



Royal Berkshire
NHS Foundation Trust



Bereavement Support

Information and guidance to
help you following the loss
of your child

Useful contact details:

Bereavement Office

Tel: 0118 322 8066 Option 1

Email: rbft.bereavementoffice@nhs.net

Opening hours: Monday to Friday 9am-4pm (by appointment only - excluding weekends and bank holidays)

Medical Examiners Service

Tel: 0118 322 8066 Option 2

Email: rbft.medexaminers@nhs.net

**Opening hours: Monday to Friday 9am – 5pm
(excluding weekends and bank holidays)**

The Mortuary Team

Tel: 0118 322 7743

Email: rbft.mortuaryrbh@nhs.net

Opening hours: Monday to Friday 9am-4pm (excluding weekends and bank holidays)

Switchboard

Tel: 0118 322 5111

Patient Advice and Liaison Service (PALS)

Tel: 0118 322 8338

Email: PALS@royalberkshire.nhs.uk

Opening hours: Monday to Friday 9am-4pm (excluding weekends and bank holidays)

This guide is for the parents and carers who have lost a child under the age of 18. We know this can be a difficult time and it can affect us in many different ways. This booklet will help you to understand what happens now, and the support that is available to you. Not all of this information will be relevant for you, but it might be helpful to keep and read again at a later time.

Where “parents and carers” are mentioned, this includes the main carers of the child who may not be the biological parents, such as carers, same sex partners and any other guardians.

Our condolences

Firstly, I would like to offer my sincere condolences to you and your family at this difficult time.

This booklet aims to help and guide you with the formalities of dealing with your loss.

If there is anything you would like to discuss please contact the Bereavement Team who will be happy to offer you support and assistance.

Chief Executive

A handwritten signature in black ink, appearing to read 'S McManus', with a horizontal line underneath.

Steve McManus

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1. What happens next?

The death of a child is the most difficult thing any family can go through. 'Child death review' is a term used to describe the formal processes that happen after a child dies. There are some elements that will need to take place after every child death, and some that may not be needed, depending on the circumstances.

Your child will be transferred into the care of the hospital mortuary while the first reviews take place and arrangements have been made for your child to be transferred to your chosen facility.

We will give you a named point of contact who will act as your **key worker** throughout the review of your child's death. This is a person who can provide information and signpost you for further advice or support.

This key worker will usually be a nurse or member of a bereavement support team from the hospital. You may already have a key worker if your child had a long-term condition.

Your key worker should act as a reliable and accessible point of contact who will assist with co-ordinating meetings, clearly communicate information with you and be your voice at meetings between professionals and feedback to you afterwards.

If you are not sure who your key worker is or have not been allocated one then please contact one of the staff members you have previously had contact with to discuss who this person should be. The name and number of your key worker may be written in the box below for reference.

Your Key Worker is:

Contact number:

2. The Bereavement Team

We provide advice, support, and assistance to parents and carers following the death of a child at the hospital.

In order for you to legally register the death, a Medical Certificate of Cause of Death (MCCD) must be completed by a Qualified Attending Practitioner (QAP). This is a doctor who attended during the last illness / admission and who is qualified to complete the MCCD.

The Bereavement Team will ensure that the practical arrangements are completed in a timely, professional and caring manner.

We can also provide advice on the following:

- Any additional paperwork required
- Viewings
- Collection of property and valuables
- How to register the death
- Making funeral arrangements
- The Medical Examiner Service
- Tissue donation
- The Coroners' Service

Your key worker can liaise with the Bereavement Team or you can speak to them directly by calling the first working day following the death of your child.

The Bereavement Team

Telephone 0118 322 8066 Option 1

**Opening hours: Monday to Friday 9am-4pm
(excluding weekends and bank holidays)**

When you call, the Bereavement Team will talk you through the next steps of the process.

If you are planning on taking your child out of the country, please let the Bereavement Team know and they can advise you of any additional paperwork required.

