



Royal Berkshire
NHS Foundation Trust



What happens next

Information for parents after
the death or stillbirth of a baby

Compassionate

Aspirational

Resourceful

Excellent

This booklet aims to help you through the next few days and weeks. You may not want to read it all in one go but refer to it in the days ahead.

We would like to say how sorry we are for the loss of your baby. We appreciate what a sad and difficult time this must be for you and your family.

As parents, you will be feeling many different emotions and this is quite normal. Talking about how you feel can sometimes help although you may not feel comfortable talking to close relatives and friends about this. If you would like to talk to someone, you can ask your midwife to contact the bereavement midwife, who will be able to help you with the practical arrangements and will offer support following the loss of your baby.

Saying goodbye to your baby

Just as you should be welcoming your baby into the world, you suddenly have to say goodbye. It is often hard to believe that such a terrible thing has happened to you and it is not unusual to feel numb and confused about what needs to be done.

The midwife caring for you will ask if you would like to see and hold your baby. Parents who have chosen to spend time holding their baby are usually pleased they did so. Your baby can be bathed and dressed in your clothes or those provided by the hospital. We can take photographs of your baby, if you wish, using your camera or the hospital's and offer to take hand and footprints from your baby. We would also provide you with a memory box for your baby and include a memory card with photos of your baby so you can choose how to share and keep these memories.

You will be given plenty of time with your baby. However, if you do not feel ready to see your baby as soon as he or she is born, it is still

possible to see them later on and at any time up until the funeral.

If you have been discharged from the hospital, you can contact the Bereavement Midwife at the hospital on 07500 123912. You may contact us urgently on 0118 322 7215 (Delivery Suite).

You may have questions to ask about why this has happened to you. The doctor caring for you will discuss this with you.

Spending time with your baby

During your stay in hospital, you can spend as much time as you would like to with your baby. Some parents wish to go home as soon as possible after the birth to be with their family and friends. The maternity team will support you with any wishes that you make. You may also wish to spend time with your baby home. Please discuss this with Delivery Suite staff or the maternity bereavement team if this feels right for you. It may be that you wish to spend time with your baby at home for a few hours and then baby can be brought back to the hospital, or you may wish to spend longer with your baby at home and make arrangements with funeral directors directly. We are able to loan equipment to help to minimise changes to your baby's appearance when spending time with your baby at home.

If taking your baby home does not feel right for you then visiting or spending time with your baby after discharge from hospital is possible. Ideally, this takes place on the Delivery Suite, Monday to Friday between 9am and 3pm. This may be possible at the weekends under special circumstances. Please be aware that the unit may be particularly busy at these times.

As parents, you may want to bring in clean clothes for your baby to be changed into or a small personal item – e.g. small toy or family photo. Please speak to the bereavement midwives to arrange to spend time with your baby. If this is outside of Monday to Friday, you must make an appointment by contacting the midwife in charge or the ward clerk on the Delivery Suite – telephone 0118 322 7215.

When you have decided on your baby's place of rest and the date of your baby's funeral, your baby will be taken in to the care of the funeral directors. This will usually be three days before the funeral. The hospital would like to help and support you during this sad and difficult time following the loss of your baby.

Memories – other ways to remember your baby

Your baby can have a naming or a blessing conducted by the hospital chaplain while you are still in hospital. The chaplain says a short prayer and asks if you wish to give your baby a name. The name is recorded on a card and sent to you by post.

The hospital chapel has a special 'Book of Remembrance' for babies and parents can write a poem or add a picture of their baby if they wish. The book is always open at the current date but you can visit the chapel and read their entry at any time. As the Book of Remembrance is kept secure in a glass case, you may need to go to the nearby reception desk in order to get the key.

Hospital memorial service

A baby remembrance service is held in the chapel bi-annually, supported by the Willows Support Group. You will be sent an invitation to the next service or you can find details and updates on the Willows website and Facebook page. Many parents find this is a very good way of remembering their baby, along with other parents who have shared the same tragedy.

