

# Ending a Pregnancy when a Fetal Anomaly has been detected

Information for patients



You have been given this leaflet because you have made the difficult decision to end your pregnancy due to a fetal anomaly being detected.

We wish to extend our sympathy to you and offer you our support at this difficult time. We hope the information in this booklet will answer a few questions and help you to make decisions that are right for you. If you need any help, please do not hesitate to ask any member of staff involved in your care.

**You will be admitted to Ward:**

**On:**

**Telephone number:**

You will be contacted on the morning of your admission with a time to come into hospital. If you do not receive a phone call, please contact the number above at 10am.

Please ring this number if you have any pain or bleeding before your date to come into hospital.

## What happens first?

Both the medical and surgical management for ending a pregnancy will be explained to you, so that you can make an informed choice. At present, the Trust is able to offer you a surgical termination up to 14 weeks of your pregnancy. After this you would be cared for by another provider outside of the Trust.

If you are less than 14 weeks of pregnancy you will be cared for on J24 at St James's Hospital, after 14 weeks you will be cared for on Delivery Suite at either St James's or the Leeds General Infirmary.

You will be asked to sign a consent form either by the Doctor caring for you prior to your admission or on the day you are admitted.

## Medical termination after 14 weeks

A medical termination is when you take medication (tablets) to end your pregnancy.

If you have decided to have a medical termination the first tablet is taken 48 hours before you are admitted to hospital. This tablet is called Mifepristone and it will prepare your body for the next stages of labour and can help to reduce the length of your labour. If you experience any pain, bleeding or any other concerns whilst waiting to return to the hospital please do not delay contacting the hospital on the number at the beginning of this leaflet.

You will be admitted to the maternity unit to continue the induction process 2 days later and will be cared for in either the Rosemary Suite at LGI or at the Snowdrop Suite at St. James's. This is an area on the delivery suite dedicated to families who are experiencing a sad and difficult time. If your pregnancy has other complications, you might need to be cared for on the delivery suite and then transferred to the Rosemary/Snowdrop suite when you are clinically well and it is safe to do so.

After 21 weeks the Royal College of Obstetrics and Gynaecology recommend the method chosen to end your pregnancy does not result in a live birth. Your Consultant will have a full discussion with you about this procedure which is called a feticide.

A termination before 22 weeks carries a small chance that your baby may be born alive, in these rare cases the midwife caring for you will advise and support you.

## **Surgical termination**

A surgical termination is a surgical procedure performed in theatre.

If you have decided to have a surgical termination and you are under 14 weeks this will be discussed with you and you will be cared for in St James's. You will be advised which ward to attend by the midwife or doctor arranging the termination.

Sometimes before 14 weeks but definitely after this, you will not be able to have a surgical termination within Leeds Teaching Hospital. You may need to attend an organisation in the independent sector such as Marie Stopes, BPAS or UPAS.

Attending these organisations does not incur a cost to you as they are not private healthcare providers. It may also be possible to refer you to the nearest NHS hospital that provides this service which is Newcastle.

### **What shall I bring with me?**

Please bring any relevant documentation, regular medication, an overnight bag with toiletries, change of clothing and sanitary towels. Plan for an overnight stay as it is difficult to predict how long your stay in hospital is likely to be. You may also wish to bring items for your baby. Good options are often small teddies or blankets.

### **Is car parking available?**

Yes, parking is available at both hospital sites but is limited at the LGI.

Some people prefer to ask a family member/friend to bring them to hospital and collect them.

### **What happens when I am admitted to hospital for medical management?**

If you are over 14 week's gestation, you will be cared for on delivery suite in the bereavement suites if this is the safest place to look after you. With your consent, a vaginal examination will be performed to assess the condition of your cervix (neck of the womb).

Prostaglandin tablets, called Misoprostol will be either given orally or placed into your vagina.

These will continue the process of induction by making your womb contract. You will continue to be given Misoprostol orally or vaginally every 3 hours for up to 24 hours until pregnancy loss occurs. It may take some time for your labour to begin and the time interval until delivery can be variable.

## What pain relief can I have?

Pain may start quite quickly, so you may decide to use self-help techniques in the early stages, for example 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 killers 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.
- Morphine Injection [Morphine, Diamorphine or Pethidine]. This 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 an anaesthetic injected into your lower back by an Anaesthetist. This creates a feeling of numbness below the injection site. An epidural will also reduce your mobility therefore you will usually need to remain on the bed. Some women may need an additional blood test prior to having an epidural. If you chose an epidural you will be cared for within the main delivery suite as you will need additional monitoring.

