



# Understanding your child's heart

## Coarctation of the aorta



## Contents

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About this booklet	5
The normal heart	6
What is congenital heart disease?	8
What causes congenital heart disease?	8
Why me? Why my child?	9
What is coarctation of the aorta?	10
What are the symptoms of coarctation of the aorta?	12
What other conditions are associated with coarctation of the aorta?	13
How is coarctation of the aorta diagnosed?	14
How is coarctation of the aorta treated?	14
What happens as my child grows up?	17
The specialist centre for congenital heart disease	18
Coping with everyday life	20
General advice for the future	23
What is the risk of having another child with congenital heart disease?	24
Support groups	25
About the British Heart Foundation	26
References	27
Contacts	28
Hospital visits	29
The medical terms and what they mean	30
Index	32
Have your say	35



## About this booklet

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This booklet is written for the parents of babies and children with coarctation of the aorta, and for their relatives and friends. It explains:

- what coarctation of the aorta is and how it is diagnosed
- how coarctation of the aorta is treated
- the benefits and risks of treatments
- how to cope as a parent of a child with coarctation of the aorta
- where to go for more support.

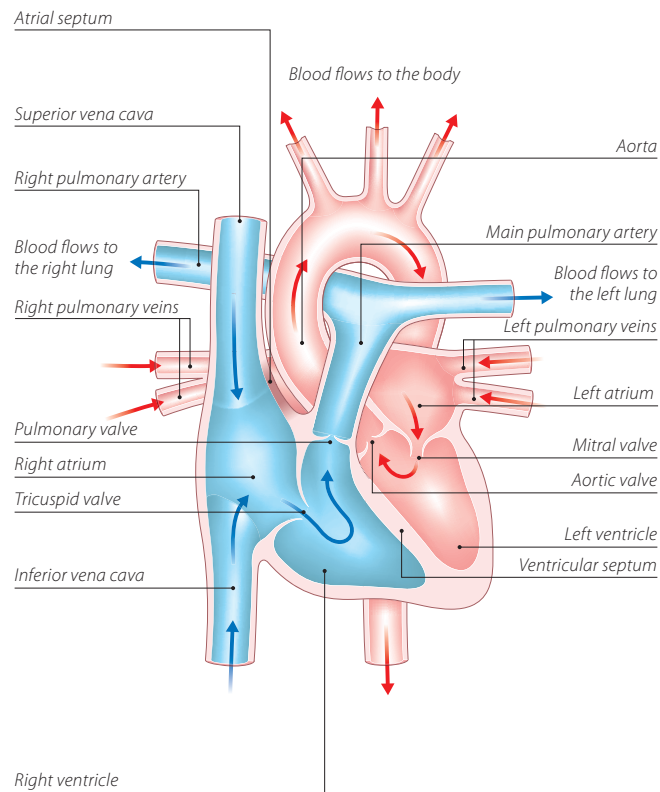
This booklet does not replace the advice that doctors or nurses may give you, but it should help you to understand what they tell you.

## The normal heart

The heart is a muscular pump which pumps blood through the body and lungs. There are four chambers in the heart. The two upper ones are called the right atrium and left atrium. These are separated by a wall called the atrial septum. The two lower chambers are called the right and left ventricles, and are separated by a wall called the ventricular septum. See the illustration opposite.

On each side of the heart, blood passes from the atrium, through a heart valve – the tricuspid valve on the right, and the mitral valve on the left – into the ventricle. The ventricles are the main pumping chambers of the heart. Each ventricle pumps blood out into an artery. The right ventricle pumps blood – blue in the illustration – into the pulmonary artery (the blood vessel that takes blood to the lungs). The left ventricle pumps blood – red in the illustration – into the aorta (the blood vessel that takes blood to the rest of the body). Blood flows from the right side of the heart, through the pulmonary valve into the pulmonary artery, and then to the lungs where it picks up oxygen. The oxygen-rich blood flows back into the left side of the heart through the pulmonary veins. The left ventricle then pumps the oxygen-rich blood out of the heart through the aortic valve and into the aorta, and all around the body. The blood then returns to the right side of the heart through two main veins – one from the upper body (superior vena cava), and the other from the lower body (inferior vena cava).