There are significant times of the year which are individual to you, where you remember those who are no longer with us and you may want to remember your baby at these times. It may be helpful to you to plant a special tree or a shrub in memory of your baby, or to keep a photograph or lock of your baby's hair in a locket.

As this may be your first experience of loss you should make sure you take time to think about, understand and talk over your feelings.

It is important to reach decisions together and this cannot be done quickly. If you are alone, it may help to talk over the way you feel and what you want to do with someone you feel comfortable with and who will support you.

If you have any queries or concerns about anything regarding your baby's death, please contact the bereavement midwife on 07500 123912 or email rbft.bereavementmidwives@nhs.net .

Potential further tests

Post mortem: A post mortem is an examination by a pathologist after death. This would normally be carried out at Oxford as this is a specialist centre with a pathologist who deals with illnesses that affect small babies. You would need to give your signed consent for a post mortem to be carried out. There is no rush – take time to talk about it together and with other family members. If your baby's death was sudden and unexpected, you may have many concerns. Why did it happen? Could I have done something to prevent it? Will I be able to have another baby? The post mortem examination may help to give some of the answers.

The doctor caring for you and/or the bereavement midwife will discuss and explain the post mortem to you as there are different types of examination.

If you feel that a post mortem is not appropriate or too upsetting for you, the placenta can be examined at the RBH and a sample of it can be sent for genetic studies to Oxford. After the examination, the placenta will not be returned to the Royal Berkshire Hospital unless you request it at the time of delivery. The placenta will be respectfully and legally disposed of as clinical waste. This is normally done with all births. These tests may be useful in our discussion and help you make decisions should you wish to have another baby.

If you consent to this examination, your baby will be away for approximately three working days, e.g. from Friday returning Tuesday

or Wednesday (this can be longer if further examination is recommended). Please be aware that the results can take up to 12-13 weeks to come back.

Referral to the Coroner: A referral may be made to the coroner if the doctor caring for your baby is uncertain of their cause of death. This applies to babies who are born alive and sadly pass away after their birth.

A coroner is someone who looks into certain types of death. Whether a coroner is involved depends on when the death occurred and whether the death is seen as being 'natural' or not. This is a term used by coroners, and a 'natural' death might include extreme prematurity (when a baby is born very early in pregnancy) or a virus. If the cause of your child's death is not 'natural', or is unknown then the law requires that the death is reported to the coroner.

The coroner usually arranges for a post mortem examination to take place for unexpected deaths, which will be carried out by a pathologist. An inquest is held after the post mortem examination if the cause of death remains uncertain, or if the cause of death is not thought to be "natural".

As a Trust we may also decide to undertake our own investigations into the circumstances surround your babys' death.

Follow-up appointment

You will be offered an appointment with a consultant to discuss any examinations or tests arranged. Appointments are offered by video call or in person at the hospital. Many families find it difficult to attend a hospital appointment and find it easier to attend a video appointment. The results do take time to come through and so it may be at least eight weeks before you receive this appointment information. This information can be emailed or posted to you, depending on your preference.

This is an opportunity for you and your partner to discuss any results, ask questions and be offered advice for a future pregnancy. If you do not wish to attend your appointment, or need to reschedule it, please let us know as soon as possible. We are also able to write a letter to explain the results if you do not feel able to attend an appointment. A copy of the letter will also be sent to your GP for their records.

If you have not heard from the hospital after eight weeks, please contact the bereavement midwife on 07500 123 912 or by email at: rbft.bereavementmidwives@nhs.net

Registration

All babies born alive or after 24 weeks of pregnancy need to be registered. If your baby was stillborn, your midwife will give you a stillbirth certificate in a sealed envelope. This should be given to the Registrar of Births and Deaths within 42 days. There is a special register for stillborn babies and you can ask to have your baby's first name written above the surname if you wish. You can also ask for a registration certificate to keep.

