



Royal Berkshire
NHS Foundation Trust



What happens next?

Information for parents after the
death or stillbirth of a baby

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 appreciate what a sad and difficult time this must be for you and your family, we are so sorry that this has happened and would like to offer our condolences and want to be here to support you as best we can.

This booklet will explain how you can spend time with your baby, in the hospital or at home and how you can capture precious memories during this time. It will also explain how we will care for your baby, including any tests or procedures, between now and when they are laid to rest according to your wishes.

As parents, you will be feeling many different emotions and this is quite normal. While family and friends are a great source of support sometimes talking to a trained professional about how you feel can sometimes help. We can help you with the practical arrangements to access this type of support. There is a full list of support available at the end of this leaflet.

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, tell us that while it is incredibly hard they are pleased they did so. However, we appreciate this is a personal choice and we respect and support your decision and will not pressurise you if this is not what you want. Your baby can be bathed and dressed in clothes from home or we have some suitable clothing which you are very welcome to use...

We can take photographs of your baby, if you wish, using your camera or the hospital's and give these to you on a memory card to take home. We also offer a sensitive service by the Medical Photography Team, who can come and take sensitive photos of your baby and provide you with a link to these when you feel you are ready. We can also take hand and footprints from your baby if you would like that and provide you with a memory box for your baby.

You will be given plenty of time with your baby. However, if you do not feel ready to see your baby as soon as they are born, it is still possible to see them later on and at any time until they leave the hospital for their burial or cremation, should that be what you choose to do.

If you have been discharged from the hospital, you can contact the Bereavement Midwife at the hospital on **07500 123912**. If you have urgent questions out of hours you may contact us 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. We also understand if you would rather be at home and can provide equipment which will allow you to take your baby home in a safe way. The team can explain how this works and any safety measures you need to be aware of. You may choose to bring your baby back to the hospital or pass their care to a funeral director when the time is right for you.

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 at 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, in order to provide appropriate support. We try to avoid other times as the hospital can be very busy, but if needed we will work with you to make this as psychologically safe as possible. 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 Maternity Bereavement Team 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 into the care of the funeral directors. This will usually be three days before the funeral.

Making memories

As well as taking photos and hand and footprints for your memory box, your baby can have a naming ceremony or a blessing - tailored to your religion or beliefs - conducted by the hospital chaplain while you are still in hospital if that is something you would like. 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 request for a poem/words to be added or add a picture of their baby if they wish. The Maternity Bereavement Team will regularly arrange for any entries to be written by a calligrapher directly into the book. The book is always open at the current date but you can visit the chapel and read your entry at any time. As the Book

of Remembrance is kept secure in a glass case in the corner of the Chapel, 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 by email, 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 similar experiences.

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

Potential further tests

Sometimes you, or your medical team may have questions about why your baby died and will either need to be reviewed, or you may want it to be reviewed. It may be that your baby weighed over a certain amount they may be able to have a post-mortem if that is what you want. The Maternity Bereavement Team can advise you if we are able to offer a post-mortem. A post-mortem does not find a definite reason why a baby died. This can be extremely disappointing. But even if no definite cause is found, a post-mortem may still answer some questions and rule out some possible causes. Finding out what did not cause the death of your baby is especially helpful if you think you may have another baby in the future; it could provide useful information to the doctors who would organise your care. The results of a post mortem can also contribute to valuable research which may prevent more deaths in the future.

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. It may also be possible to send a sample of it to Oxford for genetic studies. The Maternity Bereavement Team will be able to advise you if this is possible in your baby's circumstances. After the examination, the placenta will not be returned to you unless you request this. 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 the post mortem 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 surrounding your baby's' death.

Bereavement Postnatal Information

What happens after I am discharged from hospital?

- The Maternity Bereavement Team will get in touch with your GP, community midwife and health visitor to let them know what has happened.
- They will be able to continue offering you care and support after you leave hospital. For example, you may have questions about what's normal for recovery, or, if you had stitches, you might like a community midwife to check them if they are painful.
- You should have a six-week post-natal check-up with your family doctor (GP). This is something that you will need to arrange.
- Approximately 6 weeks following the birth, you should have an appointment to talk to a doctor or consultant at the hospital about the birth and to discuss the post-mortem and test results (if you chose to have these done). You can also talk about any post-natal issues at this appointment. Some people would like to also talk about plans for a future pregnancy at that appointment.

