

Pregnancy loss Information for women, partners, and families



You will need to come back to labour ward on (date)
Please call labour ward on (Tel)
at 9am to arrange a time to come in.

We wish to express our sincere sympathy to you, your family, and friends during this very sad time.

Please do not hesitate to ask questions if you are unclear about any matter, our staff will always be pleased to help.

"There is no footprint too small that it cannot leave an imprint on this world"

- parent



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Introduction

The loss of your baby, whether during pregnancy, labour, or after birth, is a time of great anxiety and distress for you, your partner, other children, your family, and friends.

Unfortunately, even at the most difficult times there are certain things that must be dealt with. Our aim is to provide you with support and advise you of some of the practical and official decisions that you will need to make.

The aim of this booklet is to provide you with important information and advice on more practical elements, including registration of the birth, stillbirth, or death, and making funeral arrangements, without feeling too overwhelmed.

Our team will be there to inform and support you during your admission.

It is our aim to fulfil your spiritual and cultural needs, as well as support parents and families to make as many memories as possible of those precious moments shared with your baby.

Taking time to think about what you want for your baby is important – go at your own pace.



Grief

Everybody reacts in different ways to losing a baby. Apart from differences in personality, there are a variety of circumstances, cultures, and beliefs, which will influence the way you react to grief.

It is likely that you will feel numb, angry, and emotionally confused. Although difficult to understand, these emotions are quite normal.

Grieving varies greatly from person to person and there are no set time limits dictating how long the pain will last. You may find it hard to take in what has happened, to understand why it has happened and to remember what people are saying.

Many bereaved parents have physical reactions to grief. You may have palpitations, chest pains, a lump in your throat or butterflies in your stomach. You may not feel like eating and you may feel exhausted but struggle to sleep. You may be physically, as well as emotionally, drained.

All these reactions are difficult to cope with but normal when you experience a loss. However, if you are concerned, please speak to a midwife or doctor. Please see the end of the booklet for our contact details.



What to expect next

When you are ready, our staff will clearly explain what your choices are and what is likely to happen next. Your labour may have to be started artificially, which will help to deliver your baby. If you have any questions at all, please don't hesitate to ask us. Once these have been answered, you will be asked to sign a consent form to agree to the induction of labour procedure.

The method we use to induce labour is by giving tablets. You will initially be given a medicine called 'mifepristone'. You do not need to start this immediately and we can arrange a time for when you would like to come back.

Sometimes the mifepristone can cause nausea and vomiting. You will be given a tablet to help prevent this. We will ask you to remain in the hospital for a short while after taking it.

You will be able to go home after taking the mifepristone if you are well and you wish to. Please note, you will need to return to the hospital in 36-48 hours for the next medication. The team will arrange a date and time for you to come back to the labour ward. We know this is a very difficult place to be, but our clinical colleagues will support and help you at this time.

If you have any of the following symptoms when you return home, please call the labour ward (our details are on the back of this booklet) immediately:

- Any vaginal bleeding
- Your waters break
- Pain
- Fever
- Any other concerns.

While very rare, your baby could deliver while you are at home. If this does happen, please call for an ambulance.

When you return to hospital, you will be given a medicine called 'misoprostol'. Please be aware that you'll be given this at regular intervals depending on your needs; it can take some time to take effect and you can expect to be in hospital for a minimum of one- two days.

After you have given birth to your baby, your placenta needs to be delivered. If you require any help with this, our doctors will be available to support you.



On admission to hospital

Before coming back into hospital, please call us at 9am to confirm that you are coming in:

Barnet Hospital labour ward

If you are under the care of Barnet Hospital, please call the labour ward on 020 8216 5180 to confirm that you are coming to the Butterfly Room (located on the labour ward). The team will then advise you of the time to come in.

Royal Free Hospital labour ward

If you are under the care of the Royal Free Hospital, please call the labour ward on 020 7794 0500 extension 33850 to confirm that you are coming to the Serenity Suite (located on the 5th floor, labour ward). The team will then advise you of the time to come in.

There is open visiting for your family on the labour ward, and facilities for family to stay overnight with you. However, we advise you limit yourself to two birthing partners. You will have a private room with en-suite facilities. Free Wi-Fi facilities are also available.