Parents who are not married at the time of their baby's birth and who would like the father's details to appear in the certified entry should ask the registrar to guide them.

Most parents contact the registrar within the first week of baby's death as without the certificate from the registrar, funeral arrangements will be delayed. It is preferable to telephone (in office hours) in order to make an appointment to register the stillbirth at Reading Registration Services located at the Civic Offices, Bridge Street in Reading.

If your baby died shortly after birth you will be given a death certificate in an envelope. This must be taken to the registrar within five days.

You must register both the birth and death of your baby and you will receive a birth and death certificate. A husband may register the birth and death of his baby. However, if you are unmarried, the baby can

only be registered in the partner's name if both parents are present at the registration.

The registration process may differ during the Covid-19 pandemic. The bereavement midwives will advise you accordingly.

Babies born before 24 weeks are not required by law to be registered. You may as parents want to recognise your baby's death. We at the hospital can arrange a certificate if this is your wish. In order to do so, please contact the maternity bereavement team at the hospital on 07500 123 912.

Your baby's funeral

We hope the following information will help you with the practical arrangements you need to make for your baby's funeral and remembrance.

A funeral can be almost anything you want it to be. For many parents it is a way of saying goodbye to their baby. We suggest you take time to decide what is right for you to honour and mourn your baby. Below are a few suggestions that you may wish to consider. We are here to give you as much help, advice and support as you need.

Making your own arrangements:

You can make your own arrangements with a funeral director. Once you have registered the death or stillbirth of your baby the registrar will give you a certificate. You must then contact the funeral director of your choice to arrange the service and complete your paperwork. Most funeral directors do not charge for their services under such circumstances. However, there may be charges if you choose to bury your baby in a family grave. Reading Cemetery, Henley Road, Caversham do not have special infant graves but it may be possible to arrange in your local cemetery or churchyard. There are also some 'natural' burial grounds, some of which offer burial free of charge.

Whatever you decide, allow yourself plenty of time to discuss this and to try to visit the cemetery. The Crematorium at Reading Cemetery may be contacted on 0118 937 2200. They will arrange a visit, which may help you to make your decision.

If you decide on a cremation, you will need to let the hospital know in order for them to arrange the papers, which will be sent to your funeral director.

A hospital arranged funeral:

If you feel you would prefer the hospital to organise a funeral, the hospital can arrange and pay for a basic funeral for your baby with a local funeral director. If the hospital arranges the funeral, the baby will either be buried or, with your permission, cremated.

Burial:

The hospital uses a special area at the local Reading Cemetery for all baby funerals. Your baby will have his or her own coffin with a name plaque on and will be buried in a communal grave with up to 16 other babies. Once the grave is properly finished there will be natural settlement of the ground (which can take up to 18 months). There will be a brass tree placed on top of the grave with space for a plaque with your baby's name on. This can be arranged with the crematorium directly if this is your wish. There will also be a small, designated area on the grave for memorabilia for your baby. Each funeral is individual. If you wish, the Maternity Bereavement Team can arrange for the hospital chaplain to conduct a small service in the chapel or at the graveside. If you prefer, a friend or family priest may conduct this. It might be that you do not wish to have a service and would prefer some quiet time during the burial.

You may prefer not to be present at the funeral. If so, we will inform you of the day it will take place or afterwards, if this feels right for you.

Cremation:

Alternatively, the hospital can arrange a simple cremation. This takes place at the Henley Road Crematorium and can, if you wish, involve a service with the hospital chaplain or your own priest/religious leader or person of your choice. There is also the option to have readings and music.

You will need to sign a form giving permission for the hospital to arrange the cremation. For babies born alive or after 24, paperwork will be issued following the registration of your baby, you will need to either post or hand in the green certificate given to you by the Registry Office to the hospital or funeral director. Your baby's ashes can be collected from the funeral directors or crematorium (we will advise you of this). This is usually within a couple of week of the cremation taking place. Alternatively, your baby's ashes can be scattered in the 'Garden of Remembrance' at Reading Cemetery. You are welcome to attend the scattering, if you wish. Please be aware that there may be few ashes to collect.

