

When a child dies



Information for families

3rd edition

Great Ormond Street Hospital
for Children NHS Trust

We hope this booklet will help you at this sad and difficult time, particularly with some of the practical and official matters.

When a child dies in hospital

You are welcome to stay with your child as much, or as little, as feels right to you, both before and after he or she dies. If you would like family members to be with you, staff will help to make this possible.

Some parents find it helpful to have a brief ceremony of blessing for their child, even if they are not particularly religious. Please ask your nurse if you would like the chaplain to be called, or for your own faith representative to be contacted.

You will be able to hold your child and to spend as long as you wish together. Staff will be with you but will give you time alone. If you would like to help wash and dress your child, your involvement will be encouraged. Some parents wish to take photographs of their child at this time or have staff members do this. Locks of hair can be taken, and hand and footprints. If you prefer, these mementoes can be kept safely for you in the hospital in case you want them at a later time.

Organ and tissue donation

If you have decided to donate your child's organs to help others, the donor transplant co-ordinator will visit you to discuss this further. You can decide whether to donate tissue, like corneas or heart valves, after your child has died, as this can be carried out in a simple process in the hospital mortuary.

Taking your child home

If there is no requirement for a post-mortem your child does not have to go to the mortuary, but can be taken home, to your local Children's Hospice if available, or to a Chapel of Rest (such as at a Funeral Director's) or other place of your choice. Transport can be arranged by your chosen funeral director or you may wish to consider the option of transporting your child yourself. If you would like to discuss this possibility, please do so with ward staff or a member of the End of Life Care service 020 7813 8551/8550/8416.

The mortuary

If your child is to remain with us temporarily, a nurse will take your child to the mortuary when you are ready to leave. You can visit, bring family and spend time with your son or daughter in one of the mortuary's viewing rooms as often as you wish. You will be given a map that indicates the location of the mortuary, which has its own parking bay for you to use. When you wish to visit, it will be necessary for you to telephone the nurse-in-charge on the ward first, so that arrangements can be made. If you would like any religious symbols to be displayed, please tell the nurse-in-charge when you call.

Media

Occasionally, there may be media interest in a child's death, which may be confusing to deal with at such a difficult time. The hospital Press Office can help maintain your privacy and act as 'go between' with the media. Ward staff can contact the Press Office for you if you would like their advice.

Registration

You may start making arrangements for the funeral but the death has to be registered before it is possible to complete these. It is a legal requirement for a death to be registered within **five** days. In most circumstances this is straightforward and the basic details are given below. In special situations, additional procedures are involved and these are explained later.

Where?

A person's death should be registered in the district where he or she died. For Great Ormond Street Hospital, this is the London Borough of Camden. It is possible to register a death at the office local to your home address. However, processing the relevant paperwork may cause delay in making arrangements for the funeral.

It is usual to go to Camden Town Hall, which is about ten minutes' walk or a short taxi ride from the hospital (see map). The address is:

Camden Register Office

Camden Town Hall
Judd Street
Euston Road
London WC1H 9JE

Tel: 020 7974 1900
or 020 7974 2027
or 020 7974 2068

Minicom: 020 7974 6064

When?

The Register Office is open Monday to Friday from 9.30am to 4pm

Saturday from 9.00am to 10.00am
for same day burial *only*

It is closed on the first Thursday of each month after 1pm.

You will need to phone to make an appointment.

Unfortunately, it is not possible in this district to have a death registered on a Sunday or Bank Holiday unless, for religious reasons, a child must be buried on that same day. In this case the number to ring is 020 7278 4444, and the hours are 9am to 11am.



Who?

Although it is usual for a parent to register a child's death, it is sometimes possible for a relative or friend to act on your behalf after discussion with the Registrar.

What you will need

To register the death you will need the following information:

- Medical Certificate of the Cause of Death – this is given to you by the hospital and is written by the doctor who was looking after your child.
- The child's full name, home address, and the date and place of birth.
- The parents' full names, home addresses and occupations.

What the Registrar will give you

- **A certificate for burial or cremation.** This is what you need to give the funeral director before the final arrangements can be made. An additional certificate is needed if you are planning to have your child cremated. The funeral director will arrange to get this from the doctor.
- **Form BD8 (revised) - Notification of the Registry of Death.** You will need this form if applying to the Benefits Agency for a funeral grant (see under Cost).

The registration and issue of these two forms is free. A certified copy of the death certificate is also available for a small charge. This is essential if arranging a funeral abroad or if your child had any savings accounts.