Please bring clothes and items (eg snacks, music, a laptop) to make your stay more comfortable.

The team of doctors will come to see you and answer any queries that you may have. You will also have a midwife who will be looking after you and your family. They will discuss the delivery with you when you are ready, and your personal wishes will be always respected.

After the medication is given, you might start having some period like pains, abdominal cramps, and vaginal bleeding. These symptoms are generally normal. However, we need to monitor them.

We also have anaesthetists who are expert doctors to help you with the pain relief. They will be able to discuss the options for pain relief with you and together decide the most suitable options for you to be comfortable. Please see information about pain relief on page seven.



Pain relief information

Most women require combination pain relief during labour. The best combination of pain relief (also known as 'analgesia') will depend on the type of pain you have and its severity, the side effects of the pain relief, your general health, and your preference.

The different types of pain relief you can receive includes:

Inhalational analgesia (Entonox)

This is a 50:50 mixture of nitrous oxide and oxygen. It is inhaled at the start of each painful contraction in the first and second stages of labour. The main advantages of entonox are that its administration is under your control, it takes effect within seconds and wears off quickly. It is safe but may cause disorientation and feelings of sickness.

Intramuscular analgesia (injections)

Pethidine is a strong opiate analgesic injected into the muscle. It works like morphine. A maximum of two doses can be given every four hours by your midwife. Side effects include:

- Feeling or being sick
- Constipation
- Dry mouth
- Feeling dizzy or sleepy
- Itchy skin
- Skin rash
- Sweating
- Headache
- Dry mouth
- Feeling flushed
- Difficulty passing urine
- Shallow breathing.

Patient controlled analgesia (PCA)

Morphine PCA is a way of delivering morphine directly into the veins, through a tube (drip) attached to a pump with a button. It works faster than oral morphine, and the pump is controlled by you. You can give yourself a dose every five minutes at the most (an intrinsic safety mechanism), as and when you need it.

The side effects are identical to oral morphine listed above.

Oral analgesia

These can range from simple over-the-counter medicines such as paracetamol and ibuprofen for mild to moderate pain, to combinations with stronger 'opiate' type drugs such



as dihydrocodeine (co-dydramol) or oral morphine. Oral morphine is a strong analgesic for moderate to severe pain.

They have side effects include:

- feeling or being sick
- constipation
- dry mouth
- · feeling dizzy or sleepy
- itchy skin.

Your midwife or doctor will ensure there are no contraindications to you taking these medicines.

Regional analgesia: Epidural

Pain relief from an epidural is achieved by delivering a 'local anaesthetic' drug into the lower spine, close to the nerves that transmit pain during labour, through a fine tube inserted into the lower back and connected to a pump, controlled by your midwife. It is the most effective way of relieving pain in labour.

However, it requires you to have a drip inserted, recent blood results and to be consented by an anaesthetist who is a specialist doctor trained to site epidurals. It is an invasive procedure and therefore whilst it is the most effective pain relief, you should understand the risks associated with it:

Risks of epidurals

- Failure/ineffective epidural (1:8)
- Dural puncture headache 1:100
- Nerve damage 1:10000-1:100000
- Bleeding /infection 1:100000
- Accidental brief unconsciousness
- Drop in blood pressure
- Feeling or being sick
- Shivering
- Itching
- Heavy legs
- Prolonged second stage of labour
- Slightly increased risk of instrumental delivery
- Need for temporary urinary catheterization.

Your anaesthetist can explain these in greater detail.

If you require further information on pain relief options please talk to your midwife, obstetrician, or anaesthetist. They will help you decide the safest and most effective option of pain relief for you, to help you through this difficult time



After baby is born

It is your choice as to whether you and your partner wish to see and hold your baby. Many parents may feel anxious about seeing their baby and others may be more comfortable with this. It is important that you do not feel pressured to make an immediate decision. Staff can help and advise you as to the appearance of your baby.

Decisions that were made earlier can be changed once your baby is with you in case you feel differently about the original choices you made.

After the birth is complete, you and your partner can be left to spend time in private together as a family to start creating your memories.

