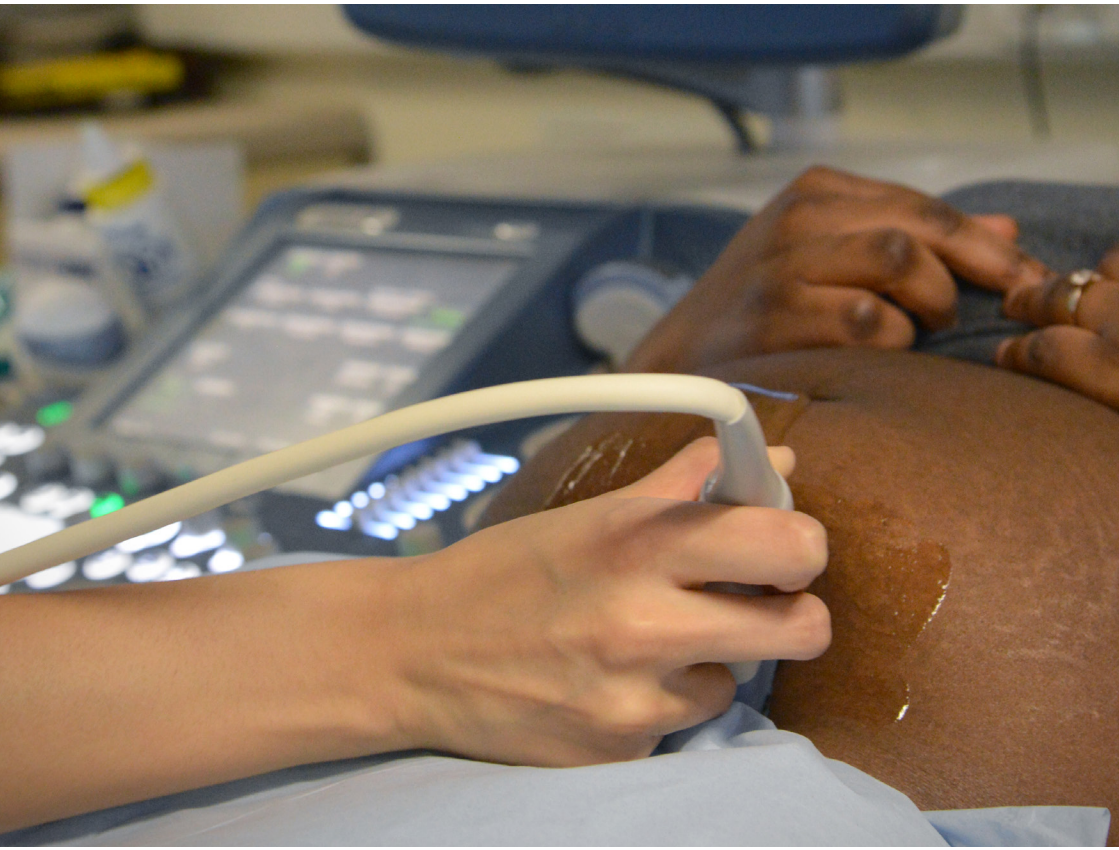
Public Health England

NHS

NHS Fetal Anomaly Screening Programme

Congenital heart disease (CHD): information for parents



This leaflet is for pregnant women whose baby is suspected of having **congenital heart disease** (CHD).

Introduction

Finding out there may be a problem with the baby's heart is likely to be a worrying time for you.

It is important to remember you are not alone. Thousands of babies every year are born in England with a heart condition.

You may want to find out as much as possible about what this may mean for the baby. Heart conditions vary in seriousness and need to be looked at individually. Some babies with CHD will need surgery, others will not.

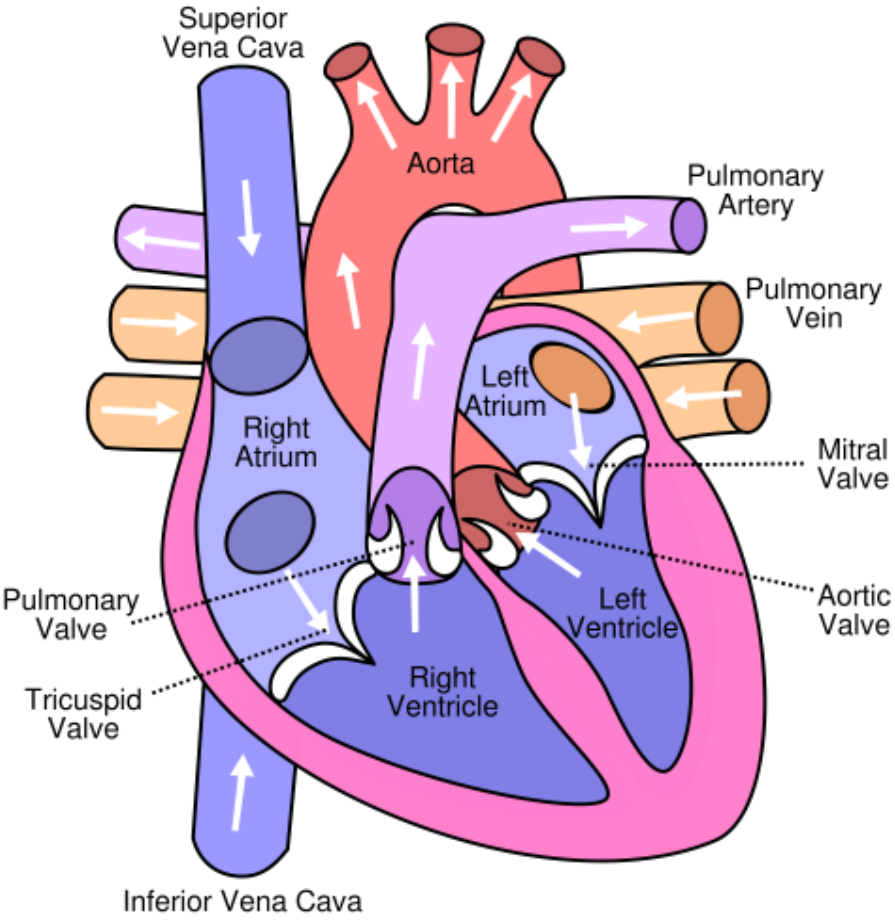
A specialist team, which includes a fetal cardiologist (heart specialist), will do their best to:

