

When your baby's heart is different

Ongoing care and support

Fetal Cardiology

Information for Patients

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Introduction

If we think your baby has a heart problem, we will discuss with you about any further scans and testing which you may wish to consider. These tests can usually take place either in Leicester or in your local hospital. Some specialised investigations however may need a visit to another centre.

After your initial appointment you may have more questions, or you may have decided what you want to do. We also know that people can change their mind over time, or after further test results.

Some couples will decide to continue the pregnancy because this is right for them but some families may not wish to continue the pregnancy.

Deciding what to do when given this type of news can be very difficult. We know and understand that you will want to make the best decision possible for you and your family. This can take time and we are always happy to provide additional support and further discussions when you need this.

What will happen next?

If you decide to continue your pregnancy and we have seen you at 20 weeks, we will usually see you again around 28 weeks, and again around 34 weeks. This is because although it is usually possible to identify the main problem with your baby's heart at the first specialist heart scan, sometimes details become clearer or change as the pregnancy progresses.

It is therefore not always simple to predict exactly what will happen after baby is born. How this will affect your baby's heart and how we manage it, will therefore be discussed with you at each appointment and sometimes plans will need to change.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

We will also try to arrange a visit to East Midlands Congenital Heart Centre (EMCHC) for you which is currently based at Glenfield Hospital.

After each scan you will receive a short typed report on the day and usually a more detailed letter through the post regarding your scan and any plans made. We will also send a copy of these to your local hospital. It is really important that your local community midwife and maternity team at your local hospital are involved in your care.

During your visit to EMCHC, you will have the opportunity to look around the children's ward, our parent's facilities and intensive care unit if appropriate. Many people find a visit useful to help go through some of the practical aspects and what happens after the birth.

Labour and delivery

Most babies can be delivered at their local hospital. This will be discussed with your local specialists both from the maternity and neonatal (special care baby unit) teams, to make sure everyone is clear, including yourself, about what happens at the time of delivery.

There are some situations when it is advisable for your baby to be delivered in Leicester, for early transfer to our cardiac unit. If this is the case, we will make appropriate arrangements but we will also keep your local centre involved and informed. If you go into labour early, you will need to attend your local centre first.

There are only a few situations where a caesarean section is recommended related to the heart problem, as in most cases a vaginal delivery helps the baby's breathing after birth. There may be a medical reason as to why your baby should not be delivered by vaginal delivery, for example if the baby is in a bottom down (breech) position. We will be guided by the team looking after you during labour (maternity team).

After baby is born

Not all babies will need treatment immediately after birth. Some babies may need a heart scan in your local centre before going home. Some will need to be transferred to the EMCHC for a heart scan and other assessments before deciding whether they need further treatment at that time or can go home. Other babies may need to attend for an outpatients appointment either at EMCHC or your local hospital for a scan at a later date, so we can re-check or monitor their heart.

If your baby needs to be transferred to the EMCHC after birth, you will be able to stay at Glenfield Hospital when you are well enough to be discharged from the maternity unit. We will arrange for our local community midwives to visit you at the EMCHC.

Your baby will be under the care of a doctor who specialises in the heart (cardiologist) after birth. This may be the same doctor you have seen during pregnancy or another member of the team.

If your baby is born early, or very small, their care may become more complex with higher risks, and the plans made before birth may need to change.

In addition, since it is not always possible to identify all problems a baby may have before birth, some may only become obvious after baby is born. This could also lead to a change in plans for your baby and you, but any changes will always be communicated to you as soon as possible.

We would always encourage you to ask questions whenever there are parts of your baby's care that are difficult to understand.

Support and information

We know this is a very worrying time for you and we want to support you and your family. We are happy to answer any questions you may have regarding your baby's scan, heart condition and care plans. You may feel overwhelmed at your first appointment by all the information you have been given and we are more than happy for you to come and meet us again to discuss the information you have been given and any queries you may have.

For further information please contact our specialist nurses on **0116 256 3338**.

Support organisations and useful websites

- Antenatal Results and Choices (ARC)
www.arc-uk.org
- Keep the Beat
www.keepthebeat.co.uk
- British Heart Foundation (BHF)
www.bhf.org.uk
- Little Heart Matters
www.lhm.org.uk
- Children's Heart association
www.downs-syndrome.org.uk
- Max Appeal
www.maxappeal.org.uk
- Heart Link
www.heartlink-glenfield.org.uk
- SOFT
www.soft.org.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk