



A lifetime of specialist care

Royal Brompton & Harefield   
NHS Foundation Trust

Royal Brompton Hospital

# Information for families following the death of a child



April 2019



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*This leaflet is about the bereavement and support services available to families whose child has died while they were a patient of Royal Brompton Hospital.*

## Introduction

Please accept our sincere condolences for your loss. The death of a child is one of the worst things that can happen to anyone.

No one will be able to tell you exactly how it feels, as everyone acts and feels differently. The experience of grief involves feelings such as numbness, disbelief, anger, guilt, sadness, emptiness and denial. You may wonder if you will ever be able to enjoy, or even bear, life again. Please be reassured that although this is terrible to go through, this is a normal reaction to the death of a child or family member.

You don't have to face grief alone. Staff at Royal Brompton will do all they can at this difficult time by offering practical help and support.

This booklet has been prepared with the help of families and those with experience of bereavement. 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 want the support of a relative, friend or a member of hospital staff before reading on.

## Spending time with your loved one

This is an important time for you as you may be faced with some difficult choices and be involved in some difficult conversations too.

At the time of your child's death, we will ensure that you and your family are well cared for. We will 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 will be able to help to wash and dress him/her if you wish. You can bring your child's own clothes and favourite things.



Hand/foot prints and other mementoes can be taken if you wish. We have a memory box available which can include these different mementoes.

When you are ready, your child will be taken to the mortuary. The mortuary is in the hospital and has a viewing room.

After your child has died and until the funeral director has been appointed, your child will remain at the hospital.

You can return to visit your child by making arrangements with the ward or the Patient Advice and Liaison Service (PALS). Their contact details are at the back of this booklet. You will need to tell us in advance about when you are planning to come in to visit. We will advise how long you can visit for.

It may be possible to take your child home. Please discuss this with PALS and/or the nursing/medical team.

## Support and spiritual care

Our doctors, nurses and chaplaincy teams will give you help and support. You will receive a letter explaining how our clinical psychology team can help you explore bereavement counselling for you or family members (including children), either near your home or here at Royal Brompton Hospital.

Some families find they would like a short blessing or ceremony for their child within the hospital. You can talk to the nursing team about this. A member of staff can contact the chaplaincy team or another preferred representative of your religious faith if you wish.

## Obtaining a medical certificate of cause of death

One of the doctors who has cared for your child will issue a medical certificate stating the cause of death as soon as possible. This means you can then register the death (see page 5).

## Post mortems

A post mortem may be necessary to help understand more about your child's illness or why your child has died. It is done with the same care that would be used if your child has an operation.

A hospital post mortem cannot be carried out without your signed consent. However, if a coroner requests a post mortem, it cannot be refused.

A coroner will ask for a post mortem if:

- the child dies very suddenly or unexpectedly
- the death occurred in unusual circumstances
- the doctors cannot determine the cause of death
- the child has undergone recent surgery.

We have information booklets on post mortems if you think that you would find further information helpful.


## Registering the death

Your child's death must be registered within five days unless a coroner is investigating the circumstances relating to the death.

To avoid delay, the death can be registered at the register office in the district where it occurred. It may be possible to register the death elsewhere, if necessary.

The register office for Royal Brompton Hospital is:

Kensington and Chelsea Register Office  
Chelsea Old Town Hall  
King's Road  
Chelsea  
London  
SW3 5EE



To avoid waiting times, you are advised to book an appointment with the register office. You can usually get same day or next day appointments. Please visit [www.rbkc.gov.uk](http://www.rbkc.gov.uk) and select 'Births, deaths, marriages and citizenship', or call **020 7361 4100** to arrange an appointment.

There is a small charge for the death certificate. You may wish to buy more than one copy of the death certificate in order to have original copies available for any agencies/departments which may need to see this.

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

- medical certificate of the cause of death (given to you by the hospital)
- parents' full names, home addresses and occupations
- child's full name, home address, and date and place of birth
- date and place of death (as shown on the medical certificate of the cause of death).

The registrar will give you two forms:

- Green Form (Certificate of Burial or Cremation). You should give this to the funeral director
- White Form (Certificate of Registration of Death). You will need this form if you are asking for help with funeral expenses (see page 7).

## Planning a funeral

A funeral is a very personal occasion and you should not be afraid to ask for any special requests.

The funeral director will ask for the Green Form, which the registrar gave you. This will allow the funeral director to collect your child from the hospital and take them to their chapel of rest.

If you have other children, it is important to involve them in discussing funeral arrangements, if appropriate. They have their own grief to bear and they may wish to be present at the funeral. If you need further information about supporting children at this very difficult time, please contact the children's clinical psychology team (contact details can be found on page 12) or visit [childbereavementuk.org](http://childbereavementuk.org).