## The normal heart



## What is congenital heart disease?

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Congenital heart disease is an abnormality of the heart that developed in the womb. In some cases, congenital heart disease is diagnosed when the baby is still developing in the womb, but in most cases the problem is not discovered until after the baby is born. There are lots of different types of congenital heart disease. *Coarctation of the aorta* is one type.

## What causes congenital heart disease?

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We know that, in most cases of congenital heart disease, something has gone wrong in the early development of the fetus, at the very early stages of the pregnancy. In most cases, we don't understand why the baby's heart did not develop normally. In some cases, congenital heart disease can be part of a syndrome that the baby is born with. (A syndrome means a group of symptoms that appear together.)

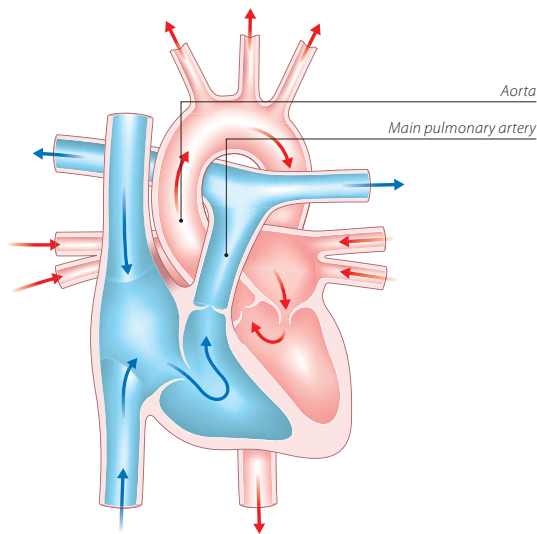
## Why me? Why my child?

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It is not unusual for parents of children with congenital heart disease to blame themselves or to be angry. Anger, disappointment, fear and guilt are all normal feelings to have when you are told that there is something wrong with your child. At first it may be difficult to cope with and it can take a while for the news to sink in. Many pregnant women or mothers, and their partners, ask themselves what they did during their pregnancy that could have caused their baby's heart to develop with heart disease. But the reality is that it can happen to anyone. In fact congenital heart disease happens in about 7 in every 1,000 pregnancies.<sup>1</sup> For more than half of these children, the heart disease is only a minor problem which either doesn't need any treatment, or which can be successfully corrected with surgery.

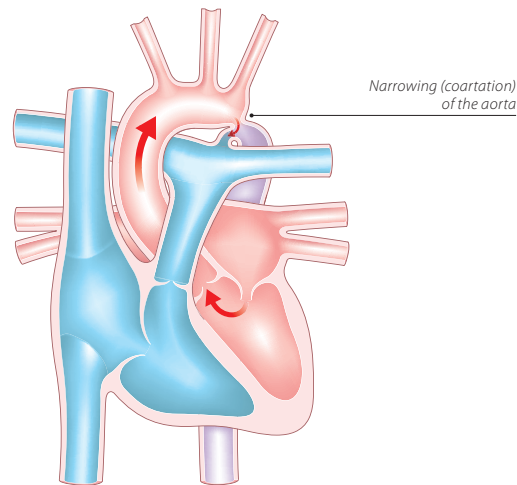
## What is coarctation of the aorta?

### The normal heart



Coarctation of the aorta is a serious abnormality, but it can be treated. The aorta is the large blood vessel that carries blood from the heart to the rest of the body. (See the illustrations above.) 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

### Coarctation of the aorta



supply the head and arms with blood. So the narrowing prevents the blood from circulating normally in the lower half of the body.

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 – often called ‘the duct’. This

closes naturally within the first few weeks after birth. In babies with coarctation of the aorta, the only way blood can flow to the lower half of the body is through the duct. So, in these babies, if the duct closes, no blood gets to the lower half of the body and the baby will die.

In some children the coarctation is not apparent early in life, but it gradually develops over time – sometimes in weeks, sometimes in years. Occasionally coarctation is not detected until adulthood.