We have a 'cuddle cot' which can be set up in your room; this helps us to keep your baby at a cool temperature. The cuddle cot does not prevent the deterioration process, it just slows it down to enable you to spend as much time as possible with your baby. When you are ready, or when you go home, your baby will be cared for by our colleagues in the mortuary department.

If you wish, once you are at home, we can arrange a viewing for you with your baby at the mortuary. Please remember that the condition of the baby changes with time. Your bereavement midwife or the bereavement office will be able to assist with this.

Creating memories

Some parents prefer to have mementos of their baby. The midwife caring for you can support you in creating these mementos. Some parents do not want physical memories relating to their baby; the midwife caring for you will understand and support your wishes.

Mementos may include photographs, handprints and footprints, an identification bracelet, and a lock of hair where possible. The midwife will suggest taking photographs of your baby if possible. Photographs are never taken without parental consent. We will offer to take photographs for you, or you may wish to take your own photographs of your baby.

You will also be offered a special box which has other additional ideas for you to create further memories of your baby if you wish. These memory boxes are donated by other bereaved parents and families.



If you would like to, you can bathe and dress your baby. The hospital can provide clothes and blankets, but if you prefer you can bring in your own. You can also bring in toys or other special objects (a letter, family photos, drawings from brothers or sisters) which will stay with the baby and can be placed in their coffin. (Please note that aluminum and glass may not be permitted by some crematoriums.)

You do not have to take any of these if you do not wish to.

'I decided that it would be better to have a photograph that I may never look at, than want a photograph that I could never have.'

Anonymous dad



Investigations

We will offer to investigate the cause of death of your baby. Despite these investigations however, it is possible that the cause may not be identified.

You will be given a booklet by Sands, a stillbirth and neonatal death charity in the UK, called: 'The Sands bereavement support pack'. This booklet contains lots of helpful information and will assist you when making your decision. This booklet is also available online: sands.org.uk/sands-bereavement-support-book.

You may be advised to have a blood, urine, and swab tests while you are with us in the hospital. Your midwife can explain what these are for.

It may be recommended that a post-mortem investigation be carried out on your baby. This is an examination of the baby's body and internal organs in close detail, to try to understand more clearly what happened. Sometimes, however, we are unable to find such a cause. It can be very difficult and distressing to think of such an examination, but sometimes a post-mortem is the only way to provide information which may help you to understand what caused your baby to die.

Post-mortem examination is helpful to confirm antenatal diagnosis such as abnormalities seen on scans, and for planning future pregnancies.

By doing a post-mortem examination, important information may be gained which can help you in the future if you wish to have another baby or help other couples who have similar problems. Some parents are certain from the beginning that they want a post-mortem, others may not be sure. It is your decision (except in a coroner's case).

Your consent is required for a post-mortem and the doctor or midwife will go through the paperwork with you before you sign the form. A copy of the paperwork you signed is available on request to you. Once you have made the decision for the examination, you will have a 'cooling off' period (usually 24 hours) in which you can change your mind.

If the coroner decides a post-mortem investigation is necessary, it can be done without your consent, however you will be kept informed at every step of the process.

Where will the post-mortem investigation be carried out?

If you have given your written consent, the examination will be carried out with care and in a sensitive manner at Great Ormond Street Hospital, by a pathologist who specialises in the examination of babies. Your baby will be transferred there by a funeral director appointed by the hospital.

Post-mortems are undertaken during weekdays (Monday to Friday) and are usually completed within two weeks. The hospital funeral director will then collect your baby once the procedure is complete and come back to us here at the hospital.



What other investigations are available?

If you do not wish to have a post-mortem, some other examinations are available. These include:

Placenta histology

If you do not wish to have a post-mortem, you are able to request an examination of the placenta only and this is also done at Great Ormond Street Hospital. A placenta histology may be able to give information about the pregnancy loss. Again, you will be asked to sign a consent form and you are entitled to a copy of this.

Cytogenetics

In addition, in some cases, we can send a small piece of the placenta to the genetics team at Great Ormond Street Hospital to give a report on your baby's chromosomes. This is known as cytogenetics. A cytogenetic test may be able to give information about the pregnancy loss. The team can advise you further about whether this test can be offered to you.

