

Handbook for Bereaved Parents

Information for parents



Leeds
Maternity Care

Introduction

We would like to offer our sincere condolences on the loss of your baby/babies. We understand that this will be a very difficult time for you and your family. There are so many different emotions and reactions after receiving bad news and every parent's experience is individual.

All staff involved in your care will explain what is happening along the way however, we appreciate that sometimes it can be difficult to remember all the information given to you and we hope this booklet will act as a support for you and your family.

Emotions which you may face

Grief is very individual. The death or loss of your baby can bring a grief that is deeper and lasts much longer than most people realise.

You may experience a range of emotional and physical reactions, some of which you may not expect. You may feel a sense of emptiness, and experience feelings such as anger, sadness and confusion. You may also find it hard to understand and remember what people are saying, these are all normal feelings.

Who will be informed?

Following diagnosis of the death of your baby, it is important that certain key people are aware. With your permission, we will inform your GP, Community Midwife and Specialist Public Health Nurse (Formally known as a Health Visitor). We will also cancel any future antenatal appointments you may have planned.

At the Hospital

Coming in to hospital

We have arranged for you to attend (please circle):

Snowdrop Suite at St James Hospital / Rosemary Suite at Leeds General Infirmary

On:

On the day of your admission please ring the Delivery Suite at **09.00am** and ask to speak to the Co-Ordinator.

LGI: 0113 392 7445 or **SJUH: 0113 206 9103**

When you arrive please call the delivery suite and a member of staff will meet you at the entrance of the Clarendon or Gledhow wing to accompany you to delivery suite.

Parking

Free onsite parking is available at both Leeds General Infirmary and St James Hospital.

At St James's please park in the multi-storey car park, this must be arranged prior to your arrival by providing your name, telephone number and car registration number. This can be done when you call the delivery suite before your arrival.

If you are having your baby at the LGI, you will need a 4 digit pass code so you can access a car park near to the Clarendon wing, you will be given the code when you ring delivery suite.

What shall I bring with me to hospital?

It can be very difficult to decide what you will need to bring with you, so we have created this list of **suggested** items as a helpful guide.

Please do not worry if you haven't got any of these items for you or your baby. The hospital has a selection of baby outfits and blankets you can choose from.

For you:

- Maternity notes
- Any prescribed medication
- Dressing gown, nightwear and slippers
- Toiletries and hair bobbles
- Maternity/Sanitary pads
- Breast pads
- Phone and/or camera
- Books, magazines, tablet with pre-loaded films, music etc.
- Personal items you may wish to have in photographs (please do not bring any valuables into hospital)
- Loose change for vending machines, coffee shops and hospital canteen

For birthing partner(s):

- Change of clothes
- Toiletries
- Snacks and drinks

For your baby:

- Clothing
- Blanket
- Cuddle toys or teddy.

When will my baby be born?

Providing there is no medical urgency to deliver your baby straight away, you will usually be given options on what you want to do when you are told your baby has died. You may want to go home and take some time to adjust to the information you have been given.

It is important you feel listened to and supported. We will discuss the options, timescales and method of delivery for your baby. This will depend on your own personal medical and obstetric history. This discussion will be with a doctor and a midwife. We will give you time, privacy and an opportunity to ask any questions.

It is normally recommended that your labour is induced and for you to have a vaginal birth. We appreciate this may be hard to contemplate, but for most, this is the safest delivery and you are more likely to make a faster physical recovery. However you may want to consider a Caesarean section. If this is the case your doctor will discuss this with you.

How will my labour start?

Usually labour is induced by taking a tablet called Mifepristone. You will be offered this medication whilst you are at the hospital. Mifepristone prepares your womb for the next stages of labour. This normally takes time to work; so it may be recommended that you return home, with an appointment to come back to hospital in 36-48 hours. If we have concerns that you are becoming unwell it may be that we advise induction prior to the recommended 36 hours.

We understand you may be too upset at the thought of going home. If you wish to stay we will try to accommodate you in the most appropriate place in hospital.

You may wish to wait longer before taking Mifepristone and we can discuss with you the implications of making this choice.