If you don't hear from your GP, a community midwife or bereavement midwife within a few days of arriving home, contact the triage line at

the Royal Berkshire Hospital (**0118 322 7304**) to find out what has happened.

These are some of the common physical changes that you might experience after giving birth.

Your breasts and breast milk

One of the most distressing physical symptoms following the death of your baby can be breast pain and the production of breast milk. The following information aims to provide you with information on how to stop your breast milk production, with some practical advice to help ease the physical symptoms of breast engorgement that you may experience during this difficult and emotional time.

Natural milk production

The amount of milk produced in the breast will vary from person to person, and will reduce naturally over a period of time.

Engorgement

Engorgement is when the breasts become swollen, firm and painful. It can happen between 2-5 days after the death of your baby. Your breasts can leak milk and feel uncomfortable for up to 7-14 days. This can settle on its own. If severely engorged, your breasts can become hard, shiny, warm and slightly lumpy to touch. Breast engorgement actually helps to suppress the production of breast milk. However, painful breast engorgement is not necessary and can be avoided.

Mastitis

Mastitis is inflammation of the breast, which, if left untreated, can develop into a more serious infection.

Symptoms include:

- red, swollen area on the breast that is hot and painful to touch
- breast lump or area of hardness on the breast
- white or blood stained nipple discharge
- flu-like symptoms including fatigue, chills, fever

If you display any of these symptoms, it is recommended that you contact your midwife, health visitor or GP as antibiotic treatment may be required.

Relieving symptoms of engorgement

There are a variety of methods that can be used to reduce milk production including prescribed medication and a milk reduction routine. These are a few suggestions to help relieve engorgement

- Take regular pain relief
- Wear a support bra all the time
- Use breast pads to absorb leaking milk
- Use cold compresses or gel packs on the breasts
- If your breasts feel very full, hand express a small amount off for comfort
- Apply washed and chilled cabbage leaves to the breasts
- Have a warm bath or shower to allow the breasts to leak naturally (ensure shower water jets are not directly on the breasts)
- Sleep in a semi upright position to avoid pressure from heavy breasts

Reducing your milk supply

If you were expressing regularly for a premature or ill baby you will need to gradually reduce the amount of breast milk produced. This can be done through increasing the time between hand or pump expressing, over a few days and eventually coming to a stop. We would suggest the following

Day 1 Pump each breast for 5 minutes every 4-5 hours

Day 2 Pump each breast for 3-5 minutes every 6 hours

Day 3 Pump each breast just long enough to relieve discomfort

Medication

Cabergoline (Dostinex) prevents / suppresses milk production by blocking the hormone that is secreted to produce milk. It should be

used alongside a milk reduction routine. Your midwife or GP will be able to arrange this

The funeral

Around the time of your baby's funeral is going to be highly emotional. This unfortunately can affect your milk production and you may experience engorgement even though you thought things were settling down. If possible, sit down and support your breasts with your arm. Let people know not to hug you too hard if your breasts are painful

Postnatal symptoms

After-pains/stomach cramps

It's common to have after-pains after giving birth. They can feel similar to labour contractions, cramps or strong period pains. This is your womb contracting back to its normal size and usual location (down inside your pelvis). Painkillers such as paracetamol and ibuprofen can help with this.

Bleeding (lochia)

After the birth, you will bleed through the vagina. This is called lochia and it is your body getting rid of the lining of your womb and blood from where your placenta was attached. Everyone is different, but for most it will be heavy for around 2 weeks and then will be lighter until around 6 weeks after the birth. At the start, it may have some lumps or small clots in it. It changes colour from red, to pink, to brown. The flow of this blood loss can increase and decrease, so don't worry if your bleeding was easing off, but then looks heavier the next day. This is normal.

To start with, the bleeding will be heavy and you will need very absorbent maternity pads - these hold more blood than normal sanitary pads. It's best not to use tampons until after your 6-week postnatal check because they can cause infection.