## Blood Tests

Depending on your circumstances, your doctor may request that a number of blood tests are taken from you for testing.

If your blood group is Rh negative, your blood will be checked to see if you require an injection of Anti D.

## Will there be any other tests?

We will discuss with you the option of further testing on tissue (such as baby's cord) for DNA/chromosome analysis. We will also discuss with you the option of a post-mortem examination.

A post-mortem may give further information, not just for this pregnancy but for future pregnancies.

## **What happens if I want a post-mortem examination for my baby?**

Either, a specialist midwife, nurse or senior doctor will discuss your options with you and get your consent to perform the post-mortem. More information is available in a separate booklet that you will be given. Once the post-mortem is complete, then you can start arranging your baby's funeral.

After all the tests have been completed, a report will be sent to your consultant. This will be discussed with you when you attend for your postnatal appointment. It can take up to 9 months for all results to be available.

## **Seeing and holding your baby**

Some parents choose to see their baby and some parents choose not to; there is no right or wrong way. You may be anxious about seeing your baby but most parents are pleased to have this precious memory.

You will be offered the opportunity to see and hold your baby if you would like to do so. You can have your baby with you for as long as you like, and may want to include other family members or friends in meeting your child.

You also have the option to take your baby home or to one of our children's hospices to spend more time with them. If this is something you would like more information about then please ask the midwife caring for you.

Some parents need to go home to make their decision. If you wish to return to see your baby, please contact the Delivery Suite who will make the arrangements or you can contact the Chapel of Rest to make an appointment.



## Photographs and mementoes

We can take photographs of your baby for you if you wish or you can take your own. We use a digital camera so photographs are available immediately. If you do not wish to see your photographs, we can give you the memory card from the camera to take home with you so you can look at them in your own time.

Unfortunately, we are not able to save your photographs in your hospital notes.

It may be possible to take hand and foot prints if you would like them, although this can be difficult with very small babies. You will be offered identity bracelets for your baby that you can take home and some will also remain with your baby. Please discuss with your midwife of any other mementoes you would like.

We have keepsake boxes that will be offered to you to keep all your mementoes in. We understand that some parents do not want any physical mementoes, this is an individual decision and we suggest you choose what is best for you.

## Naming your baby

Some parents may choose to name their baby, whilst some may prefer not to. This is a very personal decision; there is no right or wrong way. Sometimes it is not possible to identify the sex of your baby at the time of birth and your Midwife may not be able to tell you what sex your baby is.

## **Blessing your baby**

There are Chaplains in the hospital to offer confidential support and comfort. They are available for people of all faiths, at all times.

Your baby can be welcomed, named and blessed by the Hospital Chaplain or a Minister known to you. Ask your midwife caring for you and she will arrange for the Chaplain to come to the ward.

You will be discharged home when you feel physically and emotionally ready to leave the hospital.

## **Where does my baby go when I leave the hospital?**

Your baby will be transferred to the mortuary during 'normal working hours'. If your baby is born at the weekend, your baby will remain in the Rosemary Suite / Snowdrop Suite until Monday. If you have gone home and wish to come back to see your baby over the weekend, you can call the Delivery Suite to arrange a time.

## **Do I need to register my baby?**

There is no legal requirement to register a termination of pregnancy before 24 weeks of pregnancy; however, if you wish, your midwife can provide a certificate of pregnancy.

You will be asked to sign a form which is required by Leeds City Council to allow a cremation or burial.

## What funeral options are available?

You might choose to make your own private arrangements with a funeral director of your choice; alternatively, you might prefer the hospital to make arrangements. There are a number of options available to you for your baby's funeral which the Bereavement Officer, Midwife or Chaplain will be happy to discuss with you.

A separate leaflet about funeral options is available.

You will have 4 weeks to arrange a private funeral or a hospital funeral which you may attend, if you wish.

If you have not contacted the hospital Bereavement Liaison Office or a private funeral director within 4 weeks the Trust will arrange a cremation or burial for your baby.

## What will I feel like physically when I go home?

If you have no medical complications, you will go home when you feel physically and emotionally ready to leave the hospital. This may be within a few hours or you may need to stay longer.

Bleeding may continue for 2 - 4 weeks and can sometimes be quite heavy. You are advised to use sanitary towels, rather than tampons to assess bleeding and reduce the risk of infection. It is safe to bathe or shower at this time but you are advised not to resume sexual intercourse until the bleeding and discharge has settled.