Like any medication there are contraindications so you will be asked various health questions prior to taking Mifepristone and we will ask you to wait within the hospital for 30 minutes following administration. **If at home you experience any pain, bleeding or any other concerns please do not delay contacting delivery suite on the numbers you have been given.**

On your planned return to hospital nothing will happen without your consent.

You will be introduced to a named Midwife who will care for you during their shift.

You may require some blood tests and a cannula (a thin plastic tube inserted into a vein for drugs to be given through) on admission.

If your labour has not already started we will continue the induction process by giving you Misoprostol. Misoprostol causes your womb to contract and is usually given 36-48hrs after the Mifepristone. Misoprostol is given regularly as a course. How far along in your pregnancy and your individual medical history will determine how we give the drug as well as the dose and it's frequency. This will be sensitively explained to you on arrival.

Inducing labour can take some time, however the majority of births will happen within 24 hours of the Misoprostol being given.

What pain relief can I have?

The pain may start quite quickly, so you may decide to use self-help techniques in the early stages e.g. relaxation, breathing techniques, massage, TENS machine (if you have one) and regularly changing to a different position. You may also wish to have a shower or soak in the bath.

Additional pain relief is available for when you need it. There are several options to choose from and your Midwife will be able to advise you.

These options include:-

- Tablet pain relief such as **Paracetamol or Codeine**.
- **Entonox** (commonly known as gas and air). Entonox is breathed in through a mouthpiece. It is short acting and helps take the edge off the pain, but does not remove it completely.
- **Diamorphine**. Diamorphine is commonly given as an injection but can also be given through a drip in your arm. It doesn't take the pain away completely, but will reduce the pain by making you feel relaxed and sleepy.
- **Epidural**, this is a local anaesthetic injected into your lower back by an Anaesthetist. This generally stops all the pain. You may need an additional blood test prior to having an epidural. If you choose to have an epidural you will be cared for within the main delivery suite as you will need additional monitoring.

What happens when my baby is born?

The position you choose to give birth in is up to you - whilst most people deliver on the bed, there are a variety of different birthing positions you may wish to adopt depending on your individual circumstances.

After your baby is born, with your consent your Midwife will give you an injection into your thigh which will help with reducing bleeding and delivery of the placenta.

You or your birthing partner may wish to cut your baby's umbilical cord, but do not worry your Midwife will do this for you if you prefer.

Do I have to see my baby straight away?

For some parents, the idea of seeing or holding their baby may seem frightening. Deciding to see your baby or not, is a very personal decision. Some parents may want to see their baby straight away, others may wish to wait a while, and some parents may decide not to see their baby. If you are not sure what to do, please speak to your Midwife.

There is no right or wrong way; your Midwife will support your decision. If you initially decide not to see your baby, and then change your mind please let your Midwife know.

Sometimes one partner decides to see their baby while the other doesn't. This is a very individual decision and neither of you should feel under pressure to see your baby if you do not want to. The most important thing is for each person to decide what feels right for them. If you are not sure about seeing your baby you may want your Midwife to show you a picture of your baby first.

Your baby may have thin and delicate skin; there may be some areas of skin that may look sore or be discoloured. This is a normal and natural process, and we appreciate this may be distressing for you; your Midwife will be there to support you during this time.

You may want your Midwife to describe your baby's appearance to you before you see and hold them. Many parents say they are glad they saw their baby and got to spend precious time with them. If you do decide you want to spend time with your baby we have a special Moses basket for your baby called a 'Cuddle Cot'. This is a special kind of mattress that can be placed inside a Moses basket to help keep your baby cool and delay the natural changes in your baby's appearance.

Lactation choices

Following a pregnancy loss there are many complex emotions that you may go through. This can include emotional and physical pain that is experienced following childbirth and loss, which may involve continued lactation. Your midwife will discuss with you some options around lactation following birth.

- Natural Suppression
- Suppression using a medication called cabergoline. This works by stopping the hormone production of prolactin which lessens the symptoms. This medication is best taken within 12 hours of birth. This is contraindicated if you are breastfeeding another child.