If you find you're losing blood in large clots (larger than a 50p piece) let the midwife know or call the triage line (0118 322 7304). If you're filling a large maternity pad in 1 to 2 hours or if you are passing blood

clots larger than a 50p piece, please contact your local maternity unit as you may need to be checked.

Stitches

You may have some painful stitches if you had tearing or an episiotomy (cut) during the birth. Bathe in clean, warm water to help you heal. Dry the area carefully afterwards.

- It can help to have a jug of water on hand (in the toilet) so you can clean and cool the area after having a wee.
- Don't avoid going to the toilet to do a poo. Even if it feels like they will, the stitches are very unlikely to break. You can apply pressure with a clean maternity pad to your stitches while going for a poo for reassurance
- In the first few days, take care when sitting down and lie on your side rather than on your back.
- Stitches usually dissolve by the time the cut or tear has healed.
- Take painkillers according to the instructions on the pack.

If you have any concerns about infections or healing, speak to your midwife, maternity unit or GP.

Going to the toilet

It can be worrying going to the toilet after giving birth because of fear of the pain, worry about the stitches breaking and the lack of sensation, or control. Although you might want to put off having a poo in case it hurts, try not to get constipated. Eat lots of fresh fruit and vegetables, wholegrain cereals and bread. Drink lots of fluids to keep your urine diluted and your poo softer.

It might give you confidence to hold a clean pad of tissues over the stitches while you do a poo. But try not to worry, it's very unlikely that going to the toilet will affect your stitches. If you're constipated, ask your midwife about which stool softeners or laxatives you can get to help you to do a poo more comfortably.

Piles

Piles (haemorrhoids) are common after any birth and they tend to go away after a few days. Make sure you drink lots of water and get plenty of fibre by eating plenty of fruit, vegetables and wholegrains. You need to avoid getting constipated and straining.

If you are worried, or very uncomfortable, talk to your midwife or GP about getting some ointment to soothe the area.

Your pelvic floor

Your pelvic floor holds your pelvic organs (bladder, womb, bowel and vagina) in place. Its muscles give you control when you go for a wee, supporting your bladder and bowel. You might feel like you have little control of your body in the days after giving birth because your pelvic floor has weakened. If you try pelvic floor exercises (where you squeeze and hold the muscles like you are holding in a wee), you might find you have no sensation at all. Don't worry, it should come back. It usually just takes time.

Your tummy may feel soft and take time for your bump to go down. You may struggle to control your bladder, especially when you cough or move suddenly. It will get better with time and doing regular pelvic floor exercises can help with this.

If, after 3 months, you're not seeing improvements with bladder control, you may need a referral to a physiotherapist.

Recovering from a Caesarean birth

A caesarean is major surgery. You will need to take time to recover and allow your wound to heal.

If you had a Caesarean birth, you'll usually need to stay in hospital for 2 to 3 days. You may be able to go home sooner if you're doing well. You will feel uncomfortable and be offered painkillers. You may be prescribed daily injections to prevent blood clots (thrombosis).

Staff will encourage you to get mobile by getting out of bed and walking as soon as possible. They can offer advice on postnatal exercises to help you recover.

When you're well enough to go home, you'll need to arrange for someone to give you a lift as you will not be able to drive for a few weeks afterwards.

There are different types of wound dressings. Ask your midwife how long your dressing will stay on for. Some are for 1 to 2 days, and others are for 5 days. Once your dressing has been removed, you'll need to look after your wound by gently cleaning it and drying it every day. Your midwife will explain how to care for your wound and manage any pain. Please get in touch with your GP if you have any concerns about this or see signs of infection.

Getting a period

It is hard to say when your first normal period will happen after giving birth.

It's likely it will be about 4 to 6 weeks after giving birth. However, because of the timing, it can be hard to know whether it is the post-birth lochia, or your first period.

Sometimes your first period isn't like your normal period. Everyone is different. You might find your first period particularly difficult to cope with, and periods after this one too. This is totally understandable.

Postnatal check-up

Your six-week postnatal check-up is usually at your GP surgery.

