

Congenital heart disease

This leaflet gives advice and information for parents whose unborn baby has been diagnosed with a heart condition. If you have any further questions, please speak to a doctor or nurse caring for you.

When you have been given bad news from a medical professional it is common to realise afterwards that you have not taken in much of what was said. You may be stunned by the news and then not hear or remember properly what you are told. Some parents who have been in your position have told us that they would have liked more information to take away with them. Below are the answers to some of the most commonly asked questions.

Why is this happening to me?

This is a common, often angry feeling that happens in reaction to unexpected news. Unfortunately there is no answer to this question. There is rarely anything you could have done to prevent this from happening, and you must not blame yourself in any way.

What went wrong?

We know that for most heart conditions something has gone wrong at a very early stage of development, less than eight to ten weeks into pregnancy. It probably needs susceptible/predisposed genes in the baby (the material passed from each parent that makes up the next generation) to make him or her vulnerable. In some cases there may be something else wrong with the baby, for example a chromosomal problem, which will be associated with the heart defect – the doctor will have explained your individual risk of this. Occasionally, environmental factors or drugs may play a role, but in many babies we cannot identify a specific cause. Heart disease is a leading type of malformation in all parts of the world.

How frequent is heart disease in children?

Heart disease occurs in about 8 out of 1,000 normal pregnancies. About half of these are minor problems, which either do not need treatment or can be successfully corrected by surgery. About 3 out of 1,000 pregnancies, or 3 out of 8 children with heart disease, have very severe problems of heart formation, some of which are associated with a poor outlook for the baby. A poor outlook can be measured in days, weeks or years depending on the exact problem, but certainly cannot be a normal lifespan.

Could this happen in a future pregnancy?

This depends on the type of heart condition diagnosed in your baby. Your cardiologist will normally be able to advise you. If the heart condition is the only problem that your baby has, then there is usually a 1 in 50 chance of it happening again. Your risk is higher than the normal population so you should have a specialised fetal heart scan at an early stage in future pregnancies (this can be performed from around 14 weeks into your pregnancy). If you have had two children with heart disease, the risk rises to 1 in 10. This may sound a high risk, but there is still a much better chance of your baby's heart being normal than abnormal. If a heart condition does happen again in a future pregnancy it may not be as severe.

What will happen now?

You should continue as normal with the rest of your pregnancy. We will monitor the progress of your baby's heart problem as your pregnancy advances. This will help us to plan the best way of managing the baby's care. It is important that you continue with your antenatal care locally, and that any appointment you have here at the hospital should be in addition to this. Depending on the type of heart problem your baby has, it may be recommended that you give birth in London. Any decision regarding transfer of antenatal care will be made after discussion with your consultant obstetrician or general practitioner, taking account of your own wishes, and will be made later in your pregnancy.

Where can I get further help and advice?

We can provide you with booklets and information leaflets about heart problems in children. We can arrange for you to talk with one of the paediatric cardiac surgeons before your baby is born, if you would find this helpful. We can also put you in touch with a self-help group or with other parents who have been through a similar situation.

Useful sources of information

Antenatal Results and Choices (ARC) is a registered charity that offers continued support and advice to parents who face difficult decisions regarding foetal abnormalities. They have extensive experience in helping parents at this time and aim to offer both support and advice in meeting your unique needs.

t: 020 7631 0285 w: www.arc-org.uk

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: prenatalsupport@echo-evelina.org.uk w: www.echo-evelina.org.uk

Little Hearts Matter (LHM) is a national charity that offers support and information to families where a single ventricle heart condition has been diagnosed.

t: 0121 455 8982 e: info@lhm.org.uk w: www.lhm.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

The fetal cardiology nursing team are available to answer any questions you may think of when you get home and to provide ongoing support should you require it. The contact details (Monday-Friday) are **020 7188 2308 (direct line)**.

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