Shared cremation:

For babies less than 24 weeks we offer a shared cremation if you do not wish to have a formal funeral.

Your baby will be transferred to the hospital mortuary and be placed in a coffin with other babies of a similar size and a blessing will be performed by the hospital chaplain after which the coffin is transferred to the West Berkshire Crematorium, where the cremation will take place. Please note that there will be no individual ashes due to the shared nature, and there will be no time/date available for when the shared cremation occurs.

The ashes will be scattered in the Garden of Remembrance at the crematorium.

We do hope this information has helped you at this difficult time of loss. We are willing to talk with any parents at any time.

Feedback about your care

The maternity bereavement team will offer you a SANDS feedback form called the Maternity Bereavement Experience Measure (MBEM). This aims to enable parents whose baby has died the opportunity to feed back about the care they received. This feedback will be used to inform best practice and service improvements locally. It can be provided to you around the time of your follow up by paper or electronic copy. Do not feel you have to complete this, it is there for you if you feel you would like to use it.

Review of your care

If you have sadly lost your baby after 22 weeks of pregnancy, the hospital may complete a review of your care using the Perinatal Mortality Review Tool (PMRT). The maternity bereavement team will advise you if this particular review is appropriate to the circumstances of your loss and if it is, will ask if you have any questions or concerns you would like included in the review. This review will be shared with you when complete. When a baby dies before, during or after birth, the hospital (or hospitals) where the mother and baby were looked after should review the care the mother and baby received. This is called a hospital 'perinatal' or 'neonatal' review and is when a clinical team looks through the mother's and baby's hospital notes to understand events that led up to the death of the baby. It is different to a coroner's investigation or inquest.

Information about bereavement support

This information has been written to answer your queries and reduce any worries you may have. We have asked women who have had late miscarriages or stillbirths for their advice when writing this leaflet.

After the loss of a baby, people grieve in different ways. Quite often couples and families reach different stages at different times. This is normal. There are organisations which can provide advice and support if bereaved parents ask for it.

This hospital does not refer families to organisations for bereavement counselling because everyone has differing needs and lives on different timescales, so we ensure you have the information to make contact when or if you need to. It is important to know that:

- Everyone is sad.
- Some people like to talk.
- Some others feel the need to 'do'.
- Some just like to reflect quietly.
- Many are angry, at themselves, at their partners, at healthcare professionals.

Organisations who may be able to help

SANDS are a stillbirth and neonatal death charity. They operate throughout the UK, supporting anyone affected by the death of a baby, working to improve the care bereaved parents receive, and promoting research to reduce the loss of babies' lives. They have:

- A helpline.
- Local groups – there are ones for Berkshire, West Berkshire, Oxfordshire and Swindon.
- An online community.
- A family support pack, which has booklets for fathers; for when your baby dies before labour; saying goodbye; supporting other children you may already have; for grandparents; for other family and friends; and coping at Christmas. All of these can be downloaded free of charge.

The Willows Support Group at www.willowsupportgroup.co.uk

The Willows was formed in 2008 by a group of parents who wanted to share their experiences with others who would understand. These parents with the support of the Royal Berkshire Hospital set up an informal group of 3-4 parents who could share their stories with other parents who understood. The Willows meets regularly and has provided vital support for parents who have been through and continue to suffer the loss of a baby. The group also has a Facebook page. Willows are also supporting the new Rainbow Pregnancy Group for couples expecting a baby after loss, which has specialist staff providing support and advice for expectant parents away from hospital settings.

For those parents who prefer to read, rather than talk, there are increasing numbers of bloggers online who talk about life after the loss of a baby, from both a woman's and a man's perspective. All of these sites listed can be accessed without asking to join.

