



**University
Hospitals Sussex**
NHS Foundation Trust

Support for families around the time of bereavement

Patient information

What is this information about?

Please accept our deepest condolences on the death of your baby from all the staff on the Neonatal Unit.

You will probably find it difficult to think about new information at this time after the loss of your baby.

This time can be one of extreme heartache and distress for all those involved.

This booklet can help with some of the practical and emotional aspects. You can use the contents page to decide what information you want to read about.

The doctors and nurses will do what they can to answer your questions and provide you with any information that you may need.

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Can I spend time with my baby?

Following the death of your baby, you may wish to spend some time with them. We understand that this time together is very important. We will respect your wishes.

You may want to wash and dress your baby. Some people find that this is a special time. If for whatever reason you do not wish to do so, you may ask a member of your family, a friend or a member of staff to wash and dress your baby. You may use your baby's own clothes, Moses basket or carrycot or the hospital can provide these if you prefer.

What happens to my baby after I have spent time with them?

When you are ready your baby will be taken to the hospital mortuary. Any special clothing, toys or mementoes will always stay with your baby.

You can arrange to see your baby again by contacting your neonatal unit at any time. You can spend time with your baby privately on the unit. If you prefer, you can also see your baby in the chapel of rest.

When you see your baby again, please be aware that they may feel cold to touch and their colour may be different from when you last saw them.

Will my baby need a coroner's postmortem?

Some babies will have to have a postmortem examination to try to find out why they died.

The neonatal consultant will discuss all deaths that occur on the NICU with the medical examiner to ask for advice and discuss causes of death before issuing the death certificate.

Medical examiners are senior doctors who look into deaths that happen in the hospital.

Sometimes the medical examiner might need to refer the case to the coroner if the cause of your baby's death is unknown and a death certificate cannot be issued, or more information is needed to confirm the cause of death.

A coroner is a public officer who investigates the cause of death for those cases reported to them. When the coroner has all the information concerning the circumstances of your baby's death, they may decide that a postmortem is required.

The coroner's postmortem does not need your consent.

The examination is usually done within the first few days following your baby's death.

Although the results can take several weeks or months to be ready, your baby will be released much sooner than this, usually within two to four weeks, so that you can make funeral arrangements.

Will I have a choice to have a hospital postmortem on my baby even if the coroner does not think that one is needed?

Yes. If a coroner postmortem is not required, you will still be offered the choice to have one done on your behalf. You may feel that a postmortem could be helpful and your neonatal consultant may recommend this.

We will give you information which may help you to decide what is best for you and your family. You do not have to agree to a postmortem in these circumstances and it can only go ahead with your consent.

Although the postmortem may not explain why your baby died, you may feel reassured to know that everything possible had been done to find out.

Information about how your baby died could help other babies with similar problems.

What will happen if my baby has a hospital postmortem?

If you choose to have a hospital postmortem, the doctors will talk about this with you, and about how long it will take.

The examination is usually done within the first week or so of your baby's death. Your baby will usually be released back to you in two to four weeks.

Postmortems on babies are often done by specialists in other hospitals. The hospital will take your baby to, and bring them back from, these specialists.

You will still be able to see and hold your baby after the postmortem if you wish.

You may ask for copy of the examination report.

How is the birth and death registered?

Please contact the Registry Office in advance to let them know you are coming and book an appointment.

If your baby died after birth.

If your baby dies after birth, we advise that you register both the birth and the death at the same time. This must be done within five working days. You can register your baby's birth at any Registry Office. The registration of death should be done at your local Registry Office.

If you are married, only one of you needs to go, but you must take your marriage certificate with you.

If you are not married and would prefer both the parents' names to be on the register, you both need to be there when you visit the local registrar's office to sign the documents.

If you are in a civil partnership, ask the Registry Office for advice.

Registering the death when you have already registered the birth

If you have already registered the birth, you do not have to register the death in person. You may wish to ask someone close to you to do it for you.

