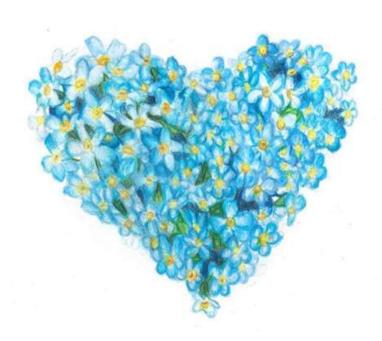


When your baby has died

Care for parents during late miscarriage or stillbirth





The following pages contain a huge amount of information. Some of it will be useful now and some in the coming days.

You might find it helpful to give it to a trusted relative or friend to read on your behalf.

Keep the booklet in a safe place for you to revisit it in the coming days and weeks.

Who you can contact

Bath Birthing Centre, Princess Anne Wing, RUH:

• Charlotte ward, Princess Anne Wing RUH:

01225 824434

01225 824834

Bereavement Midwife, Bex Walsh:

(Usual working hours: Monday-Friday 9-4)

01225 826886

07872 696 165

Ruh-tr.bereavementmidwife@nhs.net

Spiritual Care centre: 01225 824039

Your next appointment is:

Please come to:	
On:	
f you have any questions you can contact:	



Following the devastating news that your baby has died, there are decisions you will be asked to make. This leaflet will give you some information to help you. The Bereavement Midwife and Spiritual Care team are available to answer any questions over the coming days and weeks.

Please take your time in making choices and decisions. At the back of this booklet there are details of the support you can find.

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Feelings of grief

Grief is not equal to the length of time we have known someone but instead reflects the love, hope and dreams invested. Grief is often experienced in waves and can commonly include feelings of guilt, self-blame, failure, shock, sadness, anger, disbelief and fear. You may experience rapid changes of emotion and several different emotions at once, this can be confusing and exhausting. Some also experience real physical responses to grief such as aching arms, palpitations, loss of appetite and disturbed sleep. You may have flashbacks to the moment you were given the news of your baby's death or of your baby's birth. It is completely natural to want to avoid these feelings. These should become less intense and frequent overtime. However embracing the grief will enable a true understanding and provide a way of living with a reality that we don't want to be true.

Grief is exhausting so it is healthy to take a break from the emotional turmoil by distracting yourself or doing a soothing activity, such as watching TV, going for a walk, or reading a book. Taking pleasure in hobbies is a good distraction.

It is important to acknowledge that everyone experiences grief in their own unique way. Each person has their own timeline for emotions and coping mechanisms. There is no right way to grieve.

If you are worried about how you are feeling or want support please talk to the Bereavement Midwife and/or see the support available at the back of the booklet.



Birth

When your baby has died before they are born, the team looking after you will talk to you about the safest way to birth your baby.

If there is no immediate risk to your health, you can take time to consider when and how to birth. Usually the safest option is a vaginal birth however in some situations a caesarean birth will be recommended. You may start labouring naturally but most need to have their labour started (induced). Your team will explain your individual risks and options. They will help you plan for labour and birth.

Most families are able to go home prior to the birth. Here is a list of things you might want to bring with you for labour and birth.

Things you might like to bring into hospital

- Medication you are currently Slippers / Flip flops taking
- Glasses / contact lenses and •T-shirt / nightdress for labour case
- •Toiletries •Light refreshments
- •Towel •Phone charger
- Disposable pantsBooks / magazines
- Sanitary towels (we can provide these if needed)
 Baby Blanket / teddy (if you wish)
- A warm jumper

Labour can be started using medication, a hormone pessary or a balloon device. The doctor will agree an individualised plan for you. The length of time labour takes to get started is different for everyone. Labour is hard to predict and a unique experience for everyone. Your plan can be reviewed or changed if needed during the labour.

You will be offered pain relief options to suit your needs as the labour progresses. You can discuss your options with the team caring for you before your labour begins. You are encouraged to be mobile, to pass urine regularly and drink plenty. You can eat if you wish to but many feel they do not want to while in labour. In some circumstances we may ask that you do not eat, this will be explained to you if needed.

If you are not sure what is happening next please ask. Your plan for labour can be discussed as often as you need. The team are here to guide you through the process although we may not be able to predict how your labour will be.