The narrowing of the aorta makes it harder for the heart to pump. This causes high blood pressure in the blood vessels in the head and the arms, so the muscle of the left ventricle becomes thickened.

## What are the symptoms of coarctation of the aorta?

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Some newborn babies with a severe coarctation can suddenly become very pale, ill and breathless within the first few weeks of life, or even collapse. Some babies may also appear lethargic, find it difficult to feed and will not gain weight as normal.

In some infants where the abnormality is mild, it may only be found by chance, due to a heart murmur. (This is when the doctor hears an unusual sound when listening to the heart through a stethoscope.)

Sometimes coarctation may be suspected before birth, but the diagnosis can't be confirmed until after the baby is born. In these cases, the baby will need early treatment.

## What other conditions are associated with coarctation of the aorta?

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Some children with coarctation of the aorta will have other heart abnormalities, such as a hole between the ventricles. This is called a **ventricular septal defect**, or **VSD**. Other children may have a **narrowed aortic valve**. If appropriate, your cardiologist will discuss this with you.

Only a small proportion of children with coarctation have chromosome abnormalities. (Chromosome abnormalities are more common in those babies who have been diagnosed while in the womb.) The most common ones associated with coarctation are Turner's syndrome (particularly in girls), and 22q11 deletion, but other chromosomal abnormalities can also occur. Your doctor may recommend a blood test to check your child's chromosomes. For more information on Turner's syndrome and 22q11 deletion see our website [bhf.org.uk](http://bhf.org.uk)

If your baby was given a provisional diagnosis of coarctation of the aorta before birth, your doctor may discuss with you the option of having a test to check your baby's chromosomes. This test can be carried out before birth.

## How is coarctation of the aorta diagnosed?

In most cases, coarctation of the aorta is not diagnosed until after the baby is born, as part of the routine examination. However, in some cases, a provisional diagnosis may be made before birth but it cannot be confirmed until after birth. Usually, the only test that is needed to make the diagnosis is an **echocardiogram**. This is an ultrasound scan of the heart. It is very similar to the scans that are carried out during pregnancy. It doesn't hurt your baby at all.

## 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 chest' **surgery**. A very small number may have another treatment called **balloon dilatation**. We explain both these treatments below.

### Surgery

Your child will have a general anaesthetic. Most repairs are done while the heart is beating, but some will need the heart to be stopped. The function of the heart will be taken over by a 'heart-lung machine'.

The surgeon will place a clamp on the aorta to stop the blood flow and make it easier to operate. He or she will then cut out the narrowed part of the aorta and sew the ends

back together. Or, the surgeon may use a patch made of special material to enlarge the narrowing.

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

### Balloon dilatation

In recent years a new technique which avoids the need for major surgery has been developed. This technique is rarely carried out in newborn babies. It is more suitable for older children.

This involves inserting a catheter (a fine, 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 is also known as **angioplasty**.

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

### What happens after surgery or balloon dilatation?

Most children need to stay in hospital for a few days after traditional surgery, although they may need to stay in for longer than this if there are complications. Children who



have had a balloon dilatation can go home within a day or two, provided that there are no complications.

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

### **What risks are involved in surgery and balloon dilatation?**

#### **Risks of surgery**

Overall, 99 in every 100 children with coarctation of the aorta survive surgery, but the risks will vary from one child to another.<sup>2</sup> Your cardiologist will discuss your child's risk with you.

Less serious complications are quite common – for example, getting an infection on the wound, or a collection of fluid in the lining of the lungs.

Complications such as stroke and internal bleeding may occur, but they are rare. Kidney damage can also occur, but this is usually reversible.

Surgery also carries a risk of damage to the spinal cord, especially if the aorta needs to be clamped for a long time. This happens to around 1 in every 100 cases.<sup>2</sup> This is a very serious complication, as it usually causes the child's legs to become permanently paralysed.