Natural suppression

The amount of milk produced in the breast will vary from person to person. This will reduce naturally over a period of 4-7 days.

Sometimes breast engorgement may be experienced. It can happen between 2-5 days after birth.

Some suggestions to help include:

- Take regular pain relief such as paracetamol and ibuprofen. It is important you follow instructions on how to take these.
- Wear a supportive bra day and night
- Use cold compresses or gel packs

Cabergoline:

This will be prescribed by medical staff and the dose will depend on if you have been expressing previously. This will be discussed with you by the medical team.

Milk Donation:

Not everyone wants to stop lactating at this difficult time, and there is the option of donating your milk to the UK National Milk Bank for it to be used to treat premature, sick babies or for research. Chester Milk Bank offer milk gifting and further information can be found at www.milkbankatchester.org.uk/donate/

Naming your baby

Some parents may choose to name their baby, as it may help to give them an identity or help when talking about them. However, this is a personal decision, so you should not feel any pressure to do this.

Depending on what stage of pregnancy your baby was born or, if they died quite a long time before birth, it may not be possible to tell if your baby is a boy or a girl. In this situation you may wish to use a unisex name.

Creating memories

You will be offered the opportunity to create memories and collect keepsakes. Memory making may be delayed in some circumstances, your midwife will discuss this with you.

If you do choose to create memories your midwife will suggest a range of things you can do, which will be dependent on your baby's size and gestation, for example taking photographs and hand and foot prints. You can also choose to leave a personal item with your baby which will stay with them at all times.

You may want to bring something in to hospital with you to dress or wrap your baby in. If you haven't please don't worry, we have a selection of clothing and blankets available.

Some parents may wish to keep the clothes their baby wore and take them home. Please inform your Midwife who will facilitate this for you.

If there is something in particular you would like to do for your baby, please let your Midwife know.

Photographs

With your permission we can take some photographs of your baby for you, or you may wish to take your own.

If you are unsure about having photographs of your baby taken, or if you do not want to see them straight away, please discuss this with your Midwife.

Photographs could still be taken and placed in a sealed envelope or saved on to a memory card and given to a relative or friend for safe storage.

We are unable to store photographs in your hospital records.

Hospital Memorial Book and Memorial Service

You may wish to have a message entered into one of our hospital Memorial Books in memory of your baby. The hospital also holds an annual memorial service for anyone who has been affected by the death of a baby or child.

For more details please contact the hospital Chaplaincy secretary on **0113 206 4365** or **0113 206 5935**

Taking your baby home

Some parents may wish to take their baby home; there is no legal reason why you should not do this, except in cases where a coroner has ordered a post mortem.

If you would like to take your baby out of the hospital, please discuss with the Midwife. We will need to complete some paperwork and inform some key people. We will also advise you on how best to keep your baby cool to try and reduce any natural changes in your baby's appearance.

If you decide on a post-mortem, timings of when you can take your baby home will be discussed with you. If you decide to arrange your baby's funeral yourself, you will need to contact a funeral director of your choice, who will then help you to care for your baby.

Or, if the hospital is arranging your baby's funeral we will tell you when and where to bring your baby back to the hospital.

Can I come back and see my baby?

When you leave the hospital, your baby will be taken to the hospital mortuary. If you would like to see your baby once you are home you can arrange to visit your baby in the Chapel of Rest. Please be aware that an appointment is required.

To arrange this please ring the mortuary within working hours.

8am-4pm Monday - Friday, outside these hours please ring Delivery Suite at the hospital where your baby was born.

LGI Mortuary 0113 392 3313 or SJUH Mortuary 0113 206 4312

What will my baby look like if I come back to visit them?

Your baby will feel cold to touch and there may be changes to the colour and appearance of their skin. These changes are often difficult to predict. Your baby will be lying in a crib, dressed in the same clothes and wrapped in a blanket as when you last saw them.

Any belongings will stay with your baby and they will be cared for with dignity and respect at all times.

Spiritual Involvement

Depending on your beliefs, you may want to have your baby blessed, baptised or another appropriate recognition/naming ceremony performed, and you may want family members to be present. Your midwife and a member of the chaplaincy team can arrange this with you.