If you wish, you can make preliminary arrangements with a funeral director, but it is recommended that you do not book a date until the death has been registered. The funeral directors can advise you further on this. If you intend to arrange and conduct your own funeral arrangements, please contact the Mortuary Team, who can advise you further on how to do this.

3. The Medical Examiner Service

The Medical Examiner (ME) is an independent senior doctor. Their role is to scrutinise the medical records, speak to a doctor who treated your child and together agree on the wording for the Medical Certificate of Cause of Death (MCCD). Within a few days of the death, you will have the opportunity to speak to the ME.

Participation in a discussion with the ME is entirely voluntary and you can make your wishes known to your key worker.

If you would like a telephone conversation with the ME, they will inform you of the cause of death recorded on the MCCD or inform you that a Coroner's referral is required. You will also have the opportunity to ask any questions about the cause of death or about any aspect of the care received during the admission.

All child deaths will undergo a child death review process, even if there are no concerns. If you do have any concerns about the care your child received, the ME can advise on the best way to raise those and may request the Trust to undertake a case review. If this is requested, the mortality nurse will contact you and give you more information about this process and how you will receive feedback.

Following the call, if the MCCD can be issued, the ME will release the completed MCCD and any other legal documents to the Bereavement Team.

4. Registering the death

The Bereavement Team will send the Medical Certificate of Cause of Death (MCCD) to the Reading Register Office. It is possible to register outside the district by declaration, but this could cause a delay. The Bereavement Team or key worker can explain the process if required.

The Bereavement Team will then call the documented next of kin (NoK) as provided to them by the ward (or key worker if preferred) and inform you that you can contact the Register Office to book an appointment. This can be done over the telephone or via the website. Please do not book an appointment until you have been notified that the MCCD has been sent to the Registrar.

Registering a death is a legal requirement and should normally be done within five days from the date the Medical Examiner signs the certificate, unless there has been involvement of the Coroner.

Reading Register Office
Civic Offices, Bridge Street,
Reading RG1 2LU

Telephone 0118 937 3533

Website <https://www.reading.gov.uk/life-events/deaths/>

9am-5pm Monday to Friday

(excluding weekends and bank holidays)

Location of the Reading Register Office

Please note that there is no parking at the Civic Offices. The nearest car parks are at the Oracle, Holy Brook or Broad Street Mall.



Who can register?

A death can be registered by a relative, a partner, a representative, by someone who was present at the death, occupier or manager of the premises where they died, or by the person responsible for making the funeral arrangements.

During the appointment

The appointment with the registrar takes approximately 30 minutes. During the appointment, the registrar will ask you:

- Your child's full name and any previous names
- Last address
- Date and place of birth
- Date and place of death
- You (the 'informant's') name and address.

The Registrar can help with the official ‘**Tell us Once**’ service that alerts other government agencies of the death at the same time. The Registrar can provide you with the unique reference number and details of the service.

The Registrar will produce a certificate of burial or cremation (‘**green form**’), dependant on coronial involvement. This is for your appointed funeral director. It confirms that the registration has taken place and the funeral arrangements can proceed.

You may need to get copies of the death certificate for other official purposes. For example, premium bonds, bank accounts and social media accounts.

There is a fee for providing copies of the death certificate and the Registrar can advise you of the current charges.

Note

There is a charge for any amendments / corrections to registration entries. Please check very carefully before signing to say that you agree with the death certificate details before it goes to print.

5. The Coroner

Under certain circumstances, it is a legal requirement to inform the Coroner of a child’s death. If this is thought to be necessary, your key worker or the Medical Examiner’s Office will talk you through the process and a Coroner’s Officer will contact you once a referral has been made.

If there is a need to contact the Coroner, the Coroner will decide if the treating doctor can issue the Medical Certificate of Cause of Death (MCCD) or whether further investigations are needed, such as a post-mortem and / or an inquest. If the Coroner requests a post-mortem, you are not able to choose whether a post-mortem examination takes place or not. However, you can make a representation about your wishes to your key worker that the

Coroner can consider. If a post-mortem examination is required, your child will be transferred to another hospital that specialises in paediatric pathology. The Coroner's Office will provide details of this to you in advance.