#### **Risks of balloon dilatation**

Balloon dilatation is a relatively new technique, so it is too soon to tell if the risk of death is higher or lower than with traditional surgery. Current information suggests that 99 in every 100 patients survive.<sup>2</sup> Complications such as stroke and internal bleeding may occur, but they are rare. Your paediatric cardiologist and cardiac surgeon will discuss with you the specific risks associated with treatment for your child.

### **What happens as my child grows up?**

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Most children with repaired coarctation of the aorta lead normal, active lives after their operation. Your cardiologist will tell you if your child should avoid any specific forms of exercise.

Sometimes the narrowing can develop again as time goes by, 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 15 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 by medicines. Your child will need life-long reviews with a cardiologist.

## The specialist centre for congenital heart disease

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Your child will continue to have check-ups at a specialist centre for congenital heart disease throughout their life. Up to the age of about 16, he or she will go to a centre which may be called a 'specialist centre for children with congenital heart disease', or a 'specialist paediatric centre'. (Paediatric means to do with children.)

If the specialist centre is quite a distance from your home, it may be possible to make arrangements for your child to be looked after under a 'shared care' system. This means that your child will be looked after locally, but will go to the specialist centre for specialised treatment. (See page 22 for information about claiming travel expenses for visits to the specialist centre.)

### The specialist team

At the specialist centre, a large multidisciplinary team of people will be involved in caring for your child and your family's needs. (Multidisciplinary means that it includes several different types of health professionals.) The team usually consists of:

- a consultant paediatric cardiologist
- a specialist registrar (a doctor who is specifically training in children's heart problems)
- a cardiac nurse specialist or cardiac liaison nurse
- a consultant paediatric surgeon or paediatric cardiothoracic surgeon
- cardiac technicians

- a paediatric physiotherapist
- a paediatric dietitian
- ward-based paediatric nurses
- a social worker
- an occupational therapist
- a speech and language therapist, and
- a play specialist.

All of these people are involved in planning the care for each patient. You probably won't need to see all of them, but it is important to know who is there and available to help you with any problems you may come across. For example, the social worker can be a very useful source of information on what benefits you might be entitled to claim, and whether you can claim your travel expenses for visiting your child in hospital, or for visits to the specialist centre. (For more on this, see page 22.)

The specialist centre will also have access to psychology services which you can use to help your child or your family if you need help at difficult times.

### Specialist adult congenital heart disease centres

When your child grows into adulthood, it is important that he or she carries on going to a specialist centre for check-ups. There are several specialist centres in the UK for adults with congenital heart disease. Your child's care will be transferred to an adult specialist centre usually at around the age of 16. These centres usually have a multidisciplinary team with the same mix of professionals as in the children's specialist centre (see

page 18). When your child is nearing adulthood, your specialist paediatric centre will start preparing you and your child for the move to the adult specialist centre, to make the transition as smooth as possible.

## Coping with everyday life

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Having a child with a heart condition in hospital can be very difficult for a number of reasons. You are having to care for your child in hospital, and may be anxious about the treatment your child has to have or how well he or she is recovering. You might also be worrying about being away from home, or about your other children and who's looking after them, or about your work or your finances.

Hospital staff recognise the stress that you and your family might be under. Ask the nurse who is looking after your child about the support services available within the hospital – such as psychology services, welfare rights advisers and social workers. Below we give a brief guide to the benefits and help you may be able to get.

### Financial issues

Financial problems may arise because you need to stay in hospital with your child. The hospital may be a long way from home, and you may not know how long you will need to stay there for. This can affect your finances, as you may have to take time off work and will have extra costs such as travel expenses and buying meals while in hospital. This can be an extra anxiety, and difficult to cope with.

If you are worried about your finances, it is important to discuss your situation with a hospital social worker or cardiac liaison nurse, or with the Citizens Advice Bureau. They may be able to advise you on the benefits you can claim. Also, an organisation called Working Families can give you advice on the phone – on 0800 013 0313 – about your rights as an employee if you need to take time off work to be with your child.

### Low-income benefits

Benefits for people on a low income include Income Support, housing and council tax benefits, and Tax Credits. If your income goes below a certain amount, you may be able to claim benefits. However, you have to meet certain criteria in order to get these benefits. The criteria vary from one benefit to another, so you should get specialist advice from a hospital social worker, Citizens Advice Bureau or Jobcentre Plus.