How do I tell children my baby has died?

Telling anyone a baby has died can be extremely difficult, even more so when trying to explain this to children.

When talking to children it is important to be as open and as honest with them as possible. It is often hard to find the right words to explain what has happened, so use simple language and try to avoid using phrases such as 'we have lost the baby' or 'the baby has gone to sleep' as this can often cause further confusion.

Parents may worry about their children seeing them upset, depending on their age a child may not always understand what has happened but may sense that something is wrong therefore providing a simple explanation as to why you are upset may help to reassure them.

For further advice on how to support children during a bereavement, please see the Child Bereavement UK website, there is a link at the end of this booklet.

Investigations

We recognise that it is very important for parent's emotional recovery to try and find out why this might have happened. Therefore you will be offered a range of tests to try and gather as much information for you as possible. This may also help us to discover if there was a problem that could affect a future pregnancy.

The tests we will do fall into two main groups, investigations for you and investigations for your baby. Occasionally, despite doing multiple investigations no reason is found.

Investigation for you

We will ask your permission to take some routine blood tests when you are admitted to hospital for delivery. The tests required will be decided on an individual basis following a discussion with a doctor.

Placental examination

Important information can often be gained by a detailed examination of your baby's placenta. We will seek your permission to examine the placenta in detail in the laboratory to look specifically for infection and evidence of impaired blood supply. We will also take a swab from both sides of the placenta to look for any evidence of infection.

Post-mortem examination of your baby

All parents are offered the opportunity to consider a post-mortem examination for their baby. There are different types of post-mortem available to you. All post-mortems for babies are carried out at St James's hospital by specialist paediatric Pathologists;

You will be provided with an information leaflet about your options for post-mortem and it will be discussed with you in more detail during your stay in maternity services.

Hospital follow up appointment

You will be sent a letter inviting you to come back to the hospital to meet with your obstetric Consultant to discuss your personal experience, test results and any questions you may have. To ensure we have all test results available at this appointment it may not be arranged until 10-12 weeks after your baby was born.

This appointment will provide you the opportunity to ask any questions you may have, and if you were to consider another pregnancy, how to plan for it. You might find you are emotional during this appointment, so it might help to write down any questions you may have and bring them with you.

In specific circumstances a multidisciplinary review of your care will take place using the Perinatal Mortality Review Tool (PMRT). You will be supported to provide feedback regarding the care you and your baby received before the review has occurred. If this applies to you, you will be given all the relevant information prior to your discharge home.

More information regarding PMRT is available here <https://www.npeu.ox.ac.uk/pmrt/information-for-bereaved-parents>

Funeral arrangements

It is important to take your time and choose what feels right for you and your family. You can choose if you would like the hospital to arrange your baby's funeral or if you would like to contact a private funeral director of your choice to ask them to arrange it for you.

For more information about funeral options please contact the Bereavement Office:

St James Bereavement office **0113 206 6432 / 4162**

LGI bereavement office **0113 3923 560 / 392 2674**

(lines are open Monday to Friday 08.30-16.30)

Will there be a cost?

Regardless of whether you chose for the hospital to arrange your baby's funeral or whether you chose your own funeral director, Leeds City Council does not charge for a cremation or burial for babies and children who die under 17 years of age.

However, in both instances there may be additional costs for example for cars, flowers and headstones.

Can anything be put in my baby's coffin?

If your baby is going to be buried, then most items can be placed with them inside their coffin.

If your baby is being cremated, then cards, letters, small photographs and soft toys may be placed in the coffin with your baby. Anything metal or glass cannot be placed in the coffin with your baby.

Will I be able to have any ashes?

If you choose for your baby to be cremated every effort will be made to recover your baby's ashes. However if your baby is very small, there may be little or no ashes to collect.

You can choose to have your baby's ashes returned to you, or you may wish to have them scattered in the crematorium's baby garden. Parents can choose to attend the scattering of the ashes if they so wish.