## Paying for the funeral

Funeral costs vary and you may wish to contact more than one funeral director to compare the service they provide and the costs.

Some funeral directors can provide some services free of charge for a child's funeral. Please ask your funeral director about this.

Families on certain qualifying benefits may be able to apply for help towards the costs of a funeral from the government's Social Fund. Qualifying benefits include:

- Income support
- Income based jobseekers allowance
- Housing benefit
- Council tax benefit
- Tax credits
- Disability working allowance.

You should complete the 'Social Funds Form SF200'. Your funeral director may be able to give you this form. Otherwise, contact the National Bereavement Service Helpline on **0800 731 0469** or go to [www.gov.uk/funeralpayments](http://www.gov.uk/funeralpayments).



## After the funeral

One of the doctors who treated your child will offer a bereavement meeting approximately six weeks after the death. Details will be sent to you in the post.

This meeting, if you choose to attend, will allow you time to ask any questions you have. You will also have time to discuss the cause of the death and events around the time of death. These meetings can be very helpful and often families have questions. This meeting is followed up by a letter. This can be a very difficult read. You may want to wait a while until you read it, or have a trusted person to read it with you.

If your child was cared for in the paediatric intensive care unit (PICU) and died there, you will find the PICU consultant's details at the end of the discharge summary (this may be sent home with you on the day your child died, or sent afterwards). You can telephone the consultant and we can arrange a meeting if you have any questions.

## Bereavement support and counselling

Counselling and/or talking therapy can help some families. There is a list of resources and organisations that could help you at the end of this booklet.

However, searching through available resources can prove overwhelming for bereaved families. All parents of a child who has died while they were a Royal Brompton patient are contacted by a member of the paediatric clinical psychology team. They can help explore the bereavement counselling options available, either here at Royal Brompton or in your local area.

## Benefit payments

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



However, if you do not tell the child benefit office that your child has died, payments will continue. You will have to pay this back, which would be very distressing, so please inform them as soon as possible on **0300 200 3100**.

If your baby has died shortly after birth, there is information about specific benefits and entitlements at: [www.moneyadvice.service.org.uk/en/articles/if-your-baby-has-died-shortly-after-birth](http://www.moneyadvice.service.org.uk/en/articles/if-your-baby-has-died-shortly-after-birth).

## Reviews of deaths in our care

Hospital patient case note reviews are carried out in different circumstances.

Firstly, case note reviews are routinely carried out by NHS trusts on a proportion of all inpatient deaths to learn, develop and improve healthcare, as well as when a problem in care may be suspected.


A clinician (usually a doctor), who was not directly involved in the care of your child, will look carefully at their hospital case notes. They will look at each aspect of their care and how well it was provided. If a routine case note review finds any issues with care, we will contact you to discuss this further.

Case note reviews are also carried when a significant concern is raised with us about the care we provided to a patient.

We consider a 'significant concern' to mean:

- (a) any concerns raised by the family that cannot be answered at the time; or
- (b) anything that is not answered to the family's satisfaction or which does not reassure them.

This may happen when a death is sudden, unexpected, untoward or accidental. When a significant concern has been raised, we will undertake a case note review for your child and share our findings with you.



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In a small percentage of cases, there may be concerns that the death could be, or is related to, a patient safety incident. A patient safety incident is any unintended or unexpected incident, which could have, or did, lead to harm. Where there is a concern that a patient safety incident may have contributed to a patient's death, a safety investigation is undertaken.

The purpose of a safety investigation is to find out what happened and why. This is to identify if there are lessons to learn and to reduce the risk of something similar happening to other patients in the future.

If an investigation is to be held, we will contact you, explain the process to you and ask if you wish to be involved.

## **Providing feedback, raising concerns and/or making a complaint**

### **Providing feedback**

We want to hear your thoughts about your child's care. Receiving feedback from families helps us to understand the things we are doing right and need to continue and the things we need to improve upon.

### **Raising concerns**

It is very important to us that you feel able to ask any questions or raise any concerns regarding the care your child has received. In the first instance, the team that cared for your child should be able to respond to these. After this, your named consultant at Royal Brompton Hospital is the best person to answer your questions and concerns.

However, if you would prefer to speak to someone who was not directly involved in your child's care, our Patient Advice Liaison Service (PALS) will be able to help. Contact details can be found at the back of this booklet.

## **Making a complaint**

We hope that we will be able to respond to any questions or concerns that you have. Additionally, you can raise concerns as a complaint, at any point. If you do this we will ensure that we respond, in an accessible format (followed by a response in writing where appropriate), to the issues you have raised.