### Disability benefits

Some children with congenital heart disease will qualify for a **Disability Living Allowance** (DLA), but most will not. Ask the specialist nurse or social worker for advice. If your child needs extra care because of his or her condition, you may be able to apply for this benefit. There is a mobility and a care component to the benefit. It can be difficult to get Disability Living Allowance for a child. You will need to show that your child needs more attention or supervision than other children of the same age. To get a claim form for Disability Living Allowance, call 0800 88 22 00. Or you can get a form from your GP or your local Jobcentre Plus office, or claim online at [www.direct.gov.uk](http://www.direct.gov.uk)

## Carer's Allowance

You may be entitled to *Carer's Allowance* if your child is awarded the middle or higher care component of Disability Living Allowance. However, you will only get Carer's Allowance if your earnings are below a certain limit. To get a claim form for the Carer's Allowance, call 01253 856 123. Or you can get a claim form from your local Jobcentre Plus, or claim online at [www.direct.gov.uk](http://www.direct.gov.uk)

## Fares to hospital

If you get Income Support, or have a Tax Credit exemption card, or are assessed as being on a low income, you are entitled to get reimbursed for your fares to hospital appointments and inpatient treatment. If you think you might qualify because of your income, complete a form HC1. To get one, call 0845 850 1166. The forms are usually also available from Jobcentre Plus offices and NHS hospitals.

## Fares for visiting your child in hospital

If you are getting Income Support, income-based Jobseeker's Allowance, or Pension Credit, you may be able to get help towards the cost of fares for hospital visiting, from the Social Fund. You should apply for a Community Care Grant on form SF300, which is available from your local Jobcentre Plus office or from the website of the Department for Work and Pensions at [www.dwp.gov.uk](http://www.dwp.gov.uk). However, these payments are not given in all cases.

**The benefits system is very complex, so it is important to get specialist advice on what you may be entitled to, from the hospital social worker or Citizens Advice Bureau.**

## General advice for the future

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### Endocarditis

Everyone who has coarctation of the aorta is at risk of getting *infective endocarditis*, both before and after surgery or treatment. Infective endocarditis is a rare condition where the inner lining of the heart, most commonly one of the heart valves, becomes infected.

Infective endocarditis is a serious condition which can be life-threatening if it's not treated quickly. Nowadays, if it is diagnosed early, most people with it will recover well with antibiotic treatment, although some damage may occur to the heart valves as a result of the infection.

Endocarditis is caused by a bacterium, or (rarely) another type of infective organism that is in the bloodstream, which settles onto the abnormal structure or defect in the heart. Although it is not possible to prevent all bacteria from getting into the bloodstream, there are some things your child can do, as he or she grows up, to reduce the risk of getting endocarditis:

- Maintain good oral hygiene and have regular check-ups with a dentist
- Avoid body piercing and tattooing
- Never inject recreational drugs.

If your child develops flu-like symptoms with a temperature **which persist for over a week**, you should visit your GP as your child may need a blood test. Make sure that the GP knows that your child is at increased risk of getting endocarditis. You can

do this by showing the GP an *Endocarditis warning card*. You can get this card from the British Heart Foundation (BHF) by calling either the Heart HelpLine on **0300 330 3311** (local rate number) or the BHF Orderline on **0870 600 6566**.

## Pregnancy

If you have a daughter with congenital heart disease, you need to be aware that pregnancy could carry risks to both the mother and the baby. So, when your daughter gets older, it's particularly important that she avoids having an unplanned pregnancy. You will need to discuss this with your daughter in whichever way you, as a parent, think is appropriate for her. If your daughter wants to have a baby, it's best that she speaks to her cardiologist about it first, so that the pregnancy can be planned for when your daughter's heart condition is most stable.

People who have congenital heart disease themselves have an increased risk of having a child with a heart problem. This applies to both males and females. You can discuss this with your cardiologist. Early scans in pregnancy can be arranged to look for heart disease in the baby.