Instagram:

@dear-oria a page from Michelle Cottle, an NHS clinical psychologist, whose first baby girl was stillborn, and who, after her second baby, developed postnatal depression as she found parenting very much harder than she had thought. She is now well, and back at work.

Michelle has launched a new page **@from_the_other_chair**

@feathering_the_empty_nest from Elle Wright whose baby boy became very ill within a few hours of birth and died three days later.

@navigatingthewilderness is good for advice and stories on mental health support after baby loss.

@therearenowords2017.

@ben_and_breaking_the_silence has added a list of blogs discussing life after loss at their site.

Blogs:

www.hannahpontillo.com for 'Dads Grieve Too', a series of short pieces from bereaved dads about their experience of loss.

Podcasts: 13 March 2018 Fisher Price and the author Giovanna Fletcher presented a podcast called 'Happy Mum Happy Baby' with Elle Wright (feathering_the_empty_nest) and Michelle Cottle (dear_orla). This is available at the Apple Store.

A search engine tool at www.thepictame.com, using the search term #neonataldeathawareness takes you to a webpage where you might find other bloggers, Instagrammers and links that may strike a chord for you.

For those who want to do something for other families, some find joining in sponsored events in memory of their baby to raise funds for the Willow Group or SANDS healing.

Useful contacts

RBFT Maternity Bereavement Team 07500 123912 rbft.bereavementmidwives@nhs.net	
Antenatal Results & Choices 0845 077 2290 or 0207 713 7486 via mobile http://www.arc-uk.org/	
Child Bereavement Trust 0800 02 888 40 www.childbereavement.org.uk	CRUSE 0844 477 9400 01344 411919 – Bracknell 01635 523573 – Newbury www.cruse.org.uk
Dads & Lads Network https://nine4norah.co.uk/dads-lads-network	SANDS (Stillbirth and Neonatal Death Society) 020 7436 5881 www.uk-sands.org

<p>TAMBA Support for anyone affected by the death of a multiple birth https://twinstrust.org/bereavement.html</p>	<p>The Lullaby Trust https://www.lullabytrust.org.uk/bereavement-support/</p>
<p>The Mariposa Trust ‘Saying Goodbye’ 0845 293 8027 https://www.sayinggoodbye.org/support@sayinggoodbye.org</p>	<p>Willows Support Group www.willowssupportgroup.co.uk/ www.facebook.com/thewillowssupportgroup/</p>

Register offices and cemeteries

<p>Bracknell / Finchampstead Register Office Time Square, Market Street Bracknell RG12 1JD 01344 352000</p>	<p>Newbury Register Office Shaw House Church Road Shaw, Newbury 01635 279230</p>
<p>Reading Register Office Civic Offices, Bridge Street, Reading RG1 2LU 0118 937 3533 (0118 937 3737 – out of hours)</p>	<p>Wokingham Register Office Civic Offices Shute End Wokingham RG40 1WH 0118 974 6554</p>
<p>Easthampstead Park Crematorium / Cemetery South Road, Bracknell RG40 3DW 01344 420314</p>	<p>Mays Lane Cemetery Mays Lane Earley, Reading 0118 986 8995</p>

<p>Pangbourne Hill Cemetery Pangbourne 0118 984 1118</p>	<p>Reading Crematorium All Hallows Road Caversham RG4 5LP 0118 937 2200</p>
<p>St Michaels The Rectory Routh Lane Tilehurst RG30 4JX 0118 942 7331</p>	<p>Shaw Cemetery Shaw Hill Newbury RG14 2EQ 01635 40096</p>

This booklet has been written to guide parents who have sadly lost a baby while under the care of the Royal Berkshire Hospital.

The staff of the Maternity Unit and a number of parents have helped to put this information together.

We hope this information will help you make the right choices about how you will say goodbye to your baby.

Donations to the Stillbirth Fund have made it possible to publish this booklet. We would like to thank all the parents that have given so generously to the fund.

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

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

Bereavement Midwives, May 2001

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