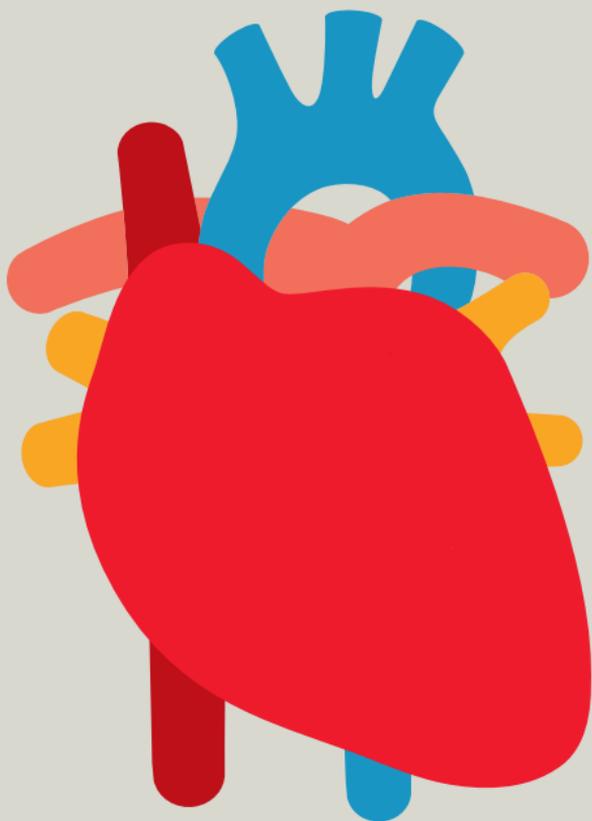




Understanding your child's heart

Coarctation of the aorta

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**FIGHT
FOR EVERY
HEARTBEAT**

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About this book

If you're reading this book, you've probably just had some very upsetting news, and have lots of questions running through your mind.

We've written this book to help answer some of those questions. We'll go through:

- what coarctation of the aorta is and how it is diagnosed
- how coarctation of the aorta is treated
- the benefits and risks of treatments
- what happens as your child grows up
- where to go for more support.

Please be aware that this booklet shouldn't replace the advice your doctors or nurses may give you. But it should help make what they tell you that little bit clearer.

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What is a congenital heart condition?

It's an abnormality of the heart that developed in the womb. Sometimes, a **congenital** heart condition is diagnosed when the baby is still developing in the womb, but most times it's not discovered until after the baby is born. There are lots of different types of **congenital** heart conditions.

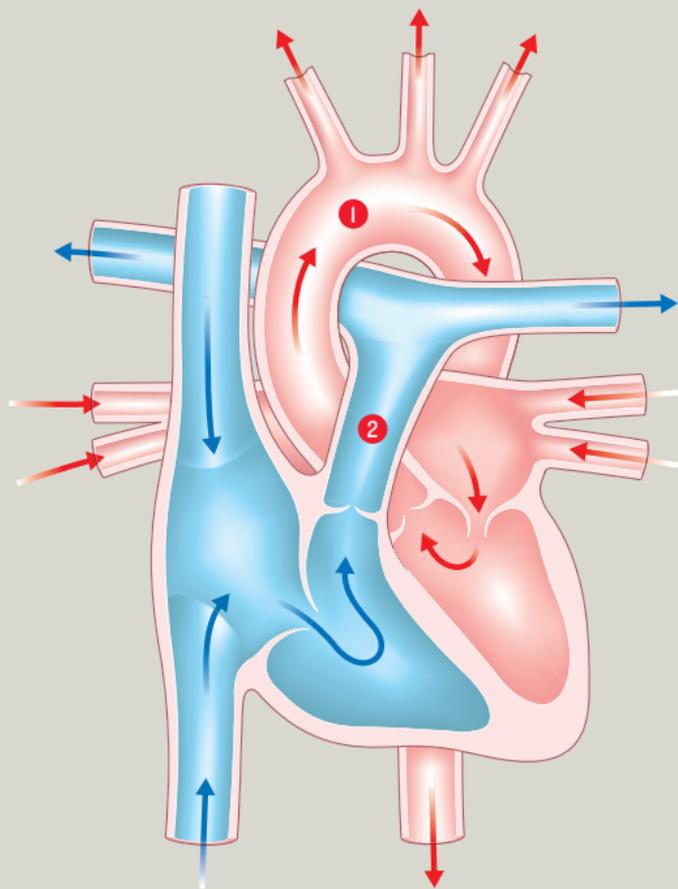
Each day 12 babies are diagnosed with a congenital heart defect in the UK. We continue to support research to improve the understanding, diagnosis and treatment of congenital heart conditions. For more information into our pioneering research visit [bhf.org.uk/research](https://www.bhf.org.uk/research)