This routine appointment is mainly focused on physical recovery after giving birth. However, if you are in a couple you may want to go together, if possible, so you can both talk about how you're coping.

You might want to ask questions about trying for another baby, the care you might get in future pregnancies, or discuss contraception options to give yourself some more time.

Consultant hospital appointment

You will be offered an appointment with a specialist midwife or consultant at your hospital to discuss any test results and findings in relation to the death of your baby.

Here are some tips which may help you prepare for this appointment:

- When you make the appointment, you might want to explain before you go in that you would prefer not to wait with other parents and newborn babies.
- Write down your questions in advance. You might feel emotional in this appointment, so it helps to take some notes with you.
- You might want to take someone with you who can take notes. It can sometimes be difficult to absorb and remember information in these circumstances.
- As follow-up appointments happen differently across the UK, you might want to speak to the bereavement midwives beforehand to find out more about what your appointment involves.
- A letter will be sent to you following the appointment detailing what has been discussed.

Follow-up appointment

You will be offered an appointment with a consultant/bereavement midwife 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 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

If your baby was born after 24 weeks you will need to register their birth and sadly their death with the Registry Office. If your baby was born before 24 weeks you don't need to register but you, or the Bereavement Team, can request a certificate to register their birth for your own memories: <https://www.gov.uk/request-baby-loss-certificate>

If your baby was stillborn, your midwife at the birth will complete the paperwork and hand it to the bereavement midwives who will help to arrange the appointment for you. 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/same sex partner details to appear in the certified entry should ask the registrar to guide them.

The bereavement midwives will usually contact the registrar within the first week of baby's death as without the certificate from the registrar, funeral arrangements will be delayed. Once the registration appointment has been made, the bereavement midwife will inform you of the details. The registration office is located at the Civic Offices, Bridge Street in Reading if your baby was born outside of Reading it will be the local Registry Office to the hospital of birth.

If your baby died shortly after birth the doctor who is present at the birth will complete the paperwork to certify their death. This will then be handed to the bereavement midwives who will help to arrange your registration appointment. A married partner may register the birth and

death of their 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.

You will be given a registration card to present at the registry office which will highlight the sensitive nature of your appointment. This will avoid you having to explain why you are there.

If you wish to make arrangements yourself you will need to call Reading registry office.

Your baby's funeral

We hope this information will help you with the practical arrangements you may want to make for your baby's funeral. Your wishes are personal to you and what happens at the burial or cremation of your baby is your decision. You may find comfort in this process but you can also choose to let the hospital and our funeral directors make the arrangements.

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 we have learnt from other bereaved parents, which 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 does 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 cremation, you will need to let the hospital know so that they can 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 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. All the babies buried within the grave will be buried at separate times so you will not share the experience with the other parents. The grave is properly finished there will be natural settlement of the ground (which can take up to 18 months). There will be a small, ornamental 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. As it is a shared grave, the Crematorium do reserve the right to remove any memorabilia, but the brass tree will always remain. 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. Please let the Maternity Bereavement Team know if you feel more than 40 people may attend so that they can help arrange the right chapel (if you choose this)

Cremation:

Alternatively, the hospital can arrange a simple cremation. This happens at the Henley Road Crematorium and can, if you wish, involve a service with a 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 weeks, 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 weeks 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 others who will have their baby's ashes scattered at the same time.

Shared cremation:

For smaller babies or babies born at less than 24 weeks, there is the option to have a shared cremation if you do not wish to have a formal funeral. This option is only available for those babies who were not born alive.

Your baby will be transferred to the hospital mortuary and be placed respectfully, in a coffin with other babies of a similar age 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 set time or date available for when the shared cremation occurs.

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

Collecting your baby from the hospital mortuary:

Why would this be necessary?

You may wish to take your baby home before either a hospital funeral or a private funeral. Or if your baby was born before 24 completed weeks of pregnancy, you wish to make family arrangements for your baby.

Who can do this?

Either parent or someone else you have designated, who has the correct permission and identification, can collect your baby.

When can we do this?

The hospital mortuary is open Monday to Friday 8am to 4pm excluding Public Holidays. An appointment must be made by ringing the mortuary staff on 0118 322 7743.