To register the death, the registrar will need the Medical Certificate of Cause of Death. The neonatal secretaries will have already emailed this over to the Registry Office.

They will also need the following information:

- The parents' names, dates and places of birth and occupations
- Your baby's first name(s) and surname (family name) and the date and time of your baby's birth and death.
- Your home address.

The registrar will issue you with both a birth certificate, if this has not already been done yet, and a death certificate. You will also be given a green form which will mean you can start to make funeral arrangements for your baby. You will need to take this green form to your chosen funeral director.

Where are the registry offices?

Usually, deaths are registered in the area in which the person has died. For the Royal Sussex County Hospital this can be done at the Town Hall in Brighton. For deaths at Princess Royal Hospital in Hayward's Heath this is done at the Registrar's Office at the Public Library. You will need to make an appointment to register.

Brighton and Hove Registry Office

Brighton Town Hall

Bartholomew Square, Brighton BN1, 1JA

Telephone: [01273 292016](tel:01273292016)

Open 9:00am - 4:30pm Monday - Friday



Hayward's Heath Registry Office

Haywards Heath Library

34 Boltro Road, Haywards Heath RH16 1BN

Telephone: [01243 642122](tel:01243642122)

Open 8:00am - 6:00pm Monday - Friday

Registering by declaration

It is possible to register your baby's birth and death in any Registry Office in England and Wales. This is called registering by declaration.

The birth and death can be registered at the same time and place. However, if you do this, you may have to wait around five days for the birth and death certificates to be posted to you.

This should not delay the planning of your baby's funeral. You can still visit the funeral directors to begin planning your baby's funeral.

Special registration for urgent burial

For religious or cultural reasons, some parents may choose to have their baby buried within a certain time scale.

If your baby has died near a weekend or bank holiday, the local registrar will be able to issue a certificate of burial to allow this to proceed, provided:

- the case is not referred to the coroner.
- your baby is not being cremated.

The doctors and nurses on the neonatal unit can provide you with more information on this if you need it.

How do we arrange a funeral?

Following your baby's death, you will need to arrange a funeral.

Preparing for this can begin as soon as you are ready. Unless you have religious or cultural reasons for holding a funeral quickly, there is no need to hurry. You can take as much time as you need to make sure that the funeral is arranged in a way that is special for you and your family.

The funeral can take place as soon as:

- your baby has been registered.
- the postmortem has been done, if they had one.

Many funeral directors will not make any charge for conducting the funeral of a baby and there is often no charge for the cremation service.

If you would like to have a burial service, you may find that your local cemetery or graveyards will charge for a baby grave.

Please ask your nurse for our list of local funeral directors in Brighton and Hove that have been used before by other families.

The funeral director will need the green form that the registrar has given you after registering your baby. Final arrangements for the funeral can then be made. The funeral director will then contact the hospital and arrange to bring your baby to their Chapel of Rest.

Are there other ways of remembering my baby?

We have a HOSPITAL BOOK OF REMEMBRANCE and annual MEMORIAL SERVICE.

The Royal Sussex County Hospital has a Book of Remembrance dedicated to babies and children who have died in the hospital. This is kept in the Hospital Chapel.

The hospital chapel is on floor 6C of the Louisa Martindale Building. If you would like your baby added the staff will give you a form to fill in. You can then post it to the Chaplaincy Office. There is no charge for an entry into the hospital Book of Remembrance.

If you would like to be invited to the annual remembrance service after your baby's death please tick the option of receiving details about this. This is in the Book of Remembrance Form. You will then be contacted by the Chaplaincy Office.

Can I contact the Neonatal Unit for help even after my baby has left the hospital?

Our care for you continues even after your baby has left the hospital and for as long as you need our support.

You can contact the Neonatal Unit at any time if you need to speak with a nurse or doctor.

