Isolated congenital complete heart block

This leaflet explains more about the rhythm of your baby’s heart.

If you have any further questions, please speak to a doctor or nurse caring for you.

What is complete heart block?
The main structure of your baby’s heart is normal. The problem is with the conduction system of the heart – the way that the heart beats.

In a normal heart, electrical impulses travel from the upper chambers of the heart (the atriums) to the lower pumping chambers of the heart (the ventricles). This stimulates the ventricles to beat.

In complete heart block there is a problem with the electrical wiring of the heart so that the electrical impulses are not effectively passed from the atriums to the ventricles. This causes the pumping chambers (the ventricles) to beat more slowly than normal.

Why has my baby got it?
Complete heart block affects about 1 in 20,000 pregnancies. In some cases, no cause is found to explain why this has happened. However, in the majority of cases the mother is found to have specific antibodies in her blood, which cross the placenta and react with the baby’s conduction tissue. It is thought that this reaction causes damage to the conduction system, which is usually permanent.

These antibodies are called anti Ro and anti La, and are often found in association with autoimmune conditions. If you are fit and well, please do not worry. We will take a blood sample, and if this is positive for these antibodies you will be referred to a specialist in rheumatology for further advice and information after your baby is born.

How serious is this condition?
This depends on how severely the baby is affected and influenced by the heart rate, and on how efficiently the heart is pumping. A build up of fluid in the baby, known as hydrops, shows that the baby has developed heart failure and is running into problems before birth. Unfortunately, once this has happened there is a high risk that your pregnancy may result in a miscarriage, or that the baby may not survive after birth. However, if no signs of heart failure develop during pregnancy, then there is a good chance that your baby will do well.
**What treatments are available?**

We usually only consider treatment before birth if there are signs of hydrops in the baby. We will discuss this with you if it is appropriate.

We will monitor the progress of your baby’s heart problem as the pregnancy advances. This means a specialised heart scan of the baby every four to six weeks with assessment at your local hospital in between.

After birth, a pacemaker may need to be fitted to your baby (see below for more information about pacemakers).

**Will I have a normal delivery?**

In complete heart block the rate of the heart is slow, which makes it difficult to use this rate to monitor the well-being of the baby during labour. This is important when deciding the best way for your baby to be born and a Caesarean section may be advised.

**What will happen to my baby after birth?**

After the baby is born, he or she will be assessed in a unit specialising in paediatric cardiology.

An electrocardiogram (ECG) and an echocardiogram (ultrasound) will be performed. The baby’s heart rhythm will also be monitored over a longer period of time, typically by a 24 hour tape. This involves having ECG stickers on the skin which are connected to a small box like an MP3 player. This records all the heart’s activity over that period, including the lowest rate.

The doctors looking after the baby will then decide if this is satisfactory for the baby. If the heart rate is too low a pacemaker will be required. This may be needed in the first few weeks, months or years of life, but regular assessments will be made to decide this.

**What is a pacemaker?**

A pacemaker consists of a battery and a complex electric circuit which controls its power. It weighs about 4oz (100g) and is about the size of a £2 coin. The battery can be implanted under the skin, and connected by a fine wire either to the outside of the heart (the epicardium), or to the inside of the heart (the endocardium) using a vein.

With the epicardial type, the wire is sewn on to the outside of the heart by an operation. With the endocardial type, the fine wire is inserted through a vein and steered into the heart under x-ray control in a catheter laboratory. The choice of method depends on factors such as the age and size of the baby.

Most pacemakers are programmable. This means that the rate, power supply and timing can be altered externally after the pacemaker has been inserted. This can be done with an electromagnetic programmer. These alterations allow the optimum settings to be obtained for each individual child.

**Will my child live a normal life?**

Techniques and technology have improved very considerably over the past decade, and the majority of pacing systems now inserted will in normal circumstances last for more than ten years.
After around ten years, the pacing box containing its batteries would need to be removed and replaced with a new one. Most often, the wire connecting the battery to the heart would not need to be replaced to accommodate your child’s growth.

In most children, the function of the heart continues to be good, but scans of the heart will be performed to check this. In a minority of patients, the function of the heart may be reduced (cardiomyopathy) which may require medication or alteration of the pacing.

Your child should live a normal life, however regular follow-up with checking of the pacemaker is required. There is very little possibility of interference from outside electrical circuits, but strong electrical fields, such as those that occur with dodgem cars at the fairground, should be avoided. Your child will be able to participate in most activities and occupations. An information booklet is provided with each individual pacemaker.

**Could this happen in future pregnancies?**

If we detect the specific antibodies in your blood, then there is a 15 to 25 in 100 chance of the problem happening again in a future pregnancy. Remember that the chances are more likely that the baby’s heart will be normal. We can see you in all your future pregnancies to monitor the heart rate.

**Useful sources of information**

**Evelina Children’s Heart Organisation (ECHO)** is a charity that supports the families of children with congenital heart disease who receive treatment at the Evelina Children’s Hospital. They have a rota of trained prenatal support volunteers who offer comfort and reassurance at this stressful time. ECHO also sponsors specialist antenatal classes for parents of heart babies to be treated at the Evelina Children’s Hospital.

[t: 07730 146 154  e: prenatailsupport@echo-evelina.org.uk  w: www.echo-evelina.org.uk]

**Heartline** is a national charity that provides support and help for children with congenital heart conditions and their families.

[t: 01276 707 636  w: www.heartline.org.uk]

**Children’s Heart Federation (CHF)** is a national charity and the umbrella body for voluntary organisations working to meet the needs of children and young people with congenital and acquired heart conditions and their families.

[t: (freephone infoline) 0808 808 5000 (9.30am - 4.30pm Mon to Fri)  w: www.childrens-heart-fed.org.uk]

**British Heart Foundation (BHF)** is a national charity providing information and support on anything heart-related.

[t: (helpline local rate) 0300 330 3311  w: www.bhf.org.uk]

**Contact us**

If you have any questions or concerns about isolated congenital complete heart block, please contact fetal cardiology on **020 7188 2308** (Monday to Friday, 9am to 5.30pm).

**Patient Advice and Liaison Service (PALS) –** To make comments or raise concerns about the Trust’s services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

[t: 020 7188 8801 at St Thomas’  t: 020 7188 8803 at Guy’s  e: pals@gstt.nhs.uk]
Knowledge & Information Centre (KIC) – For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas’ Hospital.
t: 020 7188 3416

Language support services – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.
t: 020 7188 8815  fax: 020 7188 5953

NHS Direct - Offers health information and advice from specially trained nurses over the phone 24 hours a day.
t: 0845 4647  w: www.nhsdirect.nhs.uk

NHS Choices – Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.
w: www.nhs.uk