Every effort will be made to make your hospital stay as comfortable as possible therefore you will be offered a private room for the duration of your stay. If you need anything just ask.

Visiting

There are no restrictions on visiting times. You are welcome to invite family, friends or religious leaders to support you during your hospital stay. Please consider how many people and who you choose carefully as you are likely to be physically and emotionally exhausted.

Car parking

To ease some of the stress at this difficult time, free car parking is provided for the duration of your stay. Please give the staff your car registration number each time you need to leave the car park.

Spiritual Care Team

The Spiritual Care Team are available at all times during your hospital stay, the Spiritual Care team Chaplains are pastorally trained and skilled listeners. Please ask if you wish to see a Chaplain.

Going home

If you are physically well you may go home 3-6 hours after the birth however you will be supported to stay as long as you wish.

You will be offered appointments with your community midwives either on the telephone or in your home depending on your needs.

The Bereavement Midwife will make contact by telephone to provide ongoing support and answer any questions you have.



Creating memories

Remembering your baby by creating memories such as hand/foot prints or photographs externalises your relationship. These mementoes can provide evidence of your baby's existence. What you do is a deeply personal choice, the team caring for you will support you to choose what is right for you.

Naming your baby

Many parents decide to name their baby. This gives your baby their own identity and can make it easier to talk about him or her. Some parents do not want to name their baby or may prefer to continue using the nickname they used during the pregnancy. Before you leave the hospital, the staff can arrange for the hospital chaplain to come to the ward to conduct a short service of blessing or 'act of naming' for your baby. You can include other family members or friends if you wish.

Seeing and holding your baby

You will be offered to see and hold your baby. This may seem strange however many parents find that the time they spend with their baby is the most precious memories they have.

If you are concerned about how your baby may look please ask the team looking after you. They can offer guidance to ensure you are comfortable with your experience. There is no right or wrong however research tells us that most families find seeing their baby comforting.

Depending on your baby's size and the condition of their skin, you may be able to wash and dress your baby if you would like. To enable you to spend precious time with your baby, a cold cot is recommended to slow changes to your baby's skin. Usually a family can spend 1-3 days with their baby while using the cold cot before significant changes to the skin are noticed. Please talk to the team looking after you for more information.

If you would like to see your baby after you have left the hospital, arrangements can be made for you to return to see your baby contacting the Bereavement Midwife or the team caring for you, using the numbers at the front of this booklet.

Photographs

Please feel you can take photographs with your own device, the staff can support you with this. If you prefer the staff can use the ward camera to take pictures and store them if you think you may want them at a later date. The Bereavement Midwife will be able to send the photographs to you if you wish.

Keepsakes

We will offer a special Memory Box which are kindly donated, for you to keep mementoes such as foot prints, hand prints, a lock of hair, scan photos, and/or the blanket that your baby was wrapped in.

Taking your baby home

Some parents find it comforting to take their baby home for a short time. You are welcome to do so. You will need to keep your baby as cool as possible, particularly if you have chosen to have a post mortem examination. You will need to use your own transport. Please ask if you want to

know more about this option.

Book of Remembrance

A Book of Remembrance is kept in the Spiritual Care Centre. You can record your baby's name with a short message using the form at the back of this leaflet. Either leave it with your midwife or post it to the Spiritual Care Centre. There is no charge for this although you may wish to make a donation to the 'RUH Remembrance Fund' charity.

Other ways to stay connected

Below are some options of ways to honour your baby's absence.

- Baby loss remembrance services
- Memorial brick at the SANDS memorial at Haycombe cemetery
- Have a star named after your baby
- Scattering petals
- Releasing eco-friendly balloons
- Plant a tree (consider who/how it will be looked after)

There are many other suggestions available through baby loss support websites and groups listed at the back of this booklet.



Tests to find out why my baby died

This is often the most important question for parents and every effort will be made to answer it however this isn't always possible.

We can test your blood, urine and take swabs. The placenta will be swab tested and examined under a microscope.

The tests can detect pre-eclampsia, obstetric Cholestasis, undiagnosed diabetes, thyroid function issues, clotting problems, viral infections, bacterial infections and placental problems.

Your baby will be weighed and the condition of your baby's skin and general appearance will be noted.

Your notes, including scans taken during pregnancy, will be also be reviewed.