How long will I wait for the results and how do I receive them?

You may need to wait at least 12 weeks for the results, and you will receive them when you have your follow up appointment with the consultant at the hospital. The bereavement midwife will organise this appointment for you once all the results are available. This will enable you to ask any questions and make any plans for future pregnancies.



Chaplaincy support and spiritual care

Our chaplains are here to offer you support. They are here for everyone of any faith, belief, or philosophy of life. You do not have to think of yourself as religious to use the service. We have a diverse team of chaplains in the hospital, including Christian chaplains (Anglican and Roman Catholic), an Imam and female Muslim chaplain, and a Rabbi. They can come and talk to you while you are on the ward or contact you afterwards when you return home.

Naming or blessing for your baby

Naming or blessing can be very important. Choosing a name is one way of doing something positive for your baby. It helps to give focus and identity to thoughts and feelings about your baby. It may not be possible to tell the sex of very tiny babies, but you may want to choose a name suitable for either sex.

Some people find it helpful to have a brief ceremony for naming or blessing their baby. You may like to ask someone to do this with you. The chaplaincy team can support you in this. If you would like us to arrange a naming or blessing service for your baby, the midwife will contact the chaplaincy department or another appropriate person.



Arranging the funeral

Your baby's funeral can be a way of marking the end of the first stage of grieving. For others in your family, it can be a way of acknowledging your baby's death as well as their own grief. It is important you take your time and choose what is right for you and your family.

The chaplaincy team, bereavement midwife and local funeral directors will be able to offer you the information, support, and guidance that you will need to help make your choices.

Funeral options that are available to you are:

1) Hospital to make arrangements without your involvement for a dignified communal cremation.

Parents of any baby born before 24 weeks gestation that has not shown any signs of life after being born have the option of a communal cremation. This is where babies are cremated together in a respectful way without your involvement. There is no service and the ashes are scattered in a Garden of Remembrance:

- For Barnet Hospital: Garden of Remembrance, Hendon crematorium
- For the Royal Free Hospital: The Children's Garden, Golders Green crematorium

2) Making arrangements for a private funeral yourself

You can organise the funeral yourself either through calling a funeral director of your choice directly, or by contacting your specific faith leader. If you have any questions or would like help with organising the funeral, please contact a chaplain.

3) Making arrangements together with the bereavement midwife and chaplaincy team

Individual cremation (any gestation)

If you wish for an individual cremation and service, we can organise that for you. Cremations from Barnet Hospital take place at Hendon Crematorium and cremations from The Royal Free Hospital will take place in Golders Green crematorium. We will be led by you regarding what kind of service you would like. This can include silence, reading a poem, lighting candles and/or prayers, depending on your tradition and preference. Ashes can be collected after the funeral from the crematorium office. The chaplain or crematorium will give further information on this.

Individual burial (this will be a shared grave, but each baby will have their own section) – any gestation.

Burials from Barnet Hospital take place at Hendon Cemetery, and burials from the Royal Free Hospital take place at St Pancras Cemetery in East Finchley.

The chaplain can plan the service with you depending on your individual needs. The service will take place individually, by the graveside.



If you have any questions, or would like to talk about how you feel, please contact us through the main hospital switchboard or ask your bereavement midwife for further details.

Please note there is no charge for any hospital arranged funeral

The annual remembrance service

During 'Baby Loss Awareness week' (usually every year between 9-15 October) there is a service at the Royal Free Hospital for all to attend.

Barnet Hospital holds a remembrance service on the last Sunday of November in the chapel at 3pm.

For further details please contact the chaplaincy team.



Registration

Registration must be completed before your baby can be buried or cremated.

- 1. If your baby was born after 24 weeks of pregnancy and was not alive the law requires you to register your baby's birth at the Registrar of Births, Marriages and Deaths at the local register office within 42 days. The labour ward staff will complete the stillbirth certificate, and this will be sent to the registrar. You will be contacted by the registry office by telephone to complete the registration. This is required by law to make arrangements for the funeral for your baby.
- 2. If your baby was born alive and then died the law states that your baby's death must be registered at the registrar of births, marriages, and deaths within five working days of death. The labour ward staff will complete the certificate, and this will be sent to the registrar. You will be contacted by the registry office by telephone to complete the registration. This is required by law to make arrangements for the funeral for your baby.