- provide more accurate information about your baby
- answer your questions
- help you plan the next steps

What the heart does

To understand CHD, it can be useful to understand how a healthy heart works (see diagram below).

The heart is a muscle that is about the size of your fist. Its job is to send blood around the body. That blood provides the oxygen and nutrients the body needs. The right side of the heart pumps blood to the lungs where oxygen is added. The left side pumps blood from the lungs to the rest of the body.



About CHD

CHD refers to different heart conditions that happen in the first few weeks after getting pregnant.

CHD happens in about 8 of every 1,000 births and may be detected at the 18^{+0} to 20^{+6} weeks mid-pregnancy scan, which is also known as the '20 week scan'.

This scan looks for heart conditions which mean a baby will need medical attention soon after birth, or surgery within the first year of life. Not all heart conditions can be seen before the baby is born. Sometimes they are found at later scans or after the baby is born. CHD is sometimes found during a scan earlier in pregnancy.

If the health professional who carries out your scan thinks the baby may have a heart condition they will refer you to a specialist team.

A member of the specialist team will carry out a second scan to confirm if the baby has CHD or not. Sometimes, the specialist scan finds that the baby's heart is working well and no more tests are needed.

If a problem is found with the baby's heart during the specialist scan, the fetal cardiologist and their team will be able to provide information about the condition, potential treatment and outlook for your baby.

You may be offered more ultrasound scans to monitor the baby's condition. In some cases the specialist team may recommend that the baby is born before their due date.

There are 3 main types of CHD. They are conditions that affect the:

- structure of the baby's heart
- function of the heart
- rhythm of the heart beat

Less serious conditions can include narrowed valves or a hole in the baby's heart that allows blood to flow the wrong way and mix.

In more serious cases, known as 'critical CHD', parts of the baby's heart can be missing or not formed very well. Up to a quarter of babies with CHD have critical CHD. These babies usually need surgery before their first birthday.

There is no single cause for CHD and often we do not know why it happens. The condition usually occurs because something happens during the baby's early development. In some cases, there can be changes to the baby's genetic make-up. Parents often ask if there was something they did or did not do which caused the heart condition. The answer to this is usually 'no'.

Possible outcomes and treatments

Babies with critical CHD need to be born in a maternity unit with a neonatal intensive care unit on site. This is because the baby will need specialised medical or surgical attention in a unit that is experienced in caring for babies with CHD.

CHD can sometimes be linked with other conditions such as chromosomal or genetic conditions or other structural abnormalities.

Next steps and choices

Only you know what is the best decision for you and your family.

You may be offered the choice of having an amniocentesis test in case the CHD is part of a chromosomal or genetic condition.

An amniocentesis is where a small amount of amniotic fluid (the water around the baby inside your womb) is taken for testing. The sample contains some of the baby's cells, which contain genetic information. You will have time to consider whether or not to have an amniocentesis, as it is not usually carried out on the same day as the specialist scan.

Whatever decision you make, your healthcare professionals will support you.

More information about amniocentesis can be found in the PHE Screening leaflet **CVS and amniocentesis: information for parents**. This can be downloaded from **www.gov.uk**. Simply search for CVS and amniocentesis diagnostic tests: description in brief.

If your baby has CHD, your clinical team will pass information about them on to the National Congenital Anomaly and Rare Diseases Registration Service (NCARDRS).

This helps scientists look for better ways to prevent and treat this condition. You can opt out of the register at any time.

More information

- **Antenatal Results and Choices (ARC)** is a national charity that supports people making decisions about screening and whether or not to continue a pregnancy: **www.arc-uk.org**

- **British Heart Foundation** (BHF) has simple information about heart and circulatory diseases, and their risk factors: **www.bhf.org.uk**

- **Children's Heart Federation** is a parent-led charity working with partner groups to make life better for children and young people, with acquired or congenital heart disease, in Great Britain and Northern Ireland: **www.chfed.org.uk**

- **NHS Choices** is complete guide to conditions, symptoms and treatments, including what to do and when to get help: **www.nhs.uk/conditions/congenital-heart-disease**

- **Tiny Tickers** is a charitable organisation in Britain that aims to improve the early detection, diagnosis and care of babies with congenital heart disease through a combination of improving standards, providing specialised training and increasing education and information: **www.tinytickers.org**

Find out how Public Health England and the NHS use and protect your screening information at **www.gov.uk/phe/screening-data**.

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More information about screening: www.nhs.uk/anomalyscan

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With grateful thanks to Tiny Tickers for permission to use the diagram on page 3