If a post-mortem shows that the death was due to natural causes, the Coroner will issue a notification to the Registrar. This gives the cause of death so that the death can be registered. If required, the Coroner will give your chosen funeral director a certificate for cremation. If there is to be an inquest, an interim certificate of fact of death can be issued by the Coroner.

If the Coroner decides that the doctor can issue the MCCD, the Bereavement Team will contact you and the registration process will resume as detailed on page 7.

The Coroner's Office can be contacted for further advice and information if needed.

Berkshire Coroner's Office

Telephone 0118 937 2300

Email coroner@reading.gov.uk

Website <https://www.reading.gov.uk/life-events/>

8am-4pm Monday to Friday

(excluding weekends and bank holidays)

6. Additional reviews

There are various different reviews that must take place after the death of a child. Your key worker will be able to give you further information on this. They can advise when you will be expected to receive feedback on these reviews and if your involvement is required in any way. The following are examples of the reviews that may take place, not all will be necessary – this will depend on the circumstances of the death.

JAR – Joint Agency Response: This is for deaths that are unexpected or have an unclear cause. This usually requires an initial meeting with a treating doctor, the police and the family to gather information on the circumstances of the death. A JAR meeting is then held, involving health professionals, the police and other agencies to work together to give support and try to understand how your child has died. The involved professionals will share information and eventually share this with the Coroner. You will then be informed of the conclusion from this.

Child Death Review Meeting: This is a meeting between the different professionals that were involved in your child's care, both before and after their death. This information is useful in understanding how your child died and to identify learning from this. This report is then sent to the Child Death Overview Panel.

Child Death Overview Panel (CDOP): This is a multi-agency meeting looking at all child deaths that happen in the local area. The main purpose of this is to learn from these deaths and try to prevent anything similar happening in the future. No identifiable information is given for this panel. They then make recommendations and reports about the lessons learned to those responsible locally. This report is released annually and can be accessed by the public online via the below website:

<https://www.berkshirewestsafeguardingchildrenpartnership.org.uk/scp/about-us/child-death-overview-panel-cdop>

Learning Disabilities Mortality Review (LeDeR): This is for children aged four and above with a learning disability. They work alongside the CDOP to improve the lives of those with learning disabilities.

7. Hospital consent post-mortem

The hospital doctor issuing the Medical Certificate of Cause of Death (MCCD) may ask you to consider a hospital post-mortem. This is up to you to agree to, unlike a Coroner's decision for a post-mortem. They will discuss this with you and explain the reasons why it is being recommended. These are sometimes important for further learning about the cause of death and improving treatments. You will be under no pressure to consent. It will not delay the registration process. The doctor can issue the MCCD and you can register in the usual way as detailed on page 7.

If you do agree to a hospital post-mortem, you would be invited to a meeting that involves you signing a consent form. A doctor from the treating team, a trained consent taker and a member of the mortuary or Bereavement Team will be present to guide you through the process. You have 24-hours after signing the consent form to change your decision. If you wish to withdraw consent, please call the Bereavement Office as soon as possible during this time.

If you consent to a hospital post-mortem, your child will be transferred to another hospital that specialises in paediatric pathology. The results of a hospital post-mortem usually take around 6-8 weeks and you can arrange to meet with the treating doctors to discuss the results.

8. Organ and tissue donation

Parents and carers can consent to organ or tissue donation (cornea and heart valve) of their child if they are eligible to donate and if there is an eligible recipient. Donation will not delay the funeral arrangements. The ward can arrange for a specialist nurse from the national referral centre at NHS Blood and Transplant to contact you by phone to discuss tissue donation and answer any questions you may have.

NHS Blood and Transplant
Telephone 0800 432 0559

9. Donation to medical science

During life, parents and carers may have decided with their child to donate brain or spinal cord to medical science for anatomical examination, education, training and research.

This must have been agreed and signed for in life with a written consent form direct from the organisation. If this is something that you have decided on, you should contact the relevant organisation and also inform the Bereavement Team.

