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 of numbness, disbelief, anger, guilt, sadness, emptiness, relief and denial. Many feelings may be so mixed up that 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 loved one 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 that 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 as long as you may need with practical, emotional guidance. With your consent we can visit you on the ward following your child’s death to guide through the initial stages. Please ask a member of medical/nursing team to contact us.

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 agree to a hospital post mortem or 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. Contact Bereavement Care Services if you wish to do this and arrangements can be made.

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 wish this.

If you decide to take your child home, separate advice is available from hospital staff Bereavement Care Services or the 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 doctors, nurses, Bereavement Care Services 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 mortuary is situated in the hospital grounds and has its own bereavement suite. 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. This body is carefully restored after the post-mortem so that you and your family can hold and cuddle.

You can say yes or no to a 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 unaware of the 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 appointments system for registering deaths. You should telephone Liverpool Direct at any time to make an appointment on 0151 233 3004. Bereavement Care Services can assist you with making an appointment, transport and support you at the Register Office if you require. Appointments will be offered at the Register Office during normal opening hours of:

Monday to Friday 09.00am - 4.45pm

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 the death took place. 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 five days unless the Coroner is investigating the circumstances relating to the death. This five 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 doctor on the ward).
- Parent’s full names, home address, and occupations.
- Child’s full name, home address, date and place of birth.
- Date and place of death (shown on death certificate).
The Registrar will give you two forms.

**The Green Form** must be given to the funeral director who is arranging funeral.

**The White Form**, which is the Certificate of Registration of Death, must be sent or taken to the Department of Social Security, along with any allowance books. The White Form is also 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, but you may buy a copy for a small charge, or obtain one at a later date. This can be useful as some agencies request an original. There is also a small charge for the original issue.

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.

Bereavement Care Services will continue to 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 special religious or cultural reasons.

The funeral is 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 made available by most funeral directors. You may want to ask family, friends, a local minister or priest for suggestions. Our Spiritual Care Team has conducted funerals for many parents and their experience and advice is 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 sisters, 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.

**Paying for the funeral**

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

Some funeral directors provide their own service 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
- Housing Benefit
- Council Tax Benefit
- Tax Credits
- Disability Working Allowance

You should complete DSS form 200 and discuss your claim with your funeral director and someone from your local Social Security office. 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 hospital Bereavement Care Services.**

**After the Funeral**

In our experience, many parents find it useful to return to the hospital after the child’s death to talk to the staff who have helped to care for the 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 Bereavement Care Services.

As part of good medical practice all deaths in our children’s hospital are routinely reviewed at a departmental and hospital level.
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 and have asked for. If you are unsure, ask for more time to reflect, take advice and discuss the issues before reaching the decision that is 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. This can be offered within the hospital, the community or at home and will depend on your individual needs and choices. We offer counselling, group support, sibling support and befriending. We also have a Child Death Helpline which operates seven days a week, 52 weeks of the year. Our trained Helpliners - all of whom are bereaved parents are there to offer support.

Useful hospital telephone numbers

Alder Hey

Alder Hey Children’s NHS Foundation Trust
Liverpool
L12 2AP
Website: www.alderhey.nhs.uk

Bereavement Care Services

Monday – Friday 9.00am - 5.00pm
or 24 hours via main switchboard
0151 252 5117
0151 228 4811

Spiritual Care Team
0151 252 5465

Alder Centre
(Bereavement Counselling) Monday- Friday 9.00am - 5.00pm
0151 252 5391

PALS (Patient Advice Liaison Service)
24 Hour Answerphone
0151 252 5161
0151 252 5161

Local government numbers

Coroner's office
0151 233 4713/4

Register Office
24 Hours
0151 233 3004
## Telephone numbers for support organisations, groups, and websites

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Death Helpline</strong></td>
<td>0808 800 6019 and 0800 282 986</td>
</tr>
<tr>
<td>Monday, Thursday, Friday: 10.00am - 1.00pm</td>
<td>Tuesday and Wednesday: 10.00am - 4.00pm</td>
</tr>
<tr>
<td>Every evening: 7.00pm - 10.00pm</td>
<td></td>
</tr>
</tbody>
</table>

| **Compassion Friends** | 08451 232 304 |
| National helpline | Every day: 10.00am - 4.00pm |
| Every evening: 7.00pm - 10.00pm | |

| **CRUSE Bereavement Care** | 0844 477 9400 |
| Monday - Friday: 9.30am - 5.00pm | Saturday: 3.00pm - 5.00pm |
| Sunday: 3.00pm - 7.00pm | |

| **Child Bereavement Charity** | 01494 446 648 |
| Website: [www.childbereavementuk.org/](http://www.childbereavementuk.org/) | |

| **FSID (Foundation for the study of infant Deaths)** | 0207 233 2090 |
| Monday- Friday: 9.00am - 11.00am | Saturday & Sunday: 6.00pm - 11.00pm |

| **SANDS (Still Birth and Neonatal Death Society)** | 0207 436 5881 |
| Monday- Friday: 10.00am - 4.30pm | |

| **Winston’s Wish** | 0845 2030 405 |
| Website: [www.winstonswish.org.uk/](http://www.winstonswish.org.uk/) | |

| **The Samaritans** | 08457 909090 | |
| **Liverpool Bereavement Service** | 0151 236 3932 | |
| **Young person’s Freephone helpline** | 0808 808 1677 | |
| **CHICS (Children’s Cancer Support)** | 0151 523 8886 | |
| **National Meningitis Trust (24 Hours)** | 0800 028 1828 | |
| **Road Peace** | 0845 4500 355 | (National Charity for Road Traffic Victims) |
| **SOBS** | 0844 5616 855 | (Survivors of Bereavement by Suicide) |
Please note: Alder Hey Children's NHS Foundation Trust is neither liable for the contents of any external internet site listed, nor does it endorse any commercial product or service mentioned or advised on any of the sites.

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

Alder Hey Children’s NHS Foundation Trust
Liverpool
L12 2AP
0151 228 4811
www.alderhey.nhs.uk

OGB 3/B/1  ©Alder Hey 2016  Date of next review  April 2018  PIAG 021