You can also contact our keyworker, Maggie. She is there for you to contact with any questions you may have about your baby, paperwork, funeral arrangements, support or advice.

You will invited to see one of the neonatal consultants who looked after you and your baby. This will be about 6-8 weeks after you go home. You do not have to attend this, but it will give you the chance to talk with them about the care of you and your baby and ask any questions that you may have. The doctor will also be able to talk with you about the results of the postmortem or any other test results if the results are ready. It may help to make a list of questions to have with you.

Will I be able to get time off from work?

You and your partner may be able to take time off work and get bereavement pay if:

- Your baby dies after birth.
- If you have a stillbirth after 24 weeks of pregnancy.

You may be eligible to get parental bereavement leave, statutory parental bereavement pay or both.

To qualify for parental bereavement leave and statutory parental bereavement pay, you must meet the criteria both as a parent (including if you had day to day responsibility) and an employee. You might not be eligible for both, depending on your circumstances.

To find out if you meet the criteria and for more information, please visit the government website:

www.gov.uk/parental-bereavement-pay-leave

What other support and counselling is there?

For many people, coping with the death of their baby is too much to deal with within the family without extra help. This includes siblings and wider family too.

Oscar's wish foundation

Oscar's Wish Foundation is a charity based in Sussex. It provides comfort and support to parents and siblings following the loss of a baby or babies before, during or shortly after birth.

Oscar's Wish Foundation offers six sessions of pregnancy loss counselling to parents on the Neonatal Unit who have suffered a neonatal death. These are free of charge.

We will make a referral to this charity for you. The decision to go ahead with these sessions is completely up to you. The sessions can be individual or as a couple. If you do not feel like you need these sessions now, you can use them in the future.

Contact details for sources of further information and advice.

Hospital telephone numbers

Royal Sussex County Hospital 01273 696 955

Trevor Mann Baby Unit 01273 523 450

Princess Royal Hospital 01444 441 881

Princess Royal Special Care Baby Unit 01444 441 881 Ext.68489

Maggie Beard 07909 871 262

Chaplaincy Team 01273 696955 Ext. 64122

Bereavement Office 01273 696955 Ext. 64611

Mortuary 01273 696955 Ext. 64420

Local and national support

Aching Arms

Aching Arms is here to help and support you when you have experienced the heartbreak of losing your baby, during pregnancy, at birth or soon after. The service is run by bereaved parents and gives you the opportunity to talk to someone who understands what you are going through.

Helpline: 07464 508994

www.achingarms.co.uk

BLISS

For babies born premature or sick

Email: hello@bliss.org.uk

Child Bereavement Trust

Information and support service line:

0845 357 1000 / 01494 446648

www.childbereavement.org.uk

Compassionate Friends

A self-help organisation for parents whose children have died.

National office – 01179 665202

Cruse – Bereavement Care

An organisation that promotes the well-being of the bereaved

Helpline: 0808 808 1677

Lullaby Trust

Raising awareness of sudden infant death syndrome (SIDS)

Helpline: 0808 802 6868

Email: support@lullabytrust.org.uk

Oscar's Wish Foundation

A charity which provides support for parents, families and siblings who experience the loss of their baby.

Email: oscarswishfoundation@gmail.com

SANDS

Saving babies lives. Supporting bereaved families.

Helpline: 0808 164 3332

Email: helpline@sands.org.uk

Strongmen

A charity for men to seek help and support with their mental and emotional health.

Helpline: 0800 915 0400

Email: hello@StrongMen.org.uk

Twins Trust

The Twins Trust Bereavement Service exists to support all parents and carers of twins, triplets or more who have died whether it was during or after pregnancy.

www.twintrust.org/bereavement

Winston 's Wish

Winston's Wish is a charity that helps children, teenagers and young adults (up to the age of 25) find their feet when their worlds are turned upside down by grief.

Helpline: 08088 020 021 www.winstonswish.org

This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

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