## What is the risk of having another child with congenital heart disease?

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If you have one child with congenital heart disease, there is about a 1 in 50 chance of having another child with congenital heart disease.<sup>3</sup> However, this risk may be higher (or lower) depending on the type of congenital heart disease your child

has. Because your risk of having another child with congenital heart disease is higher than it is for other people, you may be offered a special scan at an early stage in future pregnancies, to look at the baby's heart. Ask your midwife or GP for more information on having a scan earlier than usual.

If you have had two children with congenital heart disease, the risk of having another child with heart disease rises to about a 1 in 10 chance. This may sound like a high risk, but you still have a much better chance of the baby's heart being normal than abnormal. If there is a recurrence, the heart disease may not always be of the same type.<sup>3</sup>

## Support groups

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The following support groups may be able to offer you further information, advice and support:

### Action for Sick Children

36 Jacksons Edge Road  
Disley, Stockport SK12 2JL  
Phone: 0800 074 4519  
Website: [www.actionforsickchildren.org](http://www.actionforsickchildren.org)

### Children's Heart Federation

Level One, 2-4 Great Eastern Street  
London EC2A 3NW  
Phone: 0808 808 5000  
Website: [www.childrens-heart-fed.org.uk](http://www.childrens-heart-fed.org.uk)

## About the British Heart Foundation

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The British Heart Foundation is the nation's heart charity, saving lives through pioneering research, patient care and vital information.

### What you can do for us

We rely on donations to continue our vital work. If you would like to make a donation to the BHF, please ring our Supporter Services team on **0844 847 2787** or contact us through our website at **bhf.org.uk/donate** or send it to us at the address on the back cover.

## For more information

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### British Heart Foundation website

**bhf.org.uk**

For up-to-date information on heart disease, the BHF and its services.

### Heart HelpLine

**0300 330 3311** (local rate number)

For information and support on anything heart-related.

## Booklets

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### To order any of our booklets

- call the BHF Orderline on **0870 600 6566**
- email **orderline@bhf.org.uk** or
- visit **bhf.org.uk/publications**

You can also download many of our publications from our website.

For information on other BHF booklets, and on DVDs and videos, ask for a copy of the *Heart health catalogue*.

### Understanding your child's heart series

This booklet is one of the booklets in the *Understanding your child's heart* series. For a full list of the booklets available in this series, see our website **bhf.org.uk** or call the Heart HelpLine on **0300 330 3311** (local rate number).

### Operation Fix-it

A short story book about eight-year-old Tom's experience in hospital for a heart operation. Prepares children for their hospital visit in an interesting and sometimes humorous way.

## References

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2. Specific procedures national data. The congenital heart disease website. London: The Information Centre. Accessed from: [www.ccad.org.uk](http://www.ccad.org.uk)
3. 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.

## Contacts

Use this page to keep contact details of the health professionals who are caring for your child.

### Paediatric cardiologist

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## Paediatric nurse

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## Paediatrician

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## Social worker

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## Surgeon

## Others

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## Hospital visits

Use this page to write down the dates of your hospital visits.

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## The medical terms and what they mean

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<b>aorta</b>	The main artery of the heart. It supplies oxygen-rich blood to the body.
<b>atrial</b>	To do with the atrium. (See below.)
<b>atrium</b>	One of the two upper chambers of the heart.
<b>cardiac</b>	To do with the heart.
<b>cardiologist</b>	A consultant specialising in heart disease.
<b>catheter</b>	A fine, hollow tube.
<b>chromosomes</b>	Found in the nucleus of every cell in the body, chromosomes contain the genes, or hereditary elements, which establish the characteristics of an individual.
<b>congenital</b>	From birth.
<b>duct</b>	See <i>ductus arteriosus</i> .
<b>ductus arteriosus</b>	A natural connection between the aorta and the pulmonary artery. Also called the 'duct'.
<b>ECG</b>	See <i>electrocardiogram</i> .
<b>echocardiogram</b>	An ultrasound scan used to produce pictures of the heart and blood vessels.
<b>electrocardiogram</b>	A recording of the electrical activity of the heart. Also called an ECG.