Genetic testing is offered to detect chromosomal abnormalities. This requires a skin biopsy or placental biopsy to complete testing and can take up to 10 weeks for the results to be available.

In some circumstances a post mortem examination will be offered for your baby, this will be discussed further if required.

If a post mortem is offered and consented to, your baby will travel safely to Bristol where a Specialist Pathologist will perform the post mortem examination. Your baby will then return to the RUH. This usually takes up to 10 working days (occasionally this is longer).

When a post mortem examination is consented to, you will be offered a copy of the consent form and given a period of time within which you may change mind. This is normally 24 hours.

Whether or not to have a post mortem is a difficult and personal decision. If you have any questions, please ask your doctor or the Bereavement Midwife. You will be given time to make your decision.

Some results may be available in a few days and others can take several weeks or even months. We appreciate this time awaiting results may be distressing and apologise for this.

Once the results are available, you will be invited to an Obstetric Consultant appointment where these will be explained. You will also be able to ask any questions you may have.

Registration

Miscarriage

If your baby died before 24 weeks of pregnancy, for legal reasons this is called a miscarriage. In this case, the birth is not formally registered at a register office. A certificate of life can provided.

Stillbirth

If your baby died after 24 completed weeks of pregnancy and before birth you need to register your baby as stillborn within 6 weeks. You don't have to enter a name on the register, but you cannot add a name or change the name you have given after you have registered.

The hospital will email the Medical Certificate of Stillbirth to the Register Office. You can ask your midwife to give your phone number to the Register Office so they can call you to book an appointment. At the appointment you will receive a form to permit the burial or cremation and your baby's stillbirth certificate.

You can contact the Registrar office in Bath on 01225 47734 to arrange an appointment.



Funerals, Saying Goodbye

For some parents, saying goodbye to your baby can be a very important part of coming to terms with your loss. The hospital Chaplains can provide more information about this process.

The following options are available to you:

You can make arrangements with a funeral director of your choice and have the service in your desired location. Often funeral directors conduct this service free of charge or require a minimal fee. Some cemeteries make a charge for a burial. You may want to look at 'natural burial grounds' as an alternative.

The hospital chaplain can arrange the funeral on your behalf with the Hospital contract funeral Directors. There is no cost for the burial or cremation which will be conducted by the hospital chaplain at Haycombe cemetery in Bath. The chaplains will support you through the process.

Some choose to bury their baby in a private location (for example their garden). When the gestation is less than 24 weeks of pregnancy the hospital can provide the necessary paperwork and guidance. If you would like to explore this option and your baby is greater than 24 weeks of pregnancy please speak to the Bereavement Midwife or hospital Chaplains.

For babies under 24 weeks of pregnancy there is also an option for shared cremation. The Hospital Chaplains oversee this in a non-religious and respectful manner. Any ashes are scattered at the cemetery grounds.

When considering cremation for smaller babies there may only be a small amount of ashes.

When considering a burial in the butterfly section of Haycombe cemetery you would be asked to sign a declaration regarding the maintenance of your baby's plot.

Your decision whether to attend the funeral is entirely personal and will be respected.

The decision does not have to be made during your hospital stay unless you wish to. Following discharge the Bereavement Midwife and/or Chaplain will call you to discuss further.

If you have made a decision please let the team caring for you know.

If you have not confirmed your wishes with the hospital after 12 weeks the hospital will assume responsibility for making the funeral arrangements on your behalf.

Physical recovery

Your care after you go home will depend your individual circumstances and needs. You can contact your GP or community midwives if you feel concerned about your health.

Pain relief

Most women experience tenderness and 'after pains' (cramping) following birth which is easily managed with simple pain killers such as paracetamol and ibuprofen if these are safe for you. Please read the instructions and discuss with your GP if you are unsure.

Vaginal blood loss

Following birth you should expect to experience heavy period-like bleeding, typically lasting from a week to 10 days. There are occasions when bleeding can be heavier or continues for a longer period, please contact a midwife or GP in this instance. If bleeding is unusually heavy please call 999.

Reducing infection

To reduce your risk of infection wash your hands before and after visiting the toilet or changing sanitary pads. Do not use tampons and change your sanitary pads regularly.