Death of a newborn baby

If a newborn baby whose birth has not been registered dies, it is possible to register both the birth and the death together in Camden, no matter where the baby was born. A birth should be registered within 30 days. If you are married, only one parent needs to go to the office. If you are not married it is essential for the mother to be present, and both parents need to attend if you wish the father's particulars to be recorded. This means that you might prefer to register the death and then wait to register the birth

Special Situations

Reporting the death to the Coroner

In some circumstances doctors cannot immediately issue a death certificate and they are then obliged to inform the Coroner. Usually this occurs because the doctor is uncertain of the cause of death, or the death has occurred very suddenly or soon after an operation. (There are a number of other less common reasons). The Coroner then decides whether it will be necessary to have a post-mortem examination.

Coroner's post-mortem

If a post-mortem is legally required by the Coroner, it will be carried out regardless of the family's wishes. The Coroner's Office will contact the family to tell them when to collect the form from the office. The Coroner then issues a form to be taken to the Registrar authorising the issue of a death certificate. The delay is rarely more than a few days.

The Coroner's Office, adjacent to the Coroner's Court, is in Camley Street, NW1 0PP, near King's

Cross station. Tel: 020 7387 4884.

It is open from 8am to 4pm on weekdays and from 9.30am to 12.00pm on Saturdays.

Hospital post-mortem

The hospital's doctor may ask your permission to perform a post-mortem, not for legal reasons, but to gain more information about your child's illness and to increase medical knowledge for the benefit of other children with a similar condition. If this is the case, the doctor will discuss it with you, explain what is involved and ask you to sign a consent form. It will not involve any delay in giving you the death certificate. The consent form states the nature and extent of the post-mortem examination, and your explicit permission is required for retention of any organ or tissue for any purpose. An explanatory booklet will be given to you which may answer some of your questions

Burial abroad

If you want your child to be buried outside of England or Wales, the funeral director will be able to

help you arrange this. Scotland, Northern Ireland, the Channel Islands and the Isle of Man are counted as 'abroad'. When you register your child's death, you will need to buy at least two of the certified copies of the death certificate (some consulates and embassies require more). You give these to the funeral director who will obtain an 'Out of England Certificate'.

Child Death Overview Panels

Government legislation now requires every local Children's Services Authority to review the circumstances of all child deaths (up to the age of 18 years). This is because the government believes that it may help reduce overall child deaths by enabling a fuller understanding about why children die. Information about each and every child and the circumstances of their death is collected and summarised from records held by ambulance services, hospitals, community health services, schools, police, children's services and other agencies whose staff knew the child.

A Child Death Overview Panel (CDOP) of doctors, other health specialists and child care professionals consider the information to try to ascertain what caused the child's death, what, if any, support and treatment was offered to the child and their family up until the death, and what support was offered to the family after the child died. The CDOP decides whether recommendations and

actions are needed to help prevent child deaths in the future. These are shared, with your child's details anonymised, with local health trusts, public health departments, children's services and the police, as well as specialist agencies such as the fire service or traffic authorities in order to influence and improve services and life chances for children and families. If you want to know more about these processes please ask our End of Life Care Service Manager on 020 7813 8551.

Arranging a funeral

You may already know what has to be done, or be linked to an organisation which will handle things for you. If not, perhaps the following points may help. Unless there are special religious or cultural reasons for holding a funeral quickly, there is no need to hurry and you can take all the time you need to make sure the funeral is arranged in a way that will be meaningful to you.

Choosing a Funeral Director

It is possible to arrange a funeral yourself, or you can ask a funeral director to take care of everything that has to be done. It is a good idea to discuss the type of funeral arrangements you want and then ask a family member or friend to telephone round several funeral directors in your area to ask for an estimate of the cost involved. Many will charge much less for a child's funeral. (See under Cost for other help available).

The funeral director will need the certificate which the Registrar gave you before final arrangements can

be made. If your child is still at the hospital the Funeral Director will contact the mortuary staff and will arrange to bring your child to their Chapel of Rest or to wherever you request. Before collecting your child he or she will need the certificate (or an authorisation form which the ward can give you if you are not registering your child's death yourself).

If you would like your child to remain in your house until the funeral, and you want to consider embalming, your chosen funeral director should be able to arrange this. In warm weather it is advisable to consider using an air conditioning unit to cool the room where your child will be.

