

# Prenatal diagnosis of congenital heart disease

**This leaflet gives more information about your baby's heart disease. If you have any more questions or concerns, please speak to a doctor or nurse caring for you.**

Finding out there is a problem with your baby's heart can be a difficult and stressful time. Afterwards, you may realise that you did not take in or understand a lot of what was said. You will probably have a lot of questions and want more information. Below are answers to some of the most commonly asked questions?

## Why is this happening to me?

Unfortunately there is no clear answer to this. There is usually nothing you could have done to stop 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 in development. This usually happens less than eight weeks into your pregnancy. Sometimes there is an underlying diagnosis, such as a chromosomal abnormality, which may be associated with the heart defect. The doctor will have explained your individual risk of this during counselling. With advances in genetics, we realise that there may be a gene that can be present in a baby or passed through families which makes babies developing in the womb more susceptible to a heart abnormality. Occasionally, maternal conditions (such as diabetes), or exposure to certain prescribed drugs may play a role, but in many babies we cannot identify a specific cause.

## How many babies have heart disease?

Heart disease occurs in about 8 in 1,000 (just under 1%) of normal pregnancies. Just over half of these either do not need treatment, or can be successfully corrected with surgery. The rest of these children will be effected with a complex form of heart disease, some of which may be associated with a poor quality of life or shortened life span.

## What happens now?

The doctor and clinical nurse specialist will have explained the diagnosis in detail to you. They will have told you if your baby is likely to need medical or surgical treatment after birth, and the risks associated with this. They will also talk to you about the options available to you.

We recommend that your baby has a detailed scan of the other organs of their body by a fetal medicine doctor. They may suggest more tests.

We will let your local hospital and midwifery team know about your baby's heart disease, so that appropriate support is offered closer to your home, and to discuss any plans that may be needed.

We are likely to see you at least once more during your pregnancy. Not all babies who have a heart problem need to be delivered in a specialist hospital. The site of delivery will be discussed with you at the follow-up appointment. It is important that you continue with your antenatal care locally, and any appointment that you have at St Thomas' Hospital will be as well as that.

### Could this happen again in a future pregnancy?

This depends on the type of heart condition your baby has. Your fetal cardiologist will be able to tell you. If the heart condition is the only problem that your baby has, then there is usually a 1 in 50 (2%) chance of it happening again. Your risk is higher than the normal population, so we would offer an early fetal heart scan in future pregnancies. This can be done from about 13-14 weeks in to your pregnancy and we would need a referral from your midwife. If you have had two children with heart disease, the risk rises to 1 in 10 (10%). This may sound high, but there is still a higher chance of your baby's heart being normal, than not.

### Where can I get more help and advice?

We can give you leaflets about heart problems in children. We can also arrange for you to talk with one of the paediatric cardiac surgeons if you would find this helpful. We can put you in touch with a self-help group or with other parents who have been through a similar situation. The fetal cardiology clinical nurse specialist can answer any questions you may have, by telephone or email. If you would prefer to come back and discuss things again in person, we are happy to arrange this.

### 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 Evelina London. 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 Evelina London.

**t:** 07730 146 154 **e:** [prenatalsupport@echo-evelina.org.uk](mailto:prenatalsupport@echo-evelina.org.uk) **w:** [www.echo-evelina.org.uk](http://www.echo-evelina.org.uk)

**Little Hearts Matter** 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](mailto:info@lhm.org.uk) **w:** [www.lhm.org.uk](http://www.lhm.org.uk)

**Children's Heart Federation** 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.

**freephone infoline:** 0808 808 5000, Monday to Friday, 9.30am-4.30pm

**w:** [www.childrens-heart-fed.org.uk](http://www.childrens-heart-fed.org.uk)

**Antenatal Results and Choices** offers continued support and advice to parents who face difficult decisions regarding fetal abnormalities. They have extensive experience in helping parents at this time, and offer both support and advice.

**t:** 020 7631 0285 **w:** [www.arc-org.uk](http://www.arc-org.uk)

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

**t:** (helpline local rate) 0300 330 3311 **w:** [www.bhf.org.uk](http://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 give ongoing support if you need it, **t:** 020 7188 2308, Monday to Friday, 9am-5pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

## Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748, Monday to Friday, 9am-5pm

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

**t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111 **w:** [www.111.nhs.uk](http://www.111.nhs.uk)

## NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

**w:** [www.nhs.uk](http://www.nhs.uk)

## Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

**t:** 0800 731 0319 **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk) **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

**Leaflet number: 4404/VER3**

Date published: August 2020

Review date: August 2023

© 2020 Guy's and St Thomas' NHS Foundation Trust  
A list of sources is available on request