

Practical Support and Guidance for Bereaved Families

Our Message to you

The loss of your child is possibly one of the worst things that can happen to you. No-one will be able to tell you exactly how it feels, as everyone acts and feels differently. There is no right or wrong way to grieve. Experience of grief involves a range of feelings: numbness, disbelief, anger, guilt, sadness, emptiness, relief and denial. Many feelings may be so mixed up that you wonder if you are going mad or will ever be able to enjoy life again. This is a perfectly normal reaction to the range of emotions involved.

Please don't feel that you have to face this grief alone. Our care for you continues even after your child has left the hospital and for as long as you need our support.

Here at Alder Hey our staff wish to do all they can at this difficult time, by offering whatever practical help and support you might need. You will find appropriate contact details for some of them at the back of this booklet.

This booklet has been prepared with the assistance of parents and those with experience of bereavement within the Trust. We hope you find it helpful in deciding what is best for you and your family. Because of the sensitive issues addressed in this booklet, you may wish to consider reading on with the support of a relative, friend or religious contact, or with a member of staff at Alder Hey.

Immediately after your child dies

When your child has died, our staff want to help you to do whatever is right for you and your family.

Bereavement Care Services are here to offer continued support for as long as you need with practical and emotional guidance. With your consent we can visit you on the ward following your child's death to guide you through the initial stages.

This is an important time for you as decisions that are made now can have an effect for a long time. You may face some difficult choices, for instance whether to have a cremation or a burial. It may be hard to know what to do for the best.

You will be able to spend time with your child and help wash and dress him/her if you wish to do so and also arrange for photographs, hand and foot prints and other mementoes to be taken if you would like these.

While your child stays at the hospital you and members of your family and friends, with your permission, will be able to visit. Bereavement Care Services can arrange visits with you.

We will try to make sure that you have as much time as you wish to spend with your child, to cuddle, to hold and begin to say goodbye. You can of course bring your child's own clothes and favourite things such as a toy or a teddy if you wish.

Bereavement Care Services are available and can be contacted to provide advice and support. Just ask any member of staff.

If you decide to take your child home, separate advice is available from Bereavement Care Services or a funeral director.

Support

During this time you will need the support of others. Don't be afraid to speak about your feelings to someone. Your family and friends, though they may find it difficult, are ready and able to help - a list of support groups and agencies are also at the back of this booklet.

Our Bereavement Care Team and the Spiritual Care Team are available to give any help, advice or support needed.

When you feel ready to leave the hospital your child could be taken to the mortuary. If there is not a post-mortem or infectious disease you may take your child home. Alternatively, your child can be taken to the chapel of rest at the funeral directors you have chosen.

The hospital has its own bereavement suites. You may return to visit your child by making arrangements with Bereavement Care Services. Some notice will be needed to allow for arrangements to be made.

Families often find they would like a short blessing or ceremony for their child regardless of religion, within the hospital. If you wish to have contact with a representative of your religious faith at this time, a member of staff can contact a member of the Spiritual Care Team. Contact can also be made with your own family or community religious leader.

The need for a post-mortem

A post-mortem is carried out to help understand why your child has died. It is done with the same care that would be used if your child had an operation. It includes an examination of the body and internal organs. The body is carefully restored after the post-mortem so that you and your family can hold and cuddle your child.

You can say yes or no to a hospital post-mortem except when the Coroner has asked for one. The reasons a Coroner would ask for a post mortem are as follows:

- Your child dies very suddenly or unexpectedly
- The death has occurred in unusual circumstances
- The doctors are not able to give a cause of death
- Your child has undergone surgery.

Obtaining a medical certificate of death

A hospital doctor who has cared for your child will issue a medical certificate stating the cause of death as soon as possible. There may be some delay if your child's death has been referred to the Coroner. If this happens the Coroner will issue the paperwork enabling the funeral to go ahead. Following the inquest the Coroner will issue the death certificate.

Registering the death

The death must be registered at the Register Office in the registration district where it occurred. The Register Office for Liverpool is

Liverpool Register Office,
St George's Hall,
St George's Place, Liverpool, L1 1JJ.

To ensure that there is no unnecessary waiting time there is an on-line appointments system for registering deaths at www.liverpool.gov.uk/registeradeath. For general enquiries contact Liverpool Direct on 0151 233 3004.

It is also possible to make a declaration to register a death before any Registrar in England and Wales. This will be posted to the Register Office for the district where your child's death occurred. If you choose to do this there may be a delay in making the funeral arrangements and in receiving some documents.

The death needs to be registered normally within 5 days unless the Coroner is investigating the circumstances relating to the death. This 5 day period may be extended to 14 days in certain circumstances.

The Registrar will ask for some or all of the following:

- Certificate of the cause of death(this is given to you by the hospital).
- Parents' full names, home address, and occupations
- Child's full name, home address, date and place of birth
- Date and place of death (shown on medical cause of death certificate)

The Registrar will give you two forms:

The Green Form must be given to your appointed funeral director who is arranging your child's funeral.

The Certificate of Registration of Death may be needed by the Department of Social Security for official purposes. The Certificate may also be needed if you are asking for help with funeral expenses from the Social Fund.

The registrar does not automatically issue an additional copy of the death certificate. It is possible to buy additional copies at the time or at a later date.

Bereavement Care Services can assist you in the process of registering your Child's Death and accompany you to the registrar's in a taxi if you require.

When the Coroner is involved

If the cause of your child's death is not known, the coroner may ask for a post- mortem examination. Having established a cause of death, the Coroner will then issue a death certificate. Sometimes it is necessary to have an inquest to fully understand the causes.

Once the Coroner has all the information, the necessary forms will be forwarded to the Register Office. This process can take several days. Either you or a close relative may then register the death.

Arranging the Funeral

The following points may help you decide what arrangements you would like to make for your child. There is no hurry to make arrangements unless there are specific religious or cultural reasons.

Your child's funeral is a very personal occasion so don't be rushed into making any important decisions about the service. You should not be afraid to ask for any special requests which may be helpful to you and your family, or ask for explanations of anything you do not understand fully.

There are different forms of service, both religious and non-religious, which can be arranged by most funeral directors. You may want to ask family, friends, a local minister or priest for suggestions.

Our Spiritual Care Team have conducted funerals for many parents and their experience and advice are available. There may be music played (perhaps a theme tune from the television or your child's favourite song) or a reading you would like to have that holds a special meaning for you and your family.

If you have other children it is important to involve them in discussing the arrangements. They have their own confusion and grief to bear, they may wish to be present at the funeral, to see their brother or sister, to put a small favourite toy in the coffin or send a posy of flowers.

It can be surprising how a child, thought to be too young to realise what is happening, has a contribution to make when given the opportunity.

When the coroner is involved your funeral director will assist you in provisionally planning your child's funeral but nothing further can be done without the Coroner's consent until your child has been released back to you.

Paying for the funeral

Funeral costs vary and you may wish to telephone several different funeral directors to compare the services they provide.

Some funeral directors provide their own services free of charge for a child's funeral and this can help reduce the total costs. Please ask your funeral director about this.

Families on certain qualifying benefits may be able to apply for help towards the costs of the funeral from the Social Fund. The qualifying benefits are:

- Income support
- Income - based Jobseekers Allowance
- Income -related Employment and Support Allowance
- Pension Credit
- Housing Benefit
- Disability or Severe Disability Element of Working Tax Credit
- Child Tax Credit
- Universal Credit

You should complete the Social Fund's Funeral Payment Form SF200. This can be completed over the phone by contacting The National Bereavement Service Helpline on 0800 731 0453 or you can discuss your claim with your funeral director or on-line via direct.gov.uk/funeral_payments.

Please be aware that DSS limit the amount of grant payable and this may not always cover the full cost of the funeral.

If you are not eligible for help and are having difficulties meeting the cost, please seek advice from Bereavement Care Services.

After the Funeral

In our experience, many parents find it useful to return to the hospital after their child's death to talk to the staff who have cared for their child, especially the doctors. Often parents have many questions about their child's illness and death which they would like answering. Sometimes it is possible for this meeting to take place outside the hospital if you would prefer.

You can arrange to do this either by contacting the consultant's secretary directly at the hospital or through Bereavement Care Services.

Child Death Review

All child deaths are routinely reviewed within the hospital and at a local and national level. You will be given an information booklet to explain this process.

Further help for parents and families

We wish to ensure that parents, carers and families are sensitively supported at this most difficult time. We hope that you feel you are being given all the information you require. If you are unsure ask for more time to reflect, take advice and discuss the issues before reaching decisions that are right for you and your family.

Bereavement Support and Counselling

The Alder Centre, based within the hospital grounds, offers support to anyone affected by the death of a child of any age. We offer counselling, group support, sibling support, holistic therapies and befriending. We arrange an annual Remembrance Service and Therapeutic Break. We also run a Child Death Helpline which operates 7 days a week, 52 weeks of the year. Our trained Helpliners - all of whom are bereaved parents - are there to offer listening support. Freephones 0800 282 986 or 0808 800 6019

Child Benefit or Child Tax Credit

Your child benefit payments may carry on for a short while after your child has died, usually for up to 8 weeks. This could help with some of the extra costs that you may face at this difficult time.

However, if you do not tell the Child Benefit Office that your child has died, payments will continue after the 8 weeks, which could be very distressing as you would have to pay this back.

What you need to do:

You will need to tell the Child Benefit Office as soon as possible if your child or a child you have been responsible for has died.

The Child Benefit Office will record this information and also pass it on to other Departments within HM Revenue & Customs (HMRC) that need to know such as Child Tax Credit.

That way you will only have to contact HMRC once, but do check that this is possible and that they are able to do this for you.

If necessary the number for Tax Credit Helpline is **0345300 3900**

You can contact HMRC in the following ways:

To inform them by telephone:

You will need to ring Child Benefit Helpline on **0300 200 3100**.

This is open from:

Monday – Friday 8am – 8pm

Saturday 8am - 4pm

Sunday 9am – 5pm

Local government numbers

Coroner's office 0151 225 5770

Register Office 0151 233 3004

Telephone numbers for support organisations, groups & websites

Child Death Helpline 0808 800 6019 and 0800 282 986

Monday, Thursday, Friday: 10.00am - 1.00pm

Tuesday and Wednesday: 10.00am - 4.00pm

Every evening: 7.00pm - 10.00pm

CHICS (Children's Cancer Support) 0151 523 8886

Child Bereavement Charity 01494 446 648

www.childbereavement.org.uk

CLIC SARGENT

(For children and young people with cancer)

0151 252 5199

www.clicsargent.org.uk

Compassion Friends National helpline 03451 232 304

Every day: 10.00am - 4.00pm

Every evening: 7.00pm - 10.00pm

CRUSE Bereavement Care 0808 808 1677

Monday- Friday: 9.30am - 5.00pm

Saturday: 3.00pm - 5.00pm

Sunday: 3.00pm - 7.00pm

Liverpool Bereavement Service 0151 236 3932

Lullaby Trust 0808 802 6868

Monday- Friday: 10.00am - 17.00am

Saturday & Sunday: 6.00pm - 11.00pm

Meningitis Now Helpline 0800 028 1828

Support Number 0808 801 0388

Road Peace 0845 4500 355
(National Charity for Road Traffic Victims)

SANDS (Still Birth and Neonatal Death Society) 0808 164 3332

Monday, Wed, Friday: 9.30am - 5.30pm

Tue & Thurs 9.30 am-9.30pm

SOBS
(Survivors of Bereavement by Suicide)

0300 111 5065

The Samaritans
www.samaritans.org

08457 116 123

Turn2us
(to access benefits and grants)
www.turn2us.org.uk

0808 802 2000

Winston's Wish
www.winstonswish.org.uk

0808 802 0021

This information can be made available in other languages and formats if requested.

Alder Hey Children's NHS Foundation Trust
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Eaton Road
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Tel: 0151 228 4811
www.alderhey.nhs.uk