

# *What Happens When My Child Dies?*



There are not adequate words to express what we would like to say to you at this time, following the death of your child. We are so sorry that you have to face and endure this experience.

The loss of a child places you and your family on a journey you never planned or wanted to be on. There are no short cuts or a quick way to make things feel better. There is also no right or wrong way to manage what you are going through. But please remember that you are not alone as you go on this journey. Please use the support you have wherever it is most helpful – from family, friends, community, health services and charities. We are also available to answer any questions that you have. Our contact details are below.

This booklet has information about the arrangements that are made following a child's death. We hope will be helpful to you and the people around you. Sometimes practical arrangements help people to navigate the early days after the loss of their child. For others it is more than they can think about. If this is the case please don't feel you have to immediately start making arrangements. Ask others to help when you can.

We will be thinking of you at this time, and over the coming weeks and months.

The Paediatric Bereavement Team

This booklet contains information about what needs to be done after the death of your child and offers sources of help and support. This includes

- Registering the death of your child
- Visiting the viewing suite
- Funeral arrangements
- Counselling and further support
- Useful websites or numbers
- Support groups

Take one day at a time – please do not feel you are under pressure to start making arrangements immediately. Spend time with people who are helpful to be around. Ask them to help with arrangements if you need to.

Please do contact the ward if you are concerned about anything. There will always be someone to talk to you 24 hours a day.

We have allocated you a key worker, so that they can be your first point of contact should you need to speak to someone. If they are unavailable, someone else will always make time to speak to you.

Your Key Worker is: \_\_\_\_\_

Their Telephone number: \_\_\_\_\_

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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 a faith representative to be contacted.

You will be able to hold your child and spend some time together, either with a member of staff present or, if you wish, alone with family. If you would like to help wash and dress your child, your involvement is very much encouraged. Some parents wish to take photographs of their child at this time and we can arrange a remembrance photographer to do this. Memory boxes are available, with the supplies to take hand and footprints and locks of hair, as well as somewhere to keep mementoes safe.

There is no right or wrong way to grieve. The staff are here to make this difficult time as smooth as possible for you and your family, and will try and facilitate your wishes.

## **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, such as corneas and heart valves, after your child has

died. Donating tissue is a simple process that can be carried out 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 a location of your choice or to your local Children's Hospice if available. Transport can be arranged by your chosen Funeral Director or you may wish to consider the option of transporting your child yourself. You will need a form from the hospital to transport your child yourself, so please speak to a member of staff or the Family Liaison Nurse if you wish to discuss this.

### **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 and bring family to see your child in the mortuary's viewing room. We would advise you to plan around an hour for viewing your child.

When you wish to visit, you should first telephone the Family Liaison Nurse so that arrangements can be made. If you would like any religious symbols to be displayed, please mention this when you call.

Some people find it very difficult to attend the mortuary. Others do not want to see their child in the mortuary and would prefer to remember them before they died. You do not have to visit the mortuary. You can make decisions which are right for you and your family.

**Unfortunately at the moment, due to Coronavirus, there are no viewings at the mortuary.**

### **Registration**

You may start making arrangements for the funeral, but the death has to be registered before it is possible to hold the funeral. **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 St George's Hospital, this is the London Borough of Wandsworth. It is possible to register the death at the office local to your home address, although processing the relevant paperwork may cause a delay in making arrangements for the funeral.

It is usual to go to Wandsworth Town Hall, Wandsworth High Street, London, SW18 2PU.

During the Coronavirus pandemic, there is no requirement for the family to attend the Town Hall, as the certificate of Cause of Death will be scanned directly to the Registrar at Town Hall, and the Funeral Directors will receive their certificate for burial or cremation electronically.

### **When?**

Currently telephone appointments are available Monday to Friday, between 9am and 4.30pm. There is an on-call service available on Saturdays, Sundays and Bank Holidays between



9am and 11am, for funerals that need to take place within 24 hours. To make an appointment, you will need to go online <https://www.wandsworth.gov.uk/births-death-and-ceremonies/deaths/register-a-death/> and the Registrar will call you at your scheduled appointment time.

### **Who?**

Ideally, a parent should register their child's death; many parents find this a helpful experience. You are welcome to have a friend or relative with you for support 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 will be sent directly to the Registrar by the hospital
- 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 £11 per certificate and 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
- Whether the child will be buried or cremated

### **What the Registrar will give you**

The Registrar now electronically sends a certificate for burial or cremation (known as the 'green certificate') to the Funeral Directors. This is what the Funeral Director needs before the final arrangements can be made.

You will be given a BD8 (revised) form – the Notification of the Registry of Death. You will need this form if applying to the Benefits Agency for a funeral grant.

### **Death of a newborn baby**

If a newborn baby who has not yet been registered dies, it is possible to register both the birth and death together in Wandsworth, 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 details to be recorded in the birth entry. 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 happens because the doctor is

uncertain of the cause of death, or the death has occurred very suddenly or soon after an operation. 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, which will be explained to you if this is the case. When you have the post-mortem form(s), then you will be able to make an appointment to register the death. You will need to collect the form from the Coroner's Office. To arrange collection, call the Coroner to make an appointment. If the Coroner is going to open an inquest and do a full report, you will be told along with the results of the post-mortem. Even if there is to be an inquest, you will still get your child's body back after the post-mortem as the report can take a number of months to complete.

