



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Prenatal diagnosis of isolated congenital complete heart block

This information sheet from Great Ormond Street Hospital (GOSH) explains about isolated congenital heart block detected during a prenatal ultrasound scan and what this might mean for your child. It will support the information discussed with you by your doctor and nurse at your appointment and it is important to remember that every case is slightly different.

What is complete heart block?

In the majority of cases, the structure of a baby's heart is normal. The heart is made up of four chambers – two at the top called atria and two at the bottom called ventricles. The ventricles are the pumping chambers of the heart. The heart has an electrical system that makes it pump. The electrical impulses travel through the heart in a set pattern from the atria to the ventricles each time it beats.

Complete heart block is a problem with the electrical system of the heart so that the electrical impulses are not passed effectively from the atria to the ventricles. This causes the pumping chambers (the ventricles) to beat more slowly than normal.

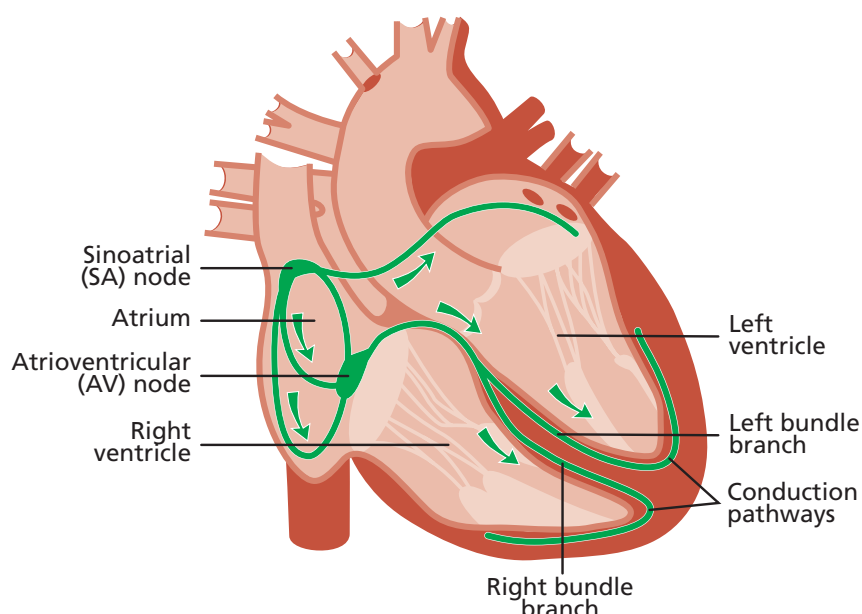
Why has my baby got it?

Complete heart block affects about 1 in 20,000 pregnancies. In some cases, no cause is found to explain why this has happened. In others it can be related to an abnormality in the structure of the heart, which affects how the electrical impulses can travel through the heart.

In the majority of cases, however, the mother is found to have specific antibodies in her blood. These antibodies are called 'anti Ro' and 'anti La', and are often found in association with autoimmune conditions (where the immune system mistakenly attacks itself rather than foreign invaders such as germs).

The antibodies cross the placenta and react with the tissue through which the impulses pass – these are called the conduction system. It is thought that this reaction damages the conduction system, which is usually permanent.

We will take a blood sample to look for these antibodies. If this is positive, you will be referred to a specialist in Rheumatology (specialist doctors for autoimmune conditions) for further advice and information after your baby is born.



How serious is this condition?

This depends on how severely baby is affected. The severity of the condition depends on the baby's heart rate and pumping efficiency. A build-up of fluid in the baby (hydrops) before birth shows that the baby has developed heart failure which indicates that the baby's body is struggling to cope with the slow heart rate. Once hydrops is present, there is a high risk that the pregnancy may result in a miscarriage or that the baby may not survive after birth.

In some, the heart rate does not change much during pregnancy, but in others it gradually slows and hydrops develops. For this reason, you will be monitored regularly and the baby may be delivered early if there are any signs of problems and the baby is mature enough.

If no signs of heart failure develop during pregnancy, then there is a good chance that the baby will do well. However, it can be difficult to predict whether the heart rate will be affected and whether the baby will survive.

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. Unfortunately, treatment is sometimes not possible or unsuccessful.

We will monitor the progress of your baby's heart problem as the pregnancy advances. There will be regular specialised heart scans of the baby at GOSH with assessment at your local hospital in between.

After birth, your baby may need to have a pacemaker - see below for further information.

Will I have a normal delivery?

Complete heart block may mean that it is difficult to use the heart rate to check your baby's well-being during labour. If your baby's heart rate is already slow, it may be difficult for the labour team to work out if they are becoming stressed.

Your obstetric team and the fetal team at GOSH will discuss together and with you the safest mode of delivery for you and your baby. This may include the possibility of early delivery or a Caesarean section. It may be safer to arrange this at a larger hospital near a cardiac unit in case your baby needs treatment very soon after birth.

What happens after the baby is born?

After the baby is born, they will be assessed in a special care baby unit. Local staff will seek advice from the team at GOSH if your baby needs to be transferred to a specialist heart unit.

The first step is to carry out an electrocardiogram (ECG) and echocardiogram (ECHO) which is an ultrasound of your baby's heart. They may also have a longer term ECG over 24 hours usually to show your baby's heart rhythm during the day and night. The results of these tests will show how your baby's heart is working and whether further treatment is needed, although this is rarely needed within the first few months of life.

Your baby's heart rate will be monitored with ECGs and ECHOs regularly – usually every six months or so – to check how it is working. If their heart rate is too slow or their heart function is affected, doctors may suggest your baby has a pacemaker.

What is a pacemaker?

A pacemaker is a device implanted under the skin on the chest that releases electrical pulses to keep the heart beating normally. There are two main types of pacemaker: endocardial (with the pulse wire(s) inside the heart) and epicardial (with the pulse wire(s) placed on the surface of the heart). Both types are inserted in a short operation under general anaesthetic. The pacemaker will be programmed to suit your baby's particular heart rhythm problem. It can automatically increase the pulses released when they are active. If their heart rate becomes irregular, it will generate a series of electrical pulses to ensure their heart beat does not fall too low. Further information about pacemakers and the operation to fit one is available on our website at www.gosh.nhs.uk

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. If you have had one child with heart problems, future pregnancies will be monitored closely.

Further information and support

Before birth, please call the Fetal Cardiac Nurse Specialists on 020 7762 6711 or send them an email to gos-tr.fetalcns@nhs.net

After birth, you can call the Electrophysiology team on 020 7405 9200 extension 5298 or send an email to gos.tr.ecg.gosh@nhs.net

Antenatal Results and Choices (ARC) is a registered charity that offers continued support and advice to parents who face difficult decisions regarding fetal abnormalities. Call them on 020 7631 0285 or visit their website at www.arc-org.uk

Heartline Families is a support group for anyone affected by a child's heart problem. Call them on 0330 022 44 66 or visit their website at 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. Call their free helpline on 0808 808 5000 (Monday to Friday from 9.30am - to 4.30pm Mon to Fri) or visit their website at www.childrens-heart-fed.org.uk

British Heart Foundation (BHF) is a national charity providing information and support to anyone of any age affected by heart problems. Call their helpline on 0300 330 3311 or visit their website at: www.bhf.org.uk

Heart Rhythm Alliance – a national charity for the support of patients with heart rhythm problems. Call them on 01789 867501 or visit their website at www.heartrhythmalliance.org