What will happen to my baby?

Your baby will be prepared by the Delivery Suite staff and transferred to the hospital mortuary by the porters.

If you wish to collect your baby directly from the Delivery Suite, please speak to the Delivery Suite staff or the bereavement midwives.

What do we need to take?

You will need something suitable in which to carry your baby. We can lend you an appropriate carrier from the Delivery Suite. Please return this when you have finished with it.

You can arrange return with the Maternity Bereavement team on 07500 123 912 or by emailing rbft.bereavementmidwives@nhs.net You will need photographic proof of ID and address, e.g. a driving licence, or, if you are not one of the baby's parents, written proof that you have permission to collect the baby, as well as proof of ID.

Collecting your baby

Please be aware that you will be asked to identify the baby from his or her name tags, which will involve viewing your baby's body. You will also be asked to sign the mortuary ledger to say that you are taking responsibility for your baby after his or her release.

Feedback about your care

If there is any way in which we can improve the care we have offered you during this difficult time we would like to know about it. 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. If you would prefer to speak to a person or feedback to a local group you can email the Royal Berkshire Maternity and Neonatal Voices Partnership (MNVP) who are an independent NHS working group, made up of parents who have experienced care, who listen to feedback and work with us to improve maternity care. They can be contacted by emailing feedback@royalberkshirermnvp.org

Review of your care: Perinatal Mortality Review Tool (PMRT)

If your baby dies 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. The Maternity PMRT Lead will contact you to ask if you have any questions or concerns you would like included in the review. This review will be shared with you when complete, and this can take up to 6 months. The PMRT review includes the hospital (or hospitals) where you and/or your baby were looked after and reviews the care you both received in order to understand events that led up to the death of your baby. It is different to a coroner's investigation or inquest.

Information about bereavement support

This information has been written by others who have experienced the death of a baby to help answer your queries and reduce any worries you may have.

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.

We do 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 and 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 free helpline 0808 164 3332.
- A free chat service on their website:
<https://www.sands.org.uk/support-you/how-we-offer-support>
- Local groups – there are ones for Berkshire, West Berkshire, Oxfordshire and Swindon.
- An online community.
- A family support pack, which has booklets for partners; for when your baby dies before birth; 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.willowssupportgroup.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.

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 parents perspective. All of these sites listed can be accessed without asking to join.

Instagram:

@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.

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](https://www.instagram.com/feathering_the_empty_nest)) and Michelle Cottle ([dear_orla](https://www.instagram.com/dear_orla)) which is available at www.shows.acast.com

A search engine tool at

<https://www.picuki.com/tag/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 <https://www.arc-uk.org/>

Child Bereavement Trust

0800 02 888 40

www.childbereavementuk.org/

CRUSE

0844 477 9400

01344 411919 – Bracknell

01635 523573 – Newbury

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

Dads & Lads Network

<https://nine4norah.co.uk/dads-lads-network>

SANDS (Stillbirth and Neonatal Death Society)

020 7436 5881

<https://www.sands.org.uk/>

TAMBA

Support for anyone affected by the death of a multiple birth

<https://twinstrust.org/bereavement.html>

The Lullaby Trust

<https://www.lullabytrust.org.uk/bereavement-support/>

The Mariposa Trust ‘Saying Goodbye’

0845 293 8027

<https://www.sayinggoodbye.org>

<https://www.sayinggoodbye.org/get-support/>

Willows Support Group

www.willowssupportgroup.co.uk/

www.facebook.com/thewillowsupportgroup/

Registry offices and cemeteries

<p>Bracknell / Finchampstead Registry Office Time Square, Market Street Bracknell RG12 1JD 01344 352000</p>	<p>Newbury Registry Office Shaw House Church Road Shaw, Newbury 01635 279230</p>
<p>Reading Registry Office Civic Offices, Bridge Street, Reading RG1 2LU 0118 937 3533 (0118 937 3737 – out of hours)</p>	<p>Wokingham Registry 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>

The staff of the Maternity Unit and a number of bereaved 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.

Notes

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

Reviewed: November 2024. Review due: November 2026