<b>endocarditis</b>	Infection of the lining of the heart or its valves.
<b>genetic</b>	To do with the information that is passed from parents to children through genes in sperm and eggs.
<b>murmur</b>	An extra sound that is sometimes heard when listening to the heart through a stethoscope.
<b>paediatric</b>	To do with paediatrics – the study of children's diseases.
<b>pulmonary</b>	To do with the lungs.
<b>septum</b>	The wall that keeps the right and left sides of the heart separate.
<b>ventricle</b>	One of the two lower chambers of the heart.
<b>ventricular</b>	To do with the ventricle or ventricles. (See above.)
<b>ventricular septal defect</b>	A hole between the two ventricles of the heart. Also called VSD.
<b>VSD</b>	See <i>ventricular septal defect</i> .



## Index

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22q11 deletion	<b>13</b>
angioplasty	<b>15</b>
aorta	<b>6, 7, 10</b>
aortic valve	<b>6, 7, 13</b>
atrium	<b>6, 7</b>
balloon dilatation	<b>14, 15</b>
benefits	<b>21</b>
Carer's Allowance	<b>22</b>
causes of congenital heart disease	<b>8</b>
centre:	
specialist centre for adults	<b>19</b>
specialist centre for children	<b>18</b>
chromosome abnormality	<b>13</b>
coarctation of the aorta	<b>10</b>
diagnosis	<b>14</b>
Disability Living Allowance	<b>21</b>
duct	<b>11</b>
ductus arteriosus	<b>11</b>
echocardiogram	<b>14</b>
endocarditis	<b>23</b>
fares to hospital	<b>22</b>
finance	<b>20</b>
future	<b>17, 23</b>
heart: how the normal heart works	<b>6</b>
infection	<b>23</b>
mitral valve	<b>6, 7</b>
money	<b>20</b>
normal heart	<b>6</b>

operation	<b>14</b>
pregnancy	<b>24</b>
professionals	<b>18</b>
pulmonary artery	<b>6, 7</b>
pulmonary valve	<b>6, 7</b>
pulmonary veins	<b>6, 7</b>
risks:	
of balloon dilatation	<b>17</b>
of surgery	<b>16</b>
septum	<b>6, 7</b>
specialist centre:	
for adults	<b>19</b>
for children	<b>18</b>
specialist team	<b>18</b>
stent	<b>15</b>
support groups	<b>25</b>
surgery	<b>14</b>
symptoms	<b>12</b>
team	<b>18</b>
travel expenses	<b>22</b>
treatment	<b>14</b>
tricuspid valve	<b>6, 7</b>
Turner's syndrome	<b>13</b>
valves	<b>6, 7</b>
ventricle	<b>6, 7</b>
ventricular septal defect	<b>13</b>
VSD	<b>13</b>



## Have your say

We would welcome your comments to help us produce the best information for you. Why not let us know what you think? Contact us through our website at [bhf.org.uk/contact](https://www.bhf.org.uk/contact) Or, write to us at the address on the back cover.

## Acknowledgements

The British Heart Foundation would like to thank:

- Children's Heart Federation
- Ms Lynda Shaughnessy, Transition Nurse, Royal Brompton Hospital
- Ms Carole Wingett, Social Worker, Royal Brompton Hospital.

Particular thanks for their work on this series of booklets are due to:

- Dr Gurleen Sharland, Consultant Fetal Cardiologist, Evelina Children's Hospital, Guy's & St Thomas' NHS Foundation Trust
- Dr James Gnanapragasam, Consultant Paediatric Cardiologist, Southampton General Hospital
- Dr John Gibbs, Consultant Paediatric Cardiologist, Leeds General Infirmary.

# HEART HELPLINE

For information and support on anything heart-related



**0300 330 3311**

local rate number



**bhf.org.uk**

Phone lines open 9am to 6pm Monday to Friday



## British Heart Foundation

Greater London House  
180 Hampstead Road  
London NW1 7AW  
Phone: 020 7554 0000  
Fax: 020 7554 0100  
Website: [bhf.org.uk](http://bhf.org.uk)