The closest centre to the Royal Berkshire Hospital is John Radcliffe Hospital in Oxford. There are restrictions to donation, so please speak to the centre directly for further information.

John Radcliffe Hospital

Telephone 01865 272181

Bequest Office

Department of Physiology, Anatomy & Genetics

University of Oxford

Sherrington Building, Parks Road, Oxford OX1 3PT

Opening hours 8.30am-2.00pm Monday-Friday

Please note there is a 5-day period between the day of a death and being able to accept.

They would be unable to accept during the Christmas and Easter periods as the department is closed.

10. Arranging to see your child

You should be given the opportunity to spend some time with your child but there are some situations where this cannot happen or when someone else is required to be present as well.

If you wish to see your child while they are still at the hospital, the Medical Certificate of Cause of Death (MCCD) must be issued to ensure the Coroner does not need to be involved. If the Coroner is involved, then they will need to authorise a viewing to take place before this can be booked. Depending on the circumstances, they may also add restrictions or require a member of staff to attend the viewing with you. Authorisation must also be sought from the documented next of kin, which is provided to the Bereavement Office via the ward.

When booking a viewing, the Bereavement Officer will ask you to confirm your child's details, such as full name, date of birth, date of death, address, name of hospital ward they were on and the NHS number (if known). We need this information to confirm the booking and pass on to the mortuary staff. When attending the viewing, you will be asked to confirm three of these identifiers again and sign paper work to this effect.

The Bereavement Team can advise you further on this.

Please bring a form of ID with you, such as a driving licence or passport.

You can also arrange to see your child at your chosen funeral directors, once they have taken your child into their care after registration of death has taken place. Your key worker may be able to advise you on other opportunities that involve spending some time with your child.

The Bereavement Team

Viewing Suite is directly next to the Bereavement Office

Telephone 0118 322 8066 Option 1

By appointment only 9am-3pm Monday to Friday
(excluding weekends and bank holidays) 30-minute appointments

11. Collecting property and valuables

If you are with your child in the hospital when they die, please ask the nursing staff to return all property and valuables to you before you leave. You can leave small items with your child if you would like and these will remain with your child and transferred with them to the funeral directors.

If you are not present or forget any items, the ward staff will send any property to the Bereavement Office. Any valuable items may remain on the ward in a secure safe.

The Bereavement Team can advise you on what items have been sent to the Bereavement Office and if any items remain on the ward. Any valuables that have been kept on the ward for safekeeping will remain on the ward for you to collect.

For any other items, the Bereavement Team will advise you on how they can be returned to you. This will be by appointment only.

Please note the Trust will dispose of any uncollected property after 28 days and valuables after one year in line with departmental policy.

12. How to find us

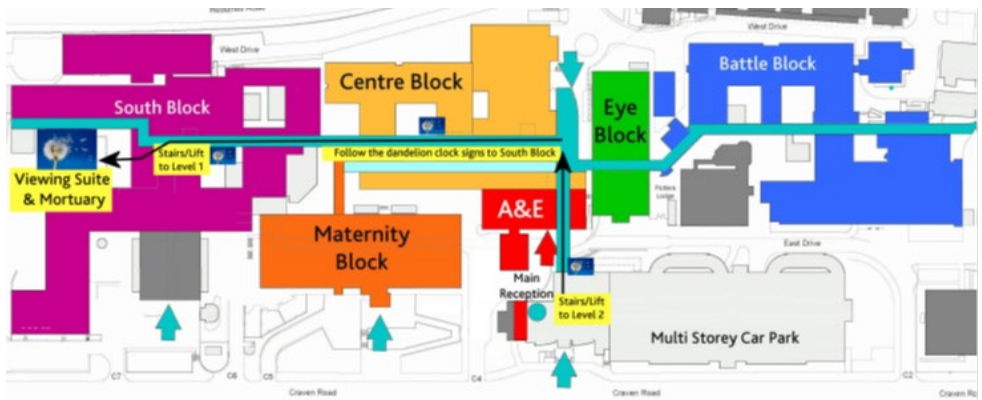
The Bereavement Office and Medical Examiner's Office are located on Level 1 in South Block. Follow the dandelion signs from the Craven Road main entrance to the office.