If you and your partner are legally married, then either of you can register your baby. If you are not legally married, the mother must register the baby and if the baby's father wants his details to be on the certificate, then both of you must be present for the call.

The registrar will ask for:

- The mother's name, occupation, date and place of birth, and any other names that the mother might have used, including maiden name if applicable.
- The father's name, occupation, date and place of birth, and any other names that the father may have used.
- The date of your baby's birth.

Please call the relevant registry office to arrange an appointment.

If you had your baby at Barnet Hospital

Please contact the Hendon Register Office.

Address: Hendon Register Office, The Burroughs, NW4 4BG Telephone: 020 8359 6400 Opening hours: Monday to Saturday, 9am-3.30pm

You can book an appointment online through their website: www.barnet.gov.uk/birthsdeaths-and-ceremonies.

If you had your baby at the Royal Free Hospital

Please contact the Camden Register.

Office Address: Camden Register Office, Camden Town Hall, Judd Street, London WC1H 9JE

Telephone: 020 7974 4444

Opening hours: Monday to Friday, 8.30am-4.30pm

You can book an appointment online through their website: www.camden.gov.uk/births-

deaths-marriages-citizenship.

The registrar will give you some paperwork which includes a certificate that is needed for



the funeral arrangements The certificate will need to be handed to either:

- Your funeral directors if you are making your baby's funeral arrangements yourself or
- The bereavement officer/bereavement midwife if the hospital is arranging your baby's funeral for you.



Taking baby home

There is no legal reason why parents should not take their baby home to make their own arrangements for the funeral unless the coroner has requested a postmortem.

For your protection and to avoid any misunderstanding, there is paperwork which will be given for you to complete.

If the baby needs to be registered, then the registration will need to be completed before the baby can go home with you.



Going home

General advice about your health

- You may experience some pain and abdominal cramps which should resolve by taking simple painkillers such as paracetamol and ibuprofen. Bleeding is to be expected but this should not be heavier than a period. We recommend you use sanitary pads. Do not use tampons until your next period.
- Do not have sexual intercourse until the bleeding has stopped.
- It is fine to shower or bath, but do not swim until after your next period.
- Your midwife will discuss and explain any medications that you may need when you go home.

If you have concerns about your health, for example:

- abnormal vaginal bleeding
- signs of infection
- severe abdominal pain
- severe headache with visual disturbances
- breathlessness
- pain/swelling in your calf
- or any other symptoms that are worrying you

Please seek urgent medical advice or come back to the labour ward.



Follow up

The community midwife will visit you at home if requested or advised.

The bereavement midwife will contact you once you are home to discuss any concerns.

You need to book an appointment with your GP in six weeks just to ensure you are well. If you have any problems or concerns seek medical advice earlier on. The GP will be able to advise about contraception.

You may need a blood test. The bereavement midwife will inform you if you require this blood test and will book you an appointment.

You will also need to have a follow-up appointment with a consultant obstetrician. This happens at the hospital where you gave birth. Test results and future pregnancy plans will be discussed with you and your birthing partner.



Review of all stillbirths, neonatal and child deaths at the Royal Free London NHS Foundation Trust

By listening to parents and health professionals, the stillbirth and neonatal death charity Sands recognised the need to improve and standardise the quality of hospital reviews of baby deaths.

When a baby dies before, during or after birth, the hospital (or hospitals) where the mother and baby were looked after should review the care the mother and baby received. This is called a hospital 'perinatal' or 'neonatal' review and is when a clinical team looks through the mother's and baby's hospital notes to understand events that led up to the death of the baby. It is different to a coroner's investigation or inquest.

The hospital review forms part of standard NHS care, which should be provided for every family after a death, so that bereaved parents have as much information as possible about why their baby died. Another important reason why hospitals carry out reviews of any baby who is stillborn or dies in their care is to learn from what happened in order to improve care and prevent, if possible, the death of other babies in the future.