### **Hospital post-mortem**

The hospital's doctor may ask your permission to perform a post-mortem. This is 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. 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 consent 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 embassies require more). The Funeral Director will need these to 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 age 18). This is because the government believes that it may help to reduce the overall numbers of child deaths by enabling a fuller understand about why children die.

Information about each 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 considers 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 the recommendations and actions are needed to help prevent child deaths in the future.

Your child's details are anonymised before sharing recommendations and actions with local hospitals, public health departments, children's services and the police. These actions/recommendations are also shared with 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 the Family Liaison Nurse.

### **Arranging a funeral**

You may already know what has to be done or be linked with an organisation which will handle things for you. If not, the following points may be helpful. 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.

### **Transferring your child**

The Funeral Director will need the Certificate for Burial or Cremation (the 'green certificate'), which the Registrar gave you, before the final arrangements can be made. If your child is still at the hospital, the Funeral Director will contact the mortuary staff and arrange to bring your child to their Chapel of Rest (or wherever you request). Before collecting your child, the Funeral Director will need the 'green certificate' or a copy of the death certificate, as well as an authorisation form called a Transfer of Care form. This will be in your pack, given to you by 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. There may be a number of other legal documents to arrange before transfer, but the mortuary and Funeral Directors will resolve these and meet your needs as quickly 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 up to you what you do with the ashes. They can be buried or scattered at the crematorium or kept at home. There will likely 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 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 ashes in a place which is special for you, in your own 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 if you are transporting your child abroad. Embalming is a process that preserves the human body with specific chemicals. Please 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 Chaplaincy and Spiritual Care department or Family Liaison Nurse at St George's 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 or the website <https://www.winstonswish.org/attending-the-funeral/> may be helpful. Leaflets are available from the Family Liaison Nurse.

## **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.

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 Family Liaison Nurse or the ward on which your child was a patient. It may be possible to obtain a small grant from a charity to help you. There are a number of charities which do provide this service.

## **Remembering your child**

There are many options for commemorating your child. Some of these are through the hospital and some that are more personal. The memory boxes are supplied by charities and can be a safe place for you to keep sentimental things. There are also siblings boxes for which you can be referred, please just ask the Family Liaison Nurse about this.

## **Memorial service**

St George's holds an annual Memorial Service to remember children who have died at or who have been connected with this hospital. 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. You will receive a letter approximately six weeks after your child's death, asking if you would like to speak to a consultant about your child's medical history and cause of death. 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 Family Liaison Nurse.

## **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. However, it may help to talk over the way you feel with someone you trust.

You may expect your partner to be a special help at this time, but 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.

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 organisations 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 Family Liaison Nurse for a referral to support services such as paediatric psychology. This service can work with siblings and support you in discussing death with children. There are also a number of helpful books for children of all ages.

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

### **Mental health**

Please be gentle with yourself during this time. It is important that you are remembering to eat and drink regularly, as well as making sure you are managing your personal care. There may be a shift in your mental health and this may take you by surprise. There is no right or wrong way to feel following a loss. There are many different factors that affect grief and how we deal with it, including the support we have around us and our previous experience of grief. You may notice changes in appetite, sleep disturbances and

physical health problems, as well as mood swings and episodes of rage. You may decide to discuss your grief with your GP and get support via your local NHS services. You may choose to use one of the many charity helplines or services available for bereavement support, listed in this booklet.

**Mind** has a useful website ([www.mind.org.uk](http://www.mind.org.uk)) where you can access information about mental health and bereavement. They list some of the self-help resources and online communities that may also help you through this difficult period.

### **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 St George's Hospital**

**Switchboard** - 020 8672 1255

**Chaplaincy and Spiritual Care Department** - 020 8725 3285

**Patient Advice and Liaison Service (PALS)** – 020 8725 2453

### **Other sources of support**

**BLISS** offers support for parents of babies in Special or Intensive Care Units and for bereaved parents. Visit their website at [www.bliss.org.uk](http://www.bliss.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](http://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](http://www.tcf.org.uk)

**Cruse Bereavement Care** offers support to all bereaved people and has local branches throughout the UK. Call their helpline on 0808 808 1677 or visit their website at [www.cruse.org.uk](http://www.cruse.org.uk)

**The Lullaby Trust** 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](http://www.lullabytrust.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 0808 164 3332 – open Monday to Friday from 10am to 3pm – or visit their website at <https://www.sands.org.uk/>

**Winston’s Wish** offers telephone help and advice for bereaved children and siblings. Call their helpline on 0808 802 0021 or visit their website at [www.winstonswish.org.uk](http://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](http://www.jbcs.org.uk)

**The Muslim Bereavement Support Service** is dedicated to supporting bereaved women in the Muslim Community. Call them on 020 3468 7333 or visit their website at [www.mbss.org.uk](http://www.mbss.org.uk)

**Sudden** is an organisation supporting suddenly bereaved people by providing access to information, advice and guidance. They also help suddenly bereaved people to access specialist care and support after their bereavement. Call the helpline on 0800 121 6510 – Monday to Friday 10am to 3pm – or visit their website at [www.suddendeath.org](http://www.suddendeath.org)

## **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](http://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 0121 711 1343 or visit their website at [www.nafd.org.uk](http://www.nafd.org.uk)

**The British Humanist Association** can provide information and officiants for non-religious funeral. Call them on 020 7324 3060 or visit their website at [www.humanism.org.uk](http://www.humanism.org.uk)

**Funeral Map** provides independent information on arranging a funeral. Call them on 0330 223 0279 or visit their website at [www.funeralmap.co.uk](http://www.funeralmap.co.uk)



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