You may produce milk about 3 days after delivery and this can obviously be very distressing for you. Your midwife will offer you a tablet before you go home to suppress your milk production, so the discomfort to your breasts should be minimal.

***It is important that you contact your GP or the Delivery Suite if you experience any of the following:***

- Pain when passing urine.
- Prolonged heavy bleeding with clots.
- Vaginal discharge that looks or smells offensive.
- Rise in temperature / feeling unwell.
- Emotional difficulties.
- Persistent pain.

### **Will my community midwife visit me at home?**

Yes, a community midwife can visit you at home if you wish. The hospital will arrange this for you. Your antenatal hospital appointments will be cancelled by the hospital. The Bereavement Support Midwife will be in touch to offer you support.

### **How will my GP find out what's happened?**

The midwife on the Delivery Suite will contact your GP via email and inform them of your circumstances. They will also receive an electronic discharge notification after you leave hospital.

### **How long should I have off work?**

This is very individual, the length of time off work varies from person to person. Your GP will be able to provide a note as you are unable to claim maternity benefits.

## **How will I feel emotionally?**

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.

## **When can I exercise again?**

After your delivery, you can resume gentle exercise such as walking straight away. Exercise such as aerobics, running, swimming and the gym should be avoided until the bleeding and discharge has settled.

## **How long should you wait before trying for another baby?**

It may take a few months for your periods to return to normal and by 6 weeks you may have had a period.

Recovery is more psychological than physical and it might take many months to feel emotionally ready to consider getting pregnant again. It is important you consider contraception until this time.

## **Do I have a follow-up appointment with my Consultant?**

You will be sent an appointment to come back and discuss your pregnancy with your obstetric consultant. Depending on the investigations that were taken this could be several months after the birth of your baby. This appointment gives you the opportunity to ask any questions you may have about the loss of your baby. It may help to make a note of any questions you have so that you do not forget to ask them at your appointment. At this appointment, you will be able to discuss the results of any investigations that have been taken and any implications they may have for future pregnancies. The Bereavement Midwife may be available to support you at this appointment if you wish.

## **Will I be offered any additional care in my next pregnancy?**

In future pregnancies, you will be cared for by your Community Midwife and referred if appropriate for Consultant Led Care. Your community midwife and/or doctor will provide personalised care to you and inform you of the care you will receive. In certain circumstances you may be offered referral to the Fetal Medicine Unit however this will be offered where appropriate as per Leeds guidance.

## Useful contacts

### *SJUH*

- **St. James's University Hospital**  
Delivery Suite, Level 05, Gledhow Wing,  
St. James's University Hospital.  
**Telephone: (0113) 206 9103**
- **Bereavement Liaison Office**  
Gledhow Wing, St. James's University Hospital.  
**Telephone: (0113) 206 4302 / 206 4162 / 206 6432**  
(all have answer machines).  
Open: Monday - Friday, 8.30 am - 4.30 pm  
(excluding bank holidays).
- **Mortuary / Chapel of Rest, St. James's University Hospital**  
**Telephone: (0113) 206 4312 or contact the Delivery Suite.**  
Open: Monday - Friday, 9.00 am - 4.00 pm viewing by  
appointment only.
- **Chaplaincy Department**  
Offers support to everyone whether of any religion or none.  
**Telephone: (0113) 206 4365 / 206 5935**  
(an answer machine is available).

## **LGI**

- **Leeds General Infirmary**  
Delivery Suite, L45, Clarendon Wing,  
Leeds General Infirmary.  
**Telephone: (0113) 392 7445**
- **Bereavement Liaison Office**  
Old Site, Leeds General Infirmary  
**Telephone: (0113) 392 3560**  
Open: Monday - Friday, 8.30 am - 4.30 pm  
(excluding bank holidays).
- **Mortuary / Chapel of Rest Leeds General Infirmary**  
**Telephone: (0113) 392 3313 or contact the Delivery Suite.**  
Open: Monday - Friday, 9.00 am - 4.00 pm viewing by  
appointment only.
- **Chaplaincy Department**  
Offers support to everyone whether of any religion or none.  
**Telephone: (0113) 392 2914 / 206 4365**  
(an answer machine is available).



## Useful organisations

- **Antenatal Results and Choices (ARC)**

A national charity offering non-directive, specialised support to parents when an abnormality is detected.