If you arranged a private funeral, your funeral director will return your baby's ashes to you. If the hospital arranged your baby's cremation, you will be contacted by the bereavement office to arrange collection of your baby's ashes.

Legal Entitlements

If your baby died before or during birth and you were 24 weeks pregnant or more, this is known as a stillbirth. By law you are entitled to the same maternity rights as a parent whose baby was born alive. The same entitlements applies if your baby was born alive and then died, regardless of how many weeks pregnant you were, this is known as a neonatal death. The Parental Bereavement Act 2020 states that all parents who have had a stillbirth or neonatal death are entitled to at least two weeks paid leave.

For further information regarding your maternity entitlements please refer to the Maternity Rights Advice Line who will be able to provide tailored information based on your individual circumstances. Contact details are provided at the end of this booklet.

Unfortunately if your baby died before 24 weeks of pregnancy you are not entitled to maternity leave or maternity allowance. However, your GP may be able to provide you with a fit note.

Returning to work

Some people feel ready or need to go back to work after a few weeks whereas others may not return to work for several months. Grieving can be a lengthy process and many people describe experiencing poor concentration and a lack of energy for a long time after their baby has died.

You may want to make contact with your employer or colleagues before you go back to tell them what has happened. You may find it helpful to visit your workplace before officially returning to work.

Your feedback is important to us

Your views are very important to us and we welcome your thoughts and feelings regarding your care.

We have previously worked with other bereaved parents to develop a questionnaire called the Maternity Bereavement Experience Measure (MBEM). This questionnaire will be sent to you via post or email and your answers will remain anonymous, unless you wish to express your care with us.

We appreciate how difficult it may be to provide us with feedback. Feedback is optional and there is no timescale in which you need to do this. We will use your answers and comments to continually improve care for other bereaved parents.

Support groups and Information for Bereaved Parents

There are a number of organisations which understand and can support you and your family who find themselves trying to cope after such a devastating event. We have listed several for you, but this is not an exhaustive list, there may be other support groups more relevant to your individual needs.

If you cannot find the support you are looking for please contact the Bereavement team who may be able to help you further.

Antenatal Results and Choices

Website: www.arc-uk.org

Tel: 0845 077 2290 or 0207 713 7486 from a mobile.
Helpline open Mon to Friday, 10.00am-5.30pm.

ARC is a national charity that offers non-directive information and support to parents before, during and after antenatal screening; when they are told their baby has an anomaly; when they are making difficult decisions about continuing with or ending a pregnancy, and when they are coping with complex and painful issues after making a decision, including bereavement.

Angels and Stars

Tel: 07858541620 - Julie

Email: angelsandstars10@gmail.com

Support service for families who have had a stillbirth. They offer Holistic therapies, Meditation, Reiki, Massage and Counselling.

Bliss - the special care baby charity

Website: www.bliss.org.uk

Tel: 0500 618 140

Email: hello@bliss.org.uk

Support, advice and information for families of babies in intensive care and special care, including in situations of loss and for future pregnancies.

British Association of Counselling & Psychotherapy

Professional association and accrediting body for counsellors.

Website: www.bacp.co.uk includes a 'Find a Counsellor' section

Tel: 0145 588 3300, Mon - Fri 08:45 - 17:00

Charlies Corner

Website: www.charliescorner.uk/

Tel: 0113 285 2899

Email: via UK counselling network on
hello@ukcounsellingnetwork.co.uk

A Leeds based charity that offers support to bereaved parents and their families.

Child Bereavement UK

Tel: 0800 028 88 40 National Helpline

Email: support@childbereavementuk.org

Website: www.childbereavementuk.org

Live chat: via the website

A charity that has a dual focus of training professionals who work with families and children affected by a death which also produces excellent resources that can be used by those who are bereaved. This includes families and professionals supporting children affected by the death of an adult or anyone affected by the death of a child.

Child Death Helpline

Tel: 0800 282 986 - Mon-Fri 10:00-13:00, Weds only 13:00-16:00, Every day 19:00-22:00

Website: www.childdeathhelpline.org

Helpline support for anyone affected by the death of a child, irrespective of the age of the child, the relationship or the length of time since the death.

