

When a child dies



Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

We hope this booklet from Great Ormond Street Hospital (GOSH) will help you at this sad and difficult time, particularly with some of the practical and official matters.

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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 they die. 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 some time 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 we can arrange a remembrance photographer do this. Locks of hair can be taken, as well as 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 Specialist Nurse for Organ Donation 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 another 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 Bereavement Service at GOSH.

The mortuary

If your child is to remain with us temporarily, a nurse will take them to the mortuary when you are ready to leave. You can visit, bring family and spend time with your son or daughter in the mortuary's bedroom. We would advise you to plan around an hour for viewing your child. You will be given a map that indicates the location of the mortuary, which has its own parking bay for you to use if taking your child from the hospital to home

When you wish to visit, you should 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. Our 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.

Where?

A person's death should be registered in the district where they died – for GOSH, 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, Judd Street, London WC1H 9JE. This is about ten minutes' walk or a short taxi ride from the hospital (see map).



When?

The Register Office is open Monday to Friday from 9.30am to 3:30pm Saturday from 9.00am to 12:00pm 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. To make an appointment, please telephone 020 7974 4444. You can also book online if you prefer at www.camden.gov.uk/ccm/content/community-and-living/lifetime-events/lifetime-events--registrar-service/deaths/registering-a-death.

If you attend without an appointment it may be more distressing for you as the office also has birth and marriage registrations taking place.

A Sunday and Bank Holiday on-call service available is available from 9am to 12 noon only for same-day issuing of a Certificate for Burial or Cremation (green certificate) if, for religious reasons, a child must be buried on that same day.

Who?

Ideally, a parent should go to the Register Office to register their child's death – many parents have said that they find this a helpful experience. You are welcome to take a friend or relative with you to support you during the registration process.

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.
- Money for additional death certificates – these cost £4 each at time of registration and the fee increases after that so it may be worth buying a few copies, particularly if the child had bank accounts that need to be closed or will be buried abroad, for instance.
- Medical Card (if available)
- Whether the child will be buried or cremated

What the Registrar will give you

- A certificate for burial or cremation (known as the green certificate). This is what you need to give the Funeral Director before the final arrangements can be made for the burial or cremation. If an additional form is needed, the Funeral Director will arrange to get this from the doctor at GOSH.

- 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.

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 42 days.

If you are married, only one parent needs to go to the office. If you are a married same sex couple, the birth mother needs to be present, and the other parent(s) needs to attend if they want their details to be registered. 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 in the birth entry. However, either parent can register the death.

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 they have issued the post-mortem form. There are a number of other forms that can be issued by the Coroner, we will explain them to you if this is the case. When you have the post-mortem form(s), this is the point at which you are able to make an appointment to register the death. You will need to collect the form from the Coroner's Office on Camley Street. To arrange collection, call them on 020 7387 4884 or 4882 between 8am and 1pm then 2pm and 4pm on weekdays.

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. We have produced a leaflet explaining post-mortem examinations – please ask for a copy if you are not given one.

A hospital post-mortem 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.

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, Republic of 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 recommendations and actions are shared, with your child's details anonymised, with local hospitals, 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 Bereavement Service Manager.

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).

Transferring your child

The Funeral Director will need the Certificate for Burial or Cremation (green 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, the Funeral Director will need the green certificate mentioned above or a copy of the death certificate, as well as an authorisation form called a Transfer Of Care form. This should be given to you with any other relevant documents when you are on the ward. This form gives your permission for the Funeral Directors to collect your child.

If you are unable to register the death and are therefore unable to collect the green certificate but would like your child collected sooner, the Transfer Of Care form must be given to the Funeral Directors who will liaise with the mortuary team to make arrangements. There are a number of other legal documents that may need to be arranged before your child can be transferred. Do not worry about these the Funeral Directors and mortuary team will make the necessary arrangements to meet your needs as quickly and professionally as possible. If you would like your child to remain in your house until the funeral, 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.

Embalming before burial

You may want your child to be embalmed before burial, especially if there is likely to be a delay before the funeral takes place or you are transporting your child abroad. Embalming is a process that preserves the human body with specific chemicals. Discuss this with your Funeral Director if you want to explore this option.

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 GOSH Chaplains or Bereavement Service staff at GOSH 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 (available online at

www.stchristophers.org.uk/leaflet/candle-children-and-funerals) may be helpful; and Bereavement Service staff can also discuss this with you.

Funeral costs

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 Work 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 Work Team. It may be possible to obtain a small grant from a charity to help you.

Remembering your child

There are many options for commemorating your child, some at GOSH and others that are more personal. The Bereavement Service has put together a list of possible organisations that can help so please ask us for a copy.

Book of Remembrance

GOSH has a Book of Remembrance in which your child's name can be inscribed. The book is kept in the chapel foyer 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, GOSH is held every year on the last Saturday in April, at the Church of St George the Martyr in 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 Bereavement 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 Bereavement Service 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 also 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 0800 282 986 from a landline or 0808 800 6019 from a mobile phone – all calls are free.

Useful numbers at GOSH

Switchboard – 020 7405 9200

Bereavement Service – 020 7813 8551 or 020 7813 8550 or 020 7813 8416.

You can also visit our website at www.gosh.nhs.uk/parents-and-visitors/clinical-support-services/bereavement-services

Chaplaincy and Spiritual Care Department – 020 7813 8232

Patient Advice and Liaison Service (Pals) – 020 7829 7862

Social Work Department – 020 7829 8896

Other sources of support

BLISS offers support for parents of babies in Special or Intensive Care Units and for bereaved parents. Telephone their helpline on 0500 618 140 – open Monday to Friday from 9am to 5pm – or visit their website at www.bliss.org.uk

The Candle Project is based at St Christopher's Hospice and offers support and advice for bereaved children and their families in South-East London. Call them on 0200 8768 4586 or visit their website at www.st-christophers.org.uk

The Child Bereavement Charity supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement. Call their helpline on 0800 02 888 40 – open Monday to Friday from 9am to 5pm – or visit their website at www.childbereavementuk.org

The Compassionate Friends is an organisation for parents who have had a child of any age die – they run local self-help groups which offer mutual support and publish helpful literature. Call their helpline on 0345 123 2304 – open every day from 10am to 4pm and 7pm to 10pm – or visit their website at www.tcf.org.uk

Cruse Bereavement Care offers support to all bereaved people and has

local branches throughout the UK. Call their helpline on 0844 477 9400 or visit their website at www.cruse.org.uk/

The Lullaby Trust (formerly FSID) provides specialist support for anyone after the sudden death of an infant. Call their helpline on 0808 802 6868 or visit their website at www.lullabytrust.org.uk

Little Hearts Matter offer support to anyone affected by single ventricle heart disease. Call their bereavement support line on 0121 455 8982 – open between 4pm and 10pm every night and at weekends – or visit their website at www.lhm.org.uk

Stillbirth and Neonatal Death Society (SANDS) provide support for bereaved parents when their baby dies at or soon after birth. Call their helpline on 020 7436 5881 – open Monday to Friday from 10am to 3pm – or visit their website at www.uk-sands.org

Winston's Wish offers telephone help and advice for bereaved children and siblings. Call their family line on 0845 503 045 or visit their website at www.winstonswish.org.uk

The Jewish Bereavement Counselling Service is dedicated to bereavement counselling for everyone in the Jewish Community. Call them on 020 8951 3881 or visit their website at www.jbcs.org.uk/

Children of Jannah is an organisation supporting Muslim parents providing practical, emotional and spiritual support. Call their Support and Information Line on 0161 480 5156 – open from Wednesday to Friday from 10am to 4pm. In addition, they offer bereavement support for mothers on Wednesday and Thursday between 10am and 1pm and fathers on Thursday between 6pm and 8pm. Visit their website at www.childrenofjannah.com

Information about funeral directors

The Institute of Civil Funerals trains, regulates and provides details of civil funeral celebrants. Call them on 01480 861 411 or visit their website at www.iocf.org.uk

The National Association of Funeral Directors (NAFD) is the largest professional association of funeral directors with a Code of Practice and Arbitration Scheme. Call them on 0845 230 1343 or visit their website at www.nafd.org.uk

The British Humanist Association can provide information and officiants for non-religious funerals. Call them on 020 7324 3060 or visit their website www.humanism.org.uk

The Natural Death Centre provides information on 'green' funerals and arranging a funeral yourself. Call them on 01962 712690 or visit their website at www.naturaldeath.org.uk

Funeral Map provides independent information on arranging a funeral. Call them on 0845 004 8608 or visit their website at www.funeralmap.co.uk

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Ref: 2015F0587

Initially compiled in 2003 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 Bereavement Services department with input from bereaved parents, the End of Life Care Group and Camden Register Office in June 2015.

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