Funeral Director or your local Benefits Office will be able to give you a Claim Form (SF200).

Arranging a Funeral

It usually takes about a week for the funeral to be arranged. You need to think about what type of funeral you want for your child (burial or cremation). You may want to talk to family and friends for suggestions before making definite arrangements.

You may like to change your child into their favourite clothes, eg a football strip, or special dress.

You can put something that was special to your child in the coffin. This may be a toy, a poster, a book—anything that you know would be special to your child. You may like to ask family and friends if they would like to write a letter, a poem or draw a picture with a special message from them. (If you have decided to have your child cremated you will not be able to put glass or metal into the coffin.)

You may be unsure where you want to scatter your child's ashes.

There is no rush or legal requirement to scatter your child's ashes. If you would like to, you can keep the ashes in a safe place at home until you make a decision.

Some parents wish their child to be flown home to another Country. If this is your choice your Funeral Director will talk to the airport authorities and advise you how to do this. In this case the doctor who provides the Medical Certificate will also complete a 'Free from Infection Diseases' form to confirm that your child may be taken out of the Country.