



# Understanding your child's heart

## Hypoplastic left heart



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## About this booklet

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This booklet is written for the parents of babies with hypoplastic left heart, and for their relatives and friends. It explains:

- what hypoplastic left heart is and how it is diagnosed
- how hypoplastic left heart is treated
- the benefits and risks of treatments
- how to cope as a parent of a baby with hypoplastic left heart
- where to go for more support.

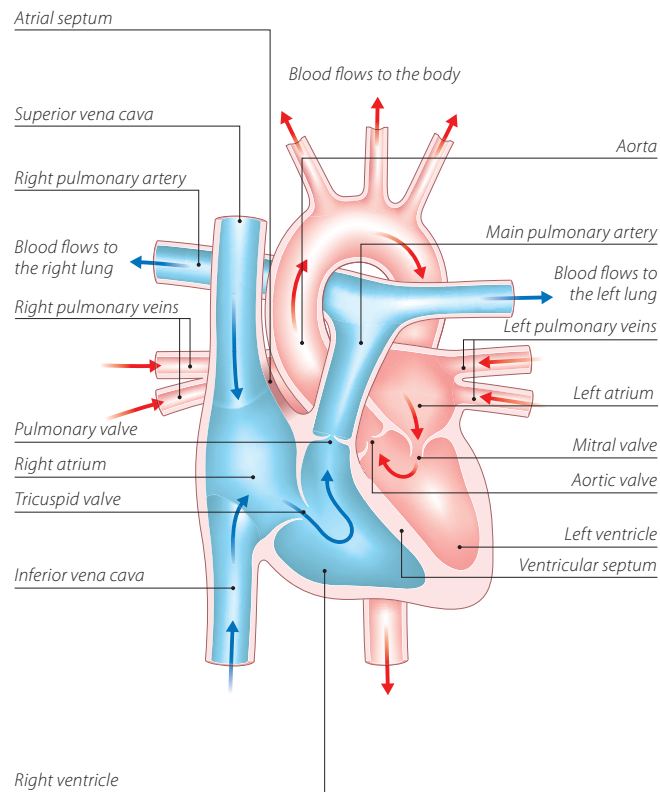
This booklet does not replace the advice that doctors or nurses may give you, but it should help you to understand what they tell you.

## 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. **Hypoplastic left heart** is a very serious 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?

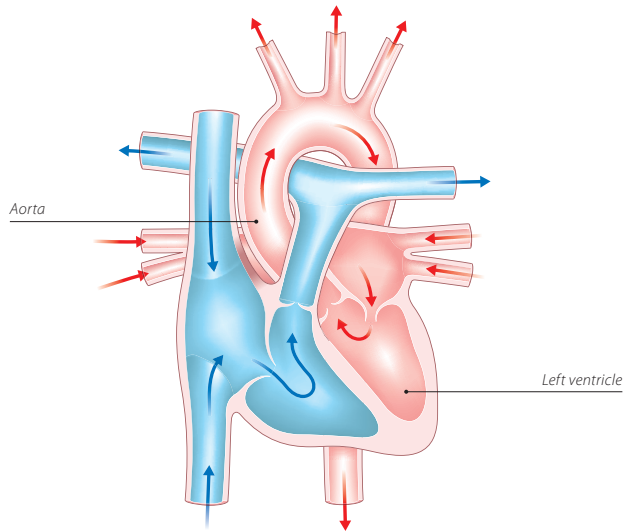
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It is not unusual for parents of children with congenital heart disease to blame themselves or to be angry. Anger, disappointment, fear and guilt are all normal feelings to have when you are told that there is something wrong with your child. At first 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. For others it is more serious and, sadly, some children don't survive. However, thanks to advances in diagnosis and treatment, most children can be helped to have a good quality of life.

## What is hypoplastic left heart?

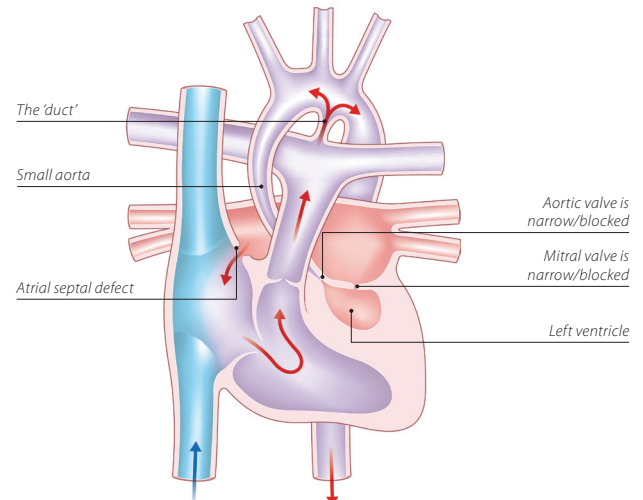
### The normal heart



Hypoplastic left heart – or HLH for short – is a very serious type of congenital heart condition. There are three main abnormalities:

- The mitral valve is either very narrow or completely blocked.

### Hypoplastic left heart



- The main pumping chamber on the left side of the heart (the left ventricle) is very under-developed.
- The aortic valve is either very narrow, or completely blocked.

See the illustration above.

In the normal circulation, blood with oxygen flows from the lungs to the left atrium, and then into the left ventricle. From there it is pumped into the aorta and around the body. In babies with HLH, the blood cannot flow normally through the left side of the heart. Instead, it passes from the left atrium to the right atrium and into the right ventricle. From there it is pumped to the pulmonary artery and back to the lungs. (See the illustration on page 11.)