What causes a congenital heart condition?

In most cases, it's caused by something going wrong during the very early stages of the pregnancy.

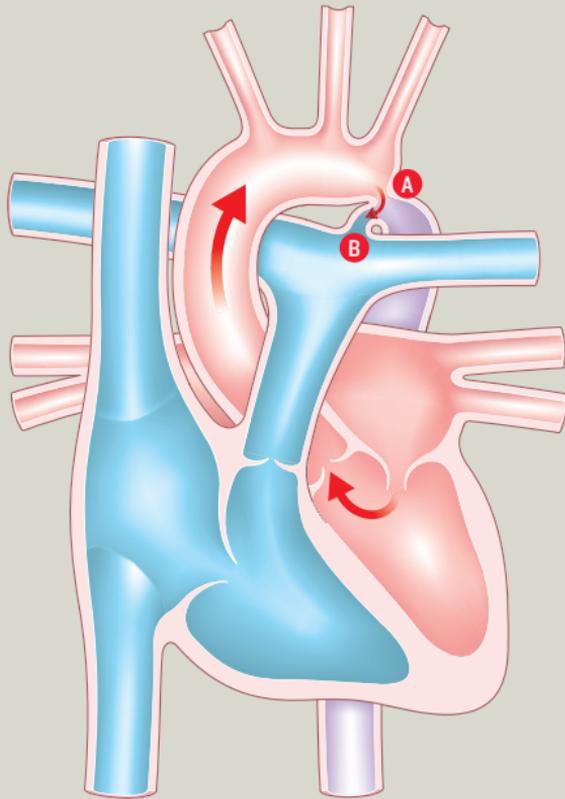
At the moment we don't fully understand why a baby's heart doesn't develop normally. But sometimes a **congenital** heart condition can be part of a syndrome which the baby is born with. *(A syndrome is a group of symptoms that commonly appear together as part of a condition).*

Normal heart



- 1 Aorta
- 2 Pulmonary artery

Coarctation of the aorta



- A** Narrowing (coarctation) of the aorta
- B** The duct

What is coarctation of the aorta?

The **aorta** is the main blood vessel that carries blood from the heart to the brain and the rest of the body. Side branches from the **aorta** supply blood to the head and arms, while the main **aorta** continues on to supply the lower half of the body.

In coarctation, a narrowing usually occurs just beyond the branches that supply the head and arms with blood. This prevents the blood from circulating normally in the lower half of the body and can be very serious.

Before babies are born, the two main arteries (*the **pulmonary artery** and the **aorta***) are joined together by a short connection called the **ductus arteriosus** (*the **duct***), which closes naturally within the first few weeks after birth.

In babies with coarctation, the only way blood can flow to the lower half of the body is through the **duct**. So if the **duct** closes, no blood gets to the lower half of the body. Sadly, this can be fatal.

In some children coarctation is not apparent early in life, but gradually develops over time. Occasionally coarctation isn't detected until adulthood.

What are the symptoms of coarctation of the aorta?

Some newborn babies with a severe coarctation can suddenly become very pale, ill, breathless or collapse. Some babies also appear lethargic, find it difficult to feed and will not gain weight as normal.