The offices are located next to the Viewing Suite and Mortuary, as indicated.

Main reception staff will be more than happy to show you the signs to look for if you need further assistance.

Visits to the office are by appointment only. Please contact the Bereavement Office to arrange a visit if required. You will be asked to show a form of identification e.g., passport or driving licence on arrival.



13. Other things to consider

- If you have received any benefits for your child, these usually continue for some weeks after your child has died, but the timing can differ. It is a good idea for you to contact the agencies that provide these to you, so you do not end up having to repay anything. Child benefit is paid for up to 8 weeks after the death, but you will need to ensure you have informed the child benefit office. You can do this via the www.gov.uk website or by contacting the child benefit office on 0300 200 3100. This can be difficult to do, so it may be a task you would like to ask someone to help you with.
- If your child has their own social media accounts, you can either deactivate them, turn them into a 'memorialised' account or leave them as 'live' accounts. To change this, you will need to

provide proof of your relationship and your child's death certificate to the social media provider.

- If your child had a mobile phone contract, the contract provider will need to be informed so that this can be cancelled, and the payments stopped. They may require a copy of the death certificate as evidence of this.
- Returning to work might not be something you can consider at this stage. Try to contact your workplace or ask someone else to help you with this so that your employer can be informed of the compassionate leave you require. You can also self-certify a sickness absence for the first week and then visit your GP for a 'fit note' for this to continue. Your manager should be able to provide you with information about your position and your rights to this leave.
- Your child may have visited various services or joined different clubs during their life, who may continue to contact you regarding appointments or attendance. There is no rush to inform these services but it may be distressing to receive phone calls or letters in the future. Examples of services you may need to inform include dentists / orthodontists, opticians, religious organisations, and local groups/clubs.

14. Royal Berks Charity

The Royal Berks Charity supports the Royal Berkshire NHS Foundation Trust across all sites. The charity's mission is to provide vital funds that enhance the care and experience of patients and staff. You may wish to make a donation in memory of your child. Giving in memory of someone special is a meaningful way to pay tribute to a loved one – honouring their life and helping others at the same time. The Royal Berks Charity is always incredibly touched and grateful to receive these donations.

For more information about the different ways to remember your child, including creating a 'Timeless Tribute' or leaving a dedication on our Memory Wall, please get in touch with us or visit our website.

Royal Berks Charity

Registered Charity No. 1052720

Telephone 0118 322 8860

Email: charity@royalberkshire.nhs.uk

Website: <https://www.royalberkscharity.co.uk>

<https://royalberkscharity.co.uk/get-involved/in-memory/>

15. Getting to Royal Berkshire Hospital

If you are travelling by car, parking at the hospital is often difficult with limited spaces. There are some pay and display parking bays (parking restrictions apply) in streets adjacent to the hospital if you are unable to find one in the hospital car park. You can find designated Blue Badge parking spaces on levels 0 and 2 of the multi-storey car park, or in North Block car park, Endoscopy car park, Melrose House car park and West Drive (Redlands Road). Due to parking restrictions, please allow plenty of time to arrive if you have a pre-arranged appointment.

If required, the Bereavement Team can provide you with a car parking permit, which can be arranged when booking your appointment.

If you are travelling by bus, there are a number of buses that travel between the hospital and Reading town centre. Up to date service details can be found by calling Reading Buses on 0118 959 4000 or by visiting www.reading-buses.co.uk.

Bicycle racks are also available near Maternity, Endoscopy, Battle Block, North Block and South Block.

16. The Spiritual Healthcare Team (Chaplaincy)

The Trust has a team of experienced chaplains drawn from a range of religious and belief traditions. They are available to offer support and guidance during this difficult time.