As a bereaved parent you will be told by your hospital that a review is going to take place and be offered the opportunity to ask questions or provide information about your care for the review panel to think about during their review. You will not be asked to attend the review meeting yourself, but we can arrange a meeting for you if you wish.



Maternity bereavement experience measure

We are always looking at ways to improve care of our patients and would value your feedback if you feel able to provide it. The information we receive it used to improve services and offer the best possible care. This questionnaire is anonymous.

Please scan the QR code below for the feedback questionnaire.

On your compatible smart phone or device, open the built-in camera app. Point the camera at the QR code, tap the banner that appears and follow the instructions given on the screen.

Thank you for your time.





Ongoing support

Please contact your bereavement midwife if you need any additional advice or support.

Counselling is available for you through the hospital and your bereavement midwife can help you with a referral, or you can speak with your GP who may be able to refer you locally.

Sands

Stillbirth and neonatal death charity.

Website: www.uk-sands.org.

Telephone helpline: 020 7436 7940.

North east London

Telephone: 07948 272 486.

West London

Telephone: 07905 714 415. Email: helpline@uk-sands.org.

The Miscarriage Association

Website: www.miscarriageassociation.org.uk.

Telephone helpline: 01924 200 799

Email: info@miscarriageassociation.org.uk.

ARC

National charity helping parents and healthcare professionals through antenatal screening and its consequences.

Website: www.arc-uk.org.

Telephone helpline: 0845 077 2290 or 020 7713 7486 from a mobile

Email: info@arc-uk.org.

Child Bereavement UK

Website: www.childbereavementuk.org. Telephone helpline: 0800 0288 840 Email: support@childbereavementuk.org.

Lighthouses Therapy Services

Website: www.lighthousestherapysevices.co.uk.

Telephone: 07584 040 223.

The Mariposa Trust

Website: www.mariposatrust.org. Telephone: 0845 293 8027.

Twins and Multiple Births Association (TAMBA)

Bereavement Support Group

Website: www.tamba.org.uk.

Telephone helpline: 01252 332 344



Email: enquiries@tamba.org.uk.

Chana

Baby loss support for the Jewish community. Telephone: 020 8201 5744 or 020 8800 0018.

Muslim Bereavement Support Service

Website: www.mbss.org.uk. Telephone: 020 34687 333 Email: info@mbss.org.uk.

Children of Jannah

Muslim support. www.childrenofjannah.com.

BLISS

Charity for babies born premature or sick.

Website: www.bliss.org.uk.

Telephone helpline: 0808 801 0322

Email: ask@bliss.org.uk.

Child Funeral Charity

Telephone: 01480 276 088.

Maternity and paternity benefits

Website: www.gov.uk.

Telephone helpline: 0800 055 668.

Noah's Ark Hospice

Telephone: 0208 449 8877.

Website: www.noahsarkhospice.org.uk.

Aching Arms

Telephone: 07464 508 994

Website: www.achingarms.co.uk.



Contact us

Bereavement midwife

Open: Monday to Friday, 9am to 5pm.

Barnet Hospital

Julie Stewart

Telephone: 020 8216 5185 or 020 8216 5180. Email: rf-tr.bereavementmidwives@nhs.net.

Royal Free Hospital

Gemma Gluckman

Telephone: 020 7794 0500, extension 32582. Email: rf-tr.bereavementmidwives@nhs.net.

Chaplains

Barnet Hospital

Telephone: 020 8216 4355

Chase Farm Hospital

Telephone: 020 8375 1078

Royal Free Hospital

Telephone: 020 7830 2742 extension 33096

Email: rf.chaplaincy@nhs.net.

24-hour medical advice

Please contact:

Barnet Hospital triage

Telephone: 020 8216 4408.

Barnet Hospital labour ward

Telephone: 020 8216 5180.

Royal Free Hospital labour ward

Telephone: 020 7794 0500, extension 33850.

Mortuary

Barnet Hospital

Telephone: 020 8216 4716.

Royal Free Hospital

Telephone: 020 7794 0500, extension 3354.



Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf-tr.communications@nhs.net

Alternative formats

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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Notes and your feedback