In some infants where the abnormality is mild, a coarctation might only be found by chance, due to a heart **murmur** (*an extra sound from the heart*). Sometimes the doctor might suspect the baby has a coarctation before they're born, but it can't be confirmed until after birth.

What other conditions are associated with coarctation of the aorta?

Some children with will have other heart abnormalities, such as a hole between the **ventricles** called a **ventricular septal defect**, or **VSD**. Other children may have a narrowed aortic valve.

A small number of children with coarctation also have **chromosome** abnormalities. The most common ones associated with coarctation are **Turner's syndrome** (*particularly in girls*), and **22q11 deletion**, but others can occur too. That's why your doctor may recommend a blood test to check your child's chromosomes.

If your baby is given a provisional diagnosis of coarctation of the aorta before they are born, your doctor will talk to you about the option of having a test to check your baby's chromosomes, which can be carried out before birth.

How is coarctation of the aorta diagnosed?

In most cases, coarctation of the aorta isn't revealed until after a baby is born, as part of the routine examination. In some cases though, a provisional diagnosis may be made before a baby is born, but it can't be confirmed until after birth using an **echocardiogram**. This is an ultrasound scan of the heart and it won't hurt your baby at all.



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For more information and support about growing up with a heart condition, visit [bhf.org.uk/heart-health/children-and-young-people](https://www.bhf.org.uk/heart-health/children-and-young-people)

How is coarctation of the aorta treated?

The narrowing of the **aorta** can be repaired with surgery. Most babies with coarctation of the aorta will have traditional 'open-heart' surgery. A very small number of babies have another treatment called balloon dilatation. We explain both these treatments on the next page.

Surgery

If your baby has surgery, they will have a general anaesthetic. Most repairs are done while the heart is beating, but some types of surgery need the heart to be stopped. The function of their heart will be taken over by a 'heart-lung machine'.

The surgeon will place a clamp on your baby's **aorta** to stop the blood flow and make it easier to operate. The surgeon will then remove the narrowed part of the **aorta** and sew the ends back together.

In some cases this might not be possible, so the surgeon may use a patch to enlarge the narrowing.

Depending on the type of surgery, your child will either have a scar in the left side of the chest and under their arm, or in the centre of their chest.

Risks of surgery

The good news is, surgery for coarctation of the aorta is usually very successful, and the fatality risks are low. Less serious complications are quite common though, such as, getting a minor infection in the wound, or a small collection of fluid in the lining of the lungs.

Complications such as stroke and internal bleeding can occur, but fortunately they're rare. Kidney damage can also happen, but this can usually be reversed.

On rare occasions, surgery does carry also carries a risk of damage to the spinal cord, particularly if the **aorta** needs to be clamped for a long time. This can cause the child's legs to become permanently paralysed. This is a very serious complication, but again it is a rare one.

Balloon dilatation

If your child is diagnosed with coarctation of the aorta as a teenager and has a balloon dilatation, an expandable metal mesh tube, called a **stent**, may be inserted to keep the narrowed area open.

This involves inserting a **catheter** (*a thin, hollow tube*) with a deflated balloon at its tip, into the artery at the top of the leg. Once the **catheter** reaches the narrowed part of the **aorta**, the balloon is inflated to make the narrowing wider.

This technique is rarely carried out in newborn babies.

Risks of balloon dilatation

Balloon dilatation is a relatively new technique, so it is too soon to tell if the risks are higher or lower than with traditional surgery. Complications such as stroke and internal bleeding can occur, but they're rare. Your paediatric **cardiologist** and cardiac surgeon will talk you through the specific risks associated with treatment for your child.

What happens after surgery or balloon dilatation?

Most children need to stay in hospital for a few days after surgery, although they may need to stay for longer if there are complications. Children who have had a balloon dilatation can go home within a day or two, provided there are no complications.

Whether your child has had traditional surgery or balloon dilation, after the procedure you will need to take your child to the outpatients clinic regularly to see the paediatric cardiologist.

What happens as my child grows up?