Perineal care

Regardless of whether you had any stitches, you may experience some perineal discomfort. Bathe or shower the area frequently without soap and change sanitary pads regularly. Resting on your side or pain relief if needed and doing pelvic floor exercises will aid healing. Talk to your GP or a midwife if you are concerned.

Passing urine

If you have any stinging or burning as you pass urine, need to pass urine frequently, are unable to pass urine or feel that you are not completely emptying your bladder, please discuss with GP.

Haemorrhoids/constipation

Avoid constipation by eating a high fibre diet and drink plenty of fluid, especially water. If you are having difficulty opening your bowels ask your midwife or GP for advice.

Headache

If you experience severe or persistent headaches, changes to your vision and/or nausea/vomiting please contact your GP or community midwives.

Exercise

If the birth did not require surgery, you can start gentle exercise as soon as you feel up to it. Listen to your body, pace yourself and make sure you get plenty of rest too.



Sex and Contraception

There are no rules about when to start having sex again after you have given birth. Should your perineum feel uncomfortable, please seek advice from the Bereavement Midwife or your GP.

You may ovulate as early as 3 weeks after the birth, even if your periods haven't started again. You can seek contraceptive advice from your GP or go to a family planning clinic for further information.

Neonatal death

If your baby was born alive at any stage of pregnancy and then died, you need to register your baby's birth and death within 5 days.

The hospital will send the relevant paperwork to the Registrar Office with your contact details. You will be contacted to book an appointment.

The Registrar will give you a Certificate of Birth which confirms that the birth has been registered. You don't have to enter a name on the register, but you cannot add a name or change the name you have given after you have registered.

The Registrar will also provide you with a Certificate of Registration of Death and a form to permit burial or cremation, which will be required for the funeral arrangements.

You can contact the Register office in Bath on 01225 47734 to arrange an appointment.

For Stillbirth and Neonatal death you may choose to purchase a full certificate at a cost of £11.

Blood Clots (VTE)

During pregnancy and following birth your blood is thicker and sticky. This happens naturally to help your blood clot following the birth and delivery of the placenta. It also means that blood clots in the legs and lungs are more common.

If experiencing sudden onset of any of the following please contact Bath Birth Centre or your GP for advice:

- Pain and swelling of one limb
- Chest pain
- Shortness of breath.

If your symptoms are extreme please contact 999.

Sepsis

Sepsis (severe infection) is a whole body response caused by an infection. It is more likely to occur during pregnancy and following the birth.

Common signs and symptoms include:

- High temperature
- Increased heart rate
- Increased breathing rate
- Confusion

If you have any concerns please contact your midwife or GP.

The time between sepsis being suspected or diagnosed is critical so please don't delay calling for advice. If you are very unwell please call 999.

Breast care

You may find that 2-5 days after birth your breasts feel full or uncomfortable as they produce milk. This is a normal bodily response following birth. If your breasts are not stimulated they will gradually stop producing milk and return to normal.

Occasionally mastitis can develop, this is where the milk is not moving and causing inflammation in your breast. Signs of mastitis may include a localised area in the breast which is painful to the touch, a lumpy breast which feels hot to touch, whole breast aches and may be swollen. You may also have flu like symptoms such as aching, increased temperature, shivering, feeling tearful and tired. If you think you have mastitis please seek advice from your GP.

Here are some management options to consider;

Let your body follow its normal process. If your breasts feel uncomfortable or painful, you may take pain relief (paracetamol or ibuprofen). Your breasts will gradually stop producing milk, become soft and less full. You may wish to hand express small amounts of milk to improve breast comfort, please ask your midwife for more information on how to do this.

Take a medication called Cabergoline that suppresses the production of milk. For most women this is effective and breastmilk is not produced. Occasionally this medication is not effective and simple pain relief is required until the milk production naturally stops. (Cabergoline is suitable for everyone, please ask for more information if you have any medical conditions).

Consider donating breast milk to the **Southwest Neonatal Donor Milk Bank**. If you wish to do this or would like to understand more please ask your midwife or contact the Milk Bank on:

Milk.bank@nbt.nhs.uk



Follow up

Bereavement Midwife

The Bereavement Midwife will make contact with you and can try to answer any questions you have over the phone or by email or by appointment depending on your needs. Contact details are at the front of this booklet.