Childhood Bereavement Network

Tel: 0207 843 6309

Website: www.childhoodbereavementnetwork.org.uk

Although this organisation is mainly a professional network their website has a good search facility on its front page to allow you to find support services for children in your local area.

Cruse Bereavement Care

Website: www.cruse.org.uk

Email: helpline@cruse.org.uk

Tel: 0808 808 1677 National helpline number Helpline opening hours: Monday - Friday 9.30am - 5pm (excluding bank holidays) with extended hours on Tuesdays, Wednesdays and Thursdays to 8pm.

Hope Bereavement Support

Website: www.hopebereavementsupport.com

Tel: 07981955674

HOPE bereavement support offer supportive and therapeutic groups for parents and families around child loss and miscarriage within our diverse communities. They also offer resilience workshops for mental health, emotional wellbeing and self-care.

Leeds IAPT

Website: www.leedscommunityhealthcare.nhs.uk/our-services-a-z/leeds-mental-wellbeing-service/home/

Mental Well-being Service which offers online and face to face counselling.

MindWell

Website: www.mindwell-leeds.org.uk

Provides a wealth of online easy-to-use and accessible information for everyone's mental health needs.

Miscarriage Association

Tel: 0192 420 0799

Website: www.miscarriageassociation.org.uk

Provides support to those who have been affected by miscarriage.

NHS Choices

Website: www.nhs.uk

Gives access to find NHS services including hospitals and local doctors and helpful information on a huge variety of health related topics.

Stillbirth and Neonatal Death Society (SANDS)

Tel: 0808 164 3332

Email: helpline@sands.org.uk

Website: www.sands.org.uk/support-you

Welcomes calls from anyone affected by a stillbirth or a baby, family, friends or professionals including long after the event.

The Samaritans

Website: www.samaritans.org

Tel: 0845 790 9090

24 hour helpline support every day of the year for anyone in distress including those who are feeling suicidal.

Tommy's

Website: www.tommys.org

Tel: 0800 0147 800 Pregnancy Line

A charity that provides information and support for anyone who has experienced the loss of a baby, whether through miscarriage, stillbirth, neonatal death, or termination for medical reasons.

Taking Baby Steps

Website:

Email: admin@takingbabysteps.co.uk

Therapeutic, one to one support sessions for parents and families affected by pregnancy loss and/or birth trauma.

Face to face or online sessions

Winston's Wish

Helpline: 0808 802 0021

Website: www.winstonswish.org.uk

Gives support for those caring for children affected by the death of a parent or a sibling and to the children themselves.

Other useful information

Baby Mailing Preference Service (MPS)

Website: www.mpsonline.org.uk/bmpsr

Address: DMA House, 70 Margaret Street, London, W1W 8SS

Tel: 0207 291 3310

Email: bmps@dma.org.uk

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

Maternity Rights Advice Line

Website: www.maternityaction.org.uk/advice-line/

Provides tailored information regarding your maternity entitlements based on your individual circumstances.

For any further support, help or advice please contact:

Bereavement Midwife at Leeds Teaching Hospitals

Mobile: 0792 002 9180 or 0776 686 2627

Available: Mon - Friday 8am - 6pm

Useful contact numbers:

Bereavement office

LGI - 0113 392 3560

SJUH - 0113 206 6432

Mortuary / Chapel of Rest

LGI - 0113 392 3313

SJUH - 0113 206 4312

Delivery Suite

LGI - 0113 392 3831

SJUH - 0113 206 9103

Car Parking Services

Tel: 0113 206 6932

Post-Mortem Consent Specialist Nurse

Tel: 0790 043 3617

Chaplaincy Department

LGI - 0113 392 2914

SJUH - 0113 206 5935

Milk Bank (Memory Milk)

Tel: 0124 436 2226



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



© The Leeds Teaching Hospitals NHS Trust • 2nd edition (Ver 1)
Developed by: Laura Walton, Acting Deputy Head of Midwifery
Produced by: Medical Illustration Services • MID code: 20230914_009/BP

LN005045
Publication date
10/2023
Review date
10/2026