Cremation

If your child is to be cremated, there may be a brief service of committal at the crematorium chapel, which can be preceded or followed by a ceremony at your own place of worship, if you have one. You can then return on another day to collect the ashes which will have been placed in a casket. Very occasionally when

a baby is cremated there may be no ashes left. Ask the funeral director to discuss this with the crematorium beforehand. It is your choice what to do with the ashes. They can be buried or scattered at the crematorium, or kept at home.

There will probably be a Book of Remembrance at the crematorium in which your child's name can be inscribed, or you can pay for a plaque in the crematorium garden, perhaps beside a rose bush or a small tree. The charges for this can be quite high and may have to be renewed every few years. It may be possible for the ashes to be buried or scattered in your local churchyard. In some areas of the United Kingdom there are especially dedicated areas of natural beauty or Gardens of Remembrance in which a child's ashes may be scattered or a memorial plaque erected.

Alternatively, you can bury or scatter the ashes in a place which is special for you, in your garden for example. Sometimes families arrange their own memorial service and plant a favourite tree or bush on the spot.

Burial

Many churchyards are now full, but if you would like your child to be buried there, you should approach the minister. Otherwise you can approach any cemetery, costs vary and will probably be less at the cemetery designated for your area. If possible, it is a good idea to visit the cemetery beforehand to choose the area where your child is to be buried.

The cost of buying a plot at the cemetery may be the most expensive part of the funeral. If you choose a private plot, other family members can be buried there later. You will be able to erect a headstone after the earth has settled (in about a year's time). Children's plots are sometimes available, perhaps in a special part of the cemetery.

It is also possible, and costs much less, for your child to be buried in an individual coffin, but in a shared grave. It may not be possible to put up a headstone but some cemeteries allow a small stone to be placed on the grave.

The ceremony

You do not have to hold a funeral ceremony in a set place and could have it in your house or garden if you wish. If you decide to have a religious service, you can choose favourite hymns, readings or alternative music. Forms of service, both religious and non-religious, are possible. Your Funeral Director, the hospital's Chaplain or the End of Life Care service staff at Great Ormond Street Hospital are available to advise you.

Many families wonder about explaining what happens at a funeral to siblings or other children who may attend. The leaflet – 'Children and Funerals' – from the Candle Project (address at the end) may be helpful; and the End of Life Care staff can also discuss this with you.

Cost

Help with the cost of a funeral in the United Kingdom is available from the Social Fund for those who receive certain benefits. You can claim on Form SF200, which is available from the Funeral Director or your social security office. For

more information, please contact the hospital's Social Care Team.

If you are not eligible for a grant from the Social Fund and are having difficulty with the cost of the funeral, please contact the hospital's Social Care Team. It may be possible to obtain a small grant from a charity to help you.

Book of Remembrance

The hospital has a Book of Remembrance in which your child's name can be inscribed. The book is kept in the chapel ante-room and you may see it at any time. The Chaplain will write to ask you if you would like your child's name included. All names are individually inscribed by hand and it usually takes a few months for each child's name to appear in the book. However, you will be informed as soon as your child's name is inscribed.

Memorial service

An annual Memorial Service to remember children who have died at, or who have been connected with, Great Ormond Street Hospital is held every year, on the last Saturday in April, at the Church of St George the Martyr, Queen Square. All parents who have had a child who died are personally invited to the first service after the death. After that there is an open invitation to return annually or less frequently as desired. Details are in the Order of Service and are also available through the chaplaincy and spiritual care department.

Returning to the hospital

Many parents find they have many questions unanswered as they think about the period of their child's illness and death. It can be helpful to come back to the hospital sometime later to talk over these questions. If no one has made a specific arrangement to see you again, do not hesitate to telephone. If you are unsure about whom to contact, please call the End of Life Care service for advice.

Meetings are usually arranged away from the ward, but please ask if you would like to go back to visit staff on the ward.

How you might feel

The death of a child is one of the worst things that can happen to anyone and no one can tell you exactly how you will feel. There is no normal or right way to be and most people experience a whole range of different emotions. Feelings may include disbelief, numbness, anger, sadness, guilt, emptiness and even a sense of relief. These feelings may be so mixed up and powerful that you wonder if you are going mad. You are not, but it may help to talk over the way you feel with someone you trust.

Although you may expect your partner to be a special help at this time, it is common for parents to grieve in different ways and at different rates and you may find it hard to help each other. You may both have to acknowledge this and allow each other space, while

finding support in your own ways. Hopefully you may have family and friends who will be there to listen. You may have to make the first move by letting friends know you want their company and that they have not 'upset' you if you cry. You may like to contact one of the addresses at the end of this booklet if you are not sure where to turn for support.