The chaplains hold an annual memorial service at the Royal Berkshire Hospital chapel. If you would like more information, please contact the chaplains directly.

Hospital Spiritual Healthcare Team (Chaplaincy)

Telephone 0118 322 7105

8am-4pm Monday to Friday

Out of hours – please ask ward staff or ward receptionist to page the on call chaplain or call switchboard on 0118 322 5111

17. Patient Advice and Liaison Service (PALS)

PALS is a service that can liaise with wards and departments to provide an answer to your enquiry.

PALS aim to provide a reply to your enquiry within five working days. Sometimes it may take longer than this, because they simply need more time to find the answer or because the enquiry is more complex. You can contact PALS using the details below:

Patient Advice and Liaison Service (PALS)

Telephone 0118 322 8338

Email: PALS@royalberkshire.nhs.uk

Main Entrance, Level 2

Royal Berkshire Hospital, Craven Road, Reading RG1 5AN

Opening hours: 9am-4pm Monday to Friday

18. Making a formal complaint

You may decide that PALS is unable to help you on this occasion and that you would like to raise a formal complaint. Or, PALS may suggest that your enquiry would be better addressed as a formal complaint. PALS is happy to discuss this further with you as detailed on page 19.

To raise a formal complaint, you will need to put the concerns in writing (if you haven't already done so via PALS).

Complaints Team

Telephone 0118 322 8338

Email: complaints@royalberkshire.nhs.uk

Main Entrance, Level 2, Royal Berkshire Hospital, Craven Road, Reading, RG1 5AN

The Complaints Team will be in contact with you directly to acknowledge your complaint and explain what happens next. The Complaints Team aim to investigate formal complaints within 25 working days and you will receive a response to your complaint, either by letter or in a meeting.

19. Ongoing help and support

Alongside the Bereavement Team, key worker, your family, friends or general practitioner (GP), you may feel that you need some extra support. You may wish to contact other services and organisations such as those listed on the following pages for ongoing help and support following your bereavement.

Child Bereavement UK

Tel: 0800 02 888 40

Website: <https://childbereavementuk.org/>

Information for bereaved children and families.

Compassionate Friends

Tel: 0345 123 2304

Email: helpline@tcf.org.uk

Website: <https://www.tcf.org.uk/>

Helpline run by bereaved parents and their families.

Cruse Bereavement Support

Tel: 0808 808 1677 (National)

Tel: 0134 441 1919 (Berkshire & Borders)

Website: <https://www.cruse.org.uk/>

Bereavement support, information and campaigning for all.

Daisy's Dream

Tel: 0118 934 2604

Website: www.daisysdream.org.uk

The charity supporting children through bereavement.

SOBS

Tel: 0300 111 5065

Website: <https://uksobs.org/>

Helpline for survivors of bereavement by suicide.

The Lullaby Trust

Tel: 0808 802 6868

Website: <https://www.lullabytrust.org.uk/>

Bereavement support for those affected by Sudden Infant Death Syndrome.

Winston's wish

Tel: 0808 020 021

Website: <https://www.winstonswish.org/>

Supports bereaved children, young people, their families and the professionals who support them.

The Mariposa Trust

Tel: 0300 323 1350

Website: <https://www.mariposatrust.org/>

Supports those affected by loss, from pregnancy to infancy.

Child Death Helpline

Tel: 0800 282 986

Website: <https://www.childdeathhelpline.org.uk/>

Helpline service for those affected by the death of a child.

4Louis – Miscarriage, stillbirth and child loss support

Website: <https://4louis.co.uk/>

Tel: 01915 144473

There are books available that can help you when explaining a death to young children:

- Chester Raccoon and the Acorn Full of Memories by Audrey Penn
- I Miss You: First look at Death by Pat Thomas
- Ida, Always by Carol Levis and Charles Santoso
- Why Do Things Die? By Katie Daynes
- Feeling All My Grief by Kim T.S
- I Can't Believe They're Gone by Karen Brough

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Author: Victoria Hunt, RBFT Senior Bereavement Officer, July 2024
Next review due: July 2026