If you are not happy with the response to a complaint, you have the right to refer the case to the Parliamentary and Health Service Ombudsman. The document below sets out what you should expect from the complaints process:

[www.ombudsman.org.uk/publications/my-expectations-raising-concerns-and-complaints](http://www.ombudsman.org.uk/publications/my-expectations-raising-concerns-and-complaints).

## **Independent information, advice and advocacy**

If you raise any concerns regarding the treatment of your child, we will provide you with information and support, and do our best to answer the questions you have.

However, we understand that it can be very helpful for you to have independent advice. We have included details below of where you can find independent specialist advice to support an investigation into your concerns. These organisations can also help ensure that medical or legal terms are explained to you.

POhWER

[www.pohwer.net](http://www.pohwer.net)

VoiceAbility

[www.nhscomplaintsadvocacy.org](http://www.nhscomplaintsadvocacy.org)  
0300 330 5454

Action against Medical Accidents

[www.avma.org.uk](http://www.avma.org.uk)  
0845 123 2352



## Contact numbers at Royal Brompton Hospital

Bereavement team	0330 128 8121 (ext 82268)
Chaplaincy support	0330 128 8121 (ext 88060)
Paediatric clinical psychology team	0330 128 8121 (ext 88251)
PALS (Patient Advice and Liaison Service)	020 7349 7715

## Charities

### BLISS

Support for bereaved parents of babies who had been in intensive care **020 7378 1122**

### Children of Jannah

Organisation supporting Muslim families **childrenofjannah.com**

### Child Bereavement UK

Support for children and teenagers who have lost someone **0800 028 8840**

### Child Death Helpline

Helpline run by parents who have experienced loss **0800 282 986 / 0808 800 6019**

### CRUSE Bereavement Care

Support for bereaved people **0844 477 9400**

### Mushkil Aasaan

Bereavement support for Asian families (multiple languages spoken) **020 8672 6581**

### Muslim Bereavement Support Service

Bereavement support for the Muslim community **020 3468 7333**

### SANDS (Still Birth and Neonatal Death Society)

Support for anyone experiencing the death of a new-born **020 7436 5881**

## **The Compassionate Friends**

Providing support and friendship to bereaved families

**0345 123 2304**

## **Turn2us**

Help with benefits and grants

**0808 802 2000**

## **Winstons Wish**

Help for grieving children and their families

**0845 2030 405**

## **Online resources/literature**

### **Child Bereavement Network**

Local and national support and guidance for bereaved children and young people. Guidance for those caring for bereaved children

[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

### **Child Bereavement UK**

Resources for parents, siblings and extended family. Local support groups signposted

[childbereavementuk.org/for-families](http://childbereavementuk.org/for-families)

### **CRUSE Bereavement Care**

Helping children to deal with death. Practical and emotional support

[www.cruse.org.uk/children/how-to-help](http://www.cruse.org.uk/children/how-to-help)

### **The Compassionate Friends**

Support for bereaved families after the death of a child

[www.tcf.org.uk](http://www.tcf.org.uk)

### **Winstons Wish**

Helpful and practical publications and resources for families

[www.winstonswish.org/supporting-you/publications-resources](http://www.winstonswish.org/supporting-you/publications-resources)



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## Note

This guide is written in line with **NHS England's Learning from deaths: Guidance for NHS trusts on working with bereaved families and carers** (July 2018).

### **With special thanks to The Brompton Fountain for help in the production of this leaflet**

The Brompton Fountain provides vital support and resources, medical equipment and services which are not normally supplied by the NHS. It works closely with the hospital teams within the paediatric intensive care unit (PICU) and children's wards. It fundraises to improve the quality of care for our young patients and their families and make a real difference when it's needed most.

[www.thebromptonfountain.org.uk](http://www.thebromptonfountain.org.uk)

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If you have any concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call Patient Advice and Liaison Service (PALS):

- Royal Brompton Hospital – 020 7349 7715
- Harefield Hospital – 01895 826 572

Alternatively email [pals@rbht.nhs.uk](mailto:pals@rbht.nhs.uk). This is a confidential service.



Royal Brompton Hospital  
Sydney Street  
London  
SW3 6NP  
tel: 0330 12 88121

Harefield Hospital  
Hill End Road  
Harefield  
Middlesex  
UB9 6JH  
tel: 0330 12 88121

Website: [www.rbht.nhs.uk](http://www.rbht.nhs.uk)

إذا كنت ترغب في الحصول على ترجمة فورية لمضمون هذه الوثيقة إلى اللغة العربية، يرجى منك الاتصال بأحد مستخدمينا بجناح المصلحة التي يتم فيها استشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosurteki bilginin Türkçe tercumesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercümenin gerçekleşmesini en kısa zamanda ayarlayacaktır.