**Address: 73 - 75 Charlotte Street, London, W1P 1LB.**

**Helpline Telephone: 0845 077 2290**

Monday - Friday, 10.00 am - 5.00 pm

**Email: [info@arc-uk.org](mailto:info@arc-uk.org)**

**Website: [www.arc-uk.org](http://www.arc-uk.org)**

- **Charlie's Angels Foundation**

Bereavement support for anyone affected by the death of a child at any age.

**Address: Charlie's Angels Bereavement Centre, Unit 6B, Ashbrooke Park, Parkside Lane, Leeds LS11 5SF.**

**Telephone: 07514116607**

**Website: [www.charlies-angel-centre.org.uk](http://www.charlies-angel-centre.org.uk)**

- **Cruse Bereavement Care**

Exists to promote the well-being of anyone bereaved by death, and to enable bereaved people to understand their grief and cope with their loss.

**Address: Centenary House, North Street, Leeds, LS2 8AY.**

**Telephone: (0113) 234 4150**

**Careline Telephone: (0113) 234 4150**

**Helpline Telephone: 0844 477940**

**Email: [Leeds@cruse.org.uk](mailto:Leeds@cruse.org.uk)**

**Website: [www.crusebereavement.org.uk](http://www.crusebereavement.org.uk)**

- **Leeds Mental Wellbeing Service**

LMWS provides a wide range of perinatal support, working together to help you in the best way possible.

**Address:** Burmantofts Health Centre, Cromwell Mount  
Leeds, LS9 7TA.

**Telephone:** (0113) 843 4388

**Email:** leeds.mws@nhs.net

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

- **Person to Person Listening Service**

A listening service for anyone who is anxious, worried or distressed.

**Address:** Oxford Place Centre, Oxford Place, Leeds, LS1 3AX.

**Telephone:** (0113) 242 5254

**Email:** op.deacon@btinternet.com

**Website:** [www.oxfordplace.orf.uk](http://www.oxfordplace.orf.uk)

- **Petals**

The baby loss counselling charity.

Providing specialist counselling after baby loss.

**Address:** Unit 1, Turnbridge Court, Turnbridge Lane,  
Bottisham, Cambridge, CB25 9TU.

**Helpline:** 0300 688 0068

**Email:** [counselling@petalscharity.org](mailto:counselling@petalscharity.org)

**Website:** [www.petalscharity.org](http://www.petalscharity.org)

- **Samaritans**

The Samaritans offer a 24 hour listening service for people who are suicidal or despairing.

**Address:** 93 Clarendon Road, Leeds, LS2 9LY

**Helpline:** (0113) 245 6789

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

**Website:** [www.samaritans.org](http://www.samaritans.org)

- **SANDS: Stillbirth and Neonatal Death Charity**  
 To improve care and support following the death of a baby. They give support to families and training to professionals.  
**Address: CAN Mezzanine, 49-51 East Road, London, N1 6AH**  
**Helpline: 08081643332**  
**Email: [helpline@sands.org.uk](mailto:helpline@sands.org.uk)**  
**Website: [www.sands.org.uk](http://www.sands.org.uk)**
- **TAMBA (Twins & Multiple Births Association) Bereavement Support Group**  
 Provides support through a network of befrienders for anyone experiencing bereavement within a multiple pregnancy, and can also help with advice for parents of surviving multiples.  
**Address: 2 The Willows, Gardener Road, Guilford, Surrey, GU1 4PG.**  
**Helpline Telephone: (01252) 332344**  
**Website: [www.tamba-bsg.org.uk](http://www.tamba-bsg.org.uk)**
- **Tommy's**  
 A national organisation to provide trusted pregnancy and baby loss information and support.  
**Address: Tommy's, Nicholas House, 3 Laurence Pountney Hill, London, EC4R 0BB**  
**Helpline: 0800 0147 800**  
**Email: [midwife@tommys.org](mailto:midwife@tommys.org)**  
**Website: <https://www.tommys.org/baby-loss-support/tfmr-terminating-pregnancy-medical-reasons>**
- **Women's Counselling and Therapy Service**  
 Provides therapy for women aged 18 and over in Leeds. It is a women only organisation, offering individual and group therapy.  
**Address: Oxford Place Centre, Oxford Place, Leeds, LS1 3AX**  
**Telephone: (0113) 245 5725**  
**Email: [info@womenstherapyleeds.org.uk](mailto:info@womenstherapyleeds.org.uk)**  
**Website: [www.womenstherapyleeds.org.uk](http://www.womenstherapyleeds.org.uk)**



## What did you think of your care?

Scan the QR code or visit [bit.ly/nhsleedsfft](https://bit.ly/nhsleedsfft)

***Your views matter***



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