If you have other children

Parents are often afraid to talk with children for fear of upsetting them, but this leaves them alone with their fears and fantasies, which are often much worse than the reality. It is most helpful if you can be honest with your other children and include them as much as possible, according to their age. Many children want an opportunity to see their brother or sister and say goodbye, and also to be involved in the funeral. Don't be afraid to show your feelings to your children and to grieve together.

If you would like help with these issues, either now or later, please

contact the End of Life Care staff to talk things over. There are also a number of helpful books for children of all ages - several websites give suggestions or you could ask at your local library or bookshop.

Finding help

If you return to the hospital, it is important to discuss how you are coping as a family and whether you would like any extra help. Some parents find it helpful to meet others whose child has died and have found help locally from groups run by Compassionate Friends or SANDS (addresses at end).

You may wish to contact one of the specialist organisations run by or offering contact with other bereaved parents.

Child Death Helpline

The Child Death Helpline is a nationally available freephone helpline for anyone affected by the death of a child of any age under any circumstances. Calls are heard in confidence and the helpline is staffed by volunteer parents who have experienced the death of their own child. The helpline can provide the opportunity for you to talk to someone sympathetic to your situation.

The helpline is open every evening, throughout the year, from 7pm to 10pm and also Monday, Thursday and Friday from 10am to 1pm and Tuesday and Wednesday from 10am until 4pm.

The number is:
Freephone 0800 282986.

Useful addresses

Great Ormond Street Hospital for Children NHS Trust

Great Ormond Street
London WC1N 3JH
Switchboard: 020 7405 9200
Website: www.childrenfirst.nhs.uk

BLISS

Support for parents of babies in Special or Intensive Care Units and for bereaved parents.

68 South Lambeth Road
London SW8 1RL
Helpline: 0500 618140
Website: www.bliss.org.uk

Candle Project

Support and advice for bereaved children and their families in South-East London.

St Christopher's Hospice
51-59 Lawrie Park Road
Sydenham
London SE26 6DZ
Tel: 020 8768 4586
Website: www.st-christophers.org.uk

Child Death Helpline

Freephone 0800 282986
York House
37 Queens Square
London WC1N 3BH
Website: www.childdeathhelpline.org.uk

The Child Bereavement Charity

Aston House High Street
West Wycombe
High Wycombe
Buckinghamshire HP14 3AG
01494 446648
Website: www.childbereavement.org.uk

Childhood Bereavement Network

8 Wakeley Street
London EC1V 7QE
Tel: 020 7843 6309
Website: www.childhoodbereavementnetwork.org.uk

Compassionate Friends

For parents who have had a child of any age die; local self help groups offer mutual support. Helpful literature available.

53 North Street
Bristol BS3 1EN
Tel: 0117 953 9639
Website: www.tcf.org.uk

Cruse Bereavement Care

Offers support to all bereaved people. Local branches throughout the UK.

126 Sheen Road
Richmond
Surrey TW9 1UR
Helpline: 0870 167 1677
Website: www.crusebereavementcare.org.uk

Foundation for the Study of Infant Deaths (FSID)

Cot death research and support.

Artillery House
11-19 Artillery Row
London SW1P 1RT
24 hour helpline: 020 7233 2090
Website: www.sids.org.uk

Heartline Association

For parents of children with heart disease – includes a bereavement group.

Community Link
Surrey Heath House
Knoll Road
Camberley GU15 3HH
Tel: 01276 707636
Website: www.heartline.org.uk

Stillbirth and Neonatal Death Society (SANDS)

Provides support for bereaved parents when their baby dies at or soon after birth.

28 Portland Place
London W1B 1LY
Helpline: 020 7436 5881 (10am - 3pm Mon - Fri)
Website: www.uk-sands.org

Winston's Wish

Telephone help and advice, especially for bereaved children and siblings.

The Clara Burgess Centre
Gloucestershire Royal Hospital
Great Western Road
Gloucester GL1 3NN
Family Line: 0845 503045
Website: www.winstonswish.org.uk

Notes

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Ref: 2008F0587

Initially compiled by the Terminal Care Group in collaboration with the Child and Family Information Group, with assistance from volunteers from the Child Death Helpline.

Revised by the End of Life Care Group with input from bereaved parents.

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www.goshfamilies.nhs.uk www.childrenfirst.nhs.uk