Consultant appointment

You will be offered an appointment with an Obstetric Consultant usually 10-16 weeks after you leave the hospital to discuss your health and the results of any test you have accepted. The appointment also gives you the opportunity to talk about possible future pregnancies and to ask any other questions that may have arisen.

Support and useful contacts

A Service to Remember Special Babies

Twice a year the RUH holds a service to remember special babies in collaboration with SANDS. In May a service of remembrance is held in the chapel close to the butterfly section at Haycombe Cemetery. In November or December a service of light is held locally. The services may include the reading of names of babies, music, poetry, lighting candles and an act of remembrance. All are welcome. The services will be publicised via RUH social media, the RUH website and through Bath SANDS Facebook and website.

Support groups in Bath

- The Butterflies Support Group is held on the third Wednesday of each month at 09.30-11.00am. (no group in August)
- At the All Saints Centre, courtyard room.

(Further information on RUH website or from the Bereavement Midwife or Chaplains)

 SANDS Support group is held on the first Tuesday of the month at 7-9pm at St Stephen's Church in the foyer.

(Further information on the Bath SANDS Facebook or website)

Support groups and useful addresses

Baby loss

www.babyloss.com

Baby loss is a UK-based resource of information and support for bereaved parents and their families who have lost a baby at any stage of pregnancy, at birth, or due to neonatal death.

Dad Still Standing

www.dadstillstanding.com

Website and podcasts where dads can share their experience.

Miscarriage Association

www.miscarriageassociation.org.uk

Support and information for those affected by pregnancy loss, including support in another pregnancy.

Helpline: 01924 200 799 Email: info@miscarriageassociation.org.uk

Sands Stillbirth and Neonatal death charity

www.sands.org.uk

Support for families following baby loss.

Helpline: 08081643332 Email: helpline@sands.org.uk

The Mariposa Trust

www.sayinggoodbye.org

Advice, information and support for families following baby loss.

Helpline: 0845 293 8027 Email: support@sayinggoodbye.org

TAMBA Bereavement Support Group

www.tamba.org.uk

Support for families who have lost one or more children from a multiple birth, including support in another pregnancy.

(Part of the Twins and Multiple Births Association – TAMBA)

Helpline: 0800 138 0509 Email: staceywills@tamba.org.uk

Cruse bereavement care

www.cruse.org.uk/Bath

Cruse Bereavement Care provides a range of services for people of all ages, including adults, children and young people.

Tel: 01761 417250 Email: crusebath@btconnect.com

Winston's Wish

www.winstonswish.org.uk

Help and support for bereaved children and young people up to age of 18.

Helpline: 0845 2030405 Email: info@winstonswish.org.uk



Child Bereavement UK

www.childbereavement.org.uk

Supporting families when a baby or child dies and when a child is bereaved, including support in another pregnancy.

Support and information: Freephone 0800 02 888 40 or 01494 568900

Baby Mailing Preference Service (MPS)

www.mpsonline.org.uk/bmpsr

Free site where you can register online to reduce baby-related mailings of samples, advertisements etc.

Address: DMA House, 70 Margaret Street, London, WIW 8SS

Tel: 020 7291 3310 Email: bmps.dma.org.uk

Aching Arms

www.achingarms.co.uk

Provides support for parents after baby loss during pregnancy at birth or

Feedback

We welcome all feedback about your experience of bereavement care as we continue to develop and improve services. If you feel able please use this QR code to give anonymous feedback.



Royal United Hospitals Bath NHS Foundation Trust Combe Park, Bath, BA1 3NG

01225 428331 | www.ruh.nhs.uk

If you would like this leaflet in email form, large print, braille or another language, please contact the Patient Support and Complaints team on 01225 825656.

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Babies Book of Remembrance

Tel: 01225 824039

Parent(s) full names.....

Baby Books of Remembrance are kept in the hospital Chapel to enable parents to record the name of their baby who died at or near the time of birth. Please use this form if you wish to have an entry made for your baby. You can either leave this form with staff caring for you or post to the Spiritual Care Centre.

Address
Baby's full name (including surname):
Male/Female/Unknown (please circle)
Date of birth:/20 Date of death:/20
Your tribute (maximum words 40):
Return this form to: Spiritual Care Centre, RUH, Combe Park. Bath BA1 3NG.