Most children lead normal, active lives after their operation. Your child's **cardiologist** will tell you if there are any specific forms of exercise or activities they should avoid.

As time goes by, the narrowing can develop again, particularly in teenage years. If this happens, your child may need further treatment. Even many years after successful treatment, some people develop a weakness in the wall of the **aorta**, which may need further treatment. In some of these cases, the newer balloon dilatation technique described on page 14 can be used, instead of your child having to have further surgery.

High blood pressure develops in some people, particularly in adulthood, and this may need to be controlled with medicines. Your child will need life-long reviews with a **cardiologist** to check everything is working as it should.

What is the risk of having another child a congenital heart condition?

If you have one child with a **congenital** heart condition, there is around a 1 in 40 chance that if you have another child, they will have a heart condition too.¹ However, this risk may be higher (*or lower*) depending on the type of **congenital** heart condition your child has. Because your risk of having another child with congenital heart condition is higher than it is for other people, your doctor may offer you a special scan at an early stage in future pregnancies, to look at the baby's heart.

Do ask your midwife or GP for more information on having a scan earlier than usual. Do be aware that if you have more than one child with **congenital** heart condition, the specific condition may not always be the same.

Coping with everyday life

For information on the topics below, please visit [bhf.org.uk/congenital](https://www.bhf.org.uk/congenital)

- Financial issues
- Low-income benefits
- Disability benefits
- Carer's Allowance
- Fares for visiting your child in hospital

The medical terms and what they mean

Aorta The main artery of the heart. It supplies oxygen-rich blood to the body.

Cardiac To do with the heart.

Cardiologist A consultant specialising in heart disease.

Catheter A fine, hollow tube.

Chromosomes Found in the nucleus of every cell in the body, chromosomes contain the genes, or hereditary elements, which establish the characteristics of an individual.

Congenital From birth.

Duct See ductus arteriosus.

Ductus arteriosus A natural connection between the aorta and the pulmonary artery. Also called the 'duct'.

ECG See electrocardiogram.

Echocardiogram An ultrasound scan used to produce pictures of the heart and blood vessels.

Electrocardiogram A recording of the electrical activity of the heart. Also called an ECG.

Turner's syndrome An inherited condition that only affects females, where one of the two X chromosomes is missing. This happens randomly when the baby is conceived.

Murmur An extra sound that is sometimes heard when listening to the heart through a stethoscope.

Paediatric To do with paediatrics – the study of children's diseases.

Pulmonary To do with the lungs.

Ventricle One of the two lower chambers of the heart.

Ventricular To do with the ventricle or ventricles. (See above.)

Ventricular septal defect A hole between the two ventricles of the heart. Also called VSD.

VSD See ventricular septal defect.

22q11 deletion An inherited condition, also known as DiGeorge syndrome, where a tiny part of a certain chromosome is missing. Children with the condition can have heart defects.

References

1. Gill HR, Splitt M, Sharland GK, Simpson JM. 2003. *Patterns of recurrence of congenital heart disease: An analysis of 6,640 consecutive pregnancies evaluated by detailed fetal echocardiography.* Journal of the American College of Cardiology; 42: 923-9.

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Notes



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For more information and support about children and young people with a heart condition, visit [bhf.org.uk/heart-health/children-and-young-people](https://www.bhf.org.uk/heart-health/children-and-young-people)



**British Heart
Foundation**

For over 50 years we've pioneered research that's transformed the lives of millions of people living with cardiovascular disease. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

But cardiovascular disease still kills around one in four people in the UK, stealing them away from their families and loved ones.

From babies born with life threatening heart problems, to the many mums, dads and grandparents who survive a heart attack and endure the daily battles of heart failure.

Join our fight for every heartbeat in the UK. Every pound raised, minute of your time and donation to our shops will help make a difference to people's lives.

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This is a charity donation service for the BHF. Texts cost £3 + 1 standard rate msg. The BHF will receive 100% of your donation to fund our life saving research. To opt out of calls and SMS text NOCOMMS BHF to 70060, or if you have any questions about your gift call 02032827862.

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