Before babies are born, the two main arteries – the pulmonary artery and the aorta – are connected by a short channel called the ***ductus arteriosus*** – often called ‘the duct’. During pregnancy the duct allows blood to bypass the lungs (the blood flows from the pulmonary artery through the duct to the aorta) because it is not necessary to pump blood to the lungs while the fetus is not breathing but is receiving oxygen from the mother’s circulation. In normal babies the duct closes shortly after birth because it is no longer required. However, in babies with HLH, the only way blood can flow to the aorta and the body is through the duct. So, if the duct closes, blood will not be circulated around the body and the baby will die.

## What are the symptoms of hypoplastic left heart?

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Most babies with HLH look normal immediately after birth, but they become breathless and very ill if they are not treated quickly.

## What other conditions are associated with hypoplastic left heart?

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Most babies with hypoplastic left heart only have the heart abnormalities described on page 10 and 11. However, a small proportion of babies may have other abnormalities, including chromosome abnormalities. Your cardiologist will discuss this further with you if necessary.

Also, children with hypoplastic left heart have a greater risk of having learning disabilities than other children.

## How is hypoplastic left heart diagnosed?

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In most cases, hypoplastic left heart is detected before birth, but in some cases it is not diagnosed until after the baby is born. 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 hypoplastic left heart treated?

It is not possible to correct hypoplastic left heart with surgery, but there are operations which can help children to have a reasonable quality of life. Your child will need to have several operations during his or her lifetime.

The very first stage of treatment is to keep the duct open. Without treatment, the duct would close and your baby would die. Your baby will be given an injection of a drug called *prostaglandin* to keep the duct open. A side effect of this drug is that it occasionally interferes with the baby's natural breathing, and so your baby may need the support of a *ventilator*.

### Initial surgery

Your baby will need surgery very early in life. In many cases the initial surgery is carried out within a few days of birth, but the exact timing varies from one baby to another.

The first operation for most babies with hypoplastic left heart is called the *Norwood procedure*. However, some babies who are very small or very ill may not be suitable for the Norwood procedure and may be offered a different treatment to start with, called the *hybrid procedure*. We describe both these procedures in the next section.

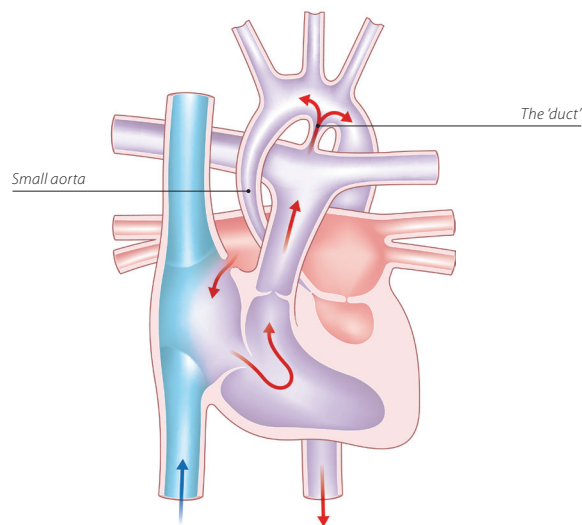
### The Norwood procedure

Your baby will be given a general anaesthetic. The Norwood procedure is an open-heart operation where the heart is stopped and the function of the heart is taken over by a heart-lung machine. The aim of the operation is to use the right ventricle to pump blood into the aorta. To do this, the surgeon separates the main pulmonary artery from the right and left branches and joins it to the upper part of the aorta. (See the illustration on page 17). The blood supply to the right and left pulmonary arteries is then provided by a 'shunt' – a tube, made of synthetic material, which is placed between the aorta and the pulmonary artery (or sometimes between the right ventricle and the pulmonary artery). After the surgery, your baby will have a vertical scar in the middle of the chest, along the breast bone.

How long your baby needs to stay in hospital after the surgery depends very much on how well he or she progresses, and whether there are any complications. Most babies are allowed home within a few weeks. After the operation, you will need to take your baby to the outpatients department to see the paediatric cardiologist for regular check-ups.



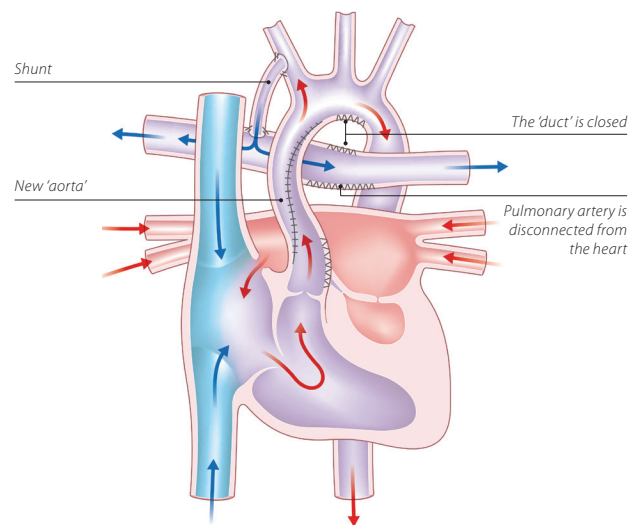
## Hypoplastic left heart



### What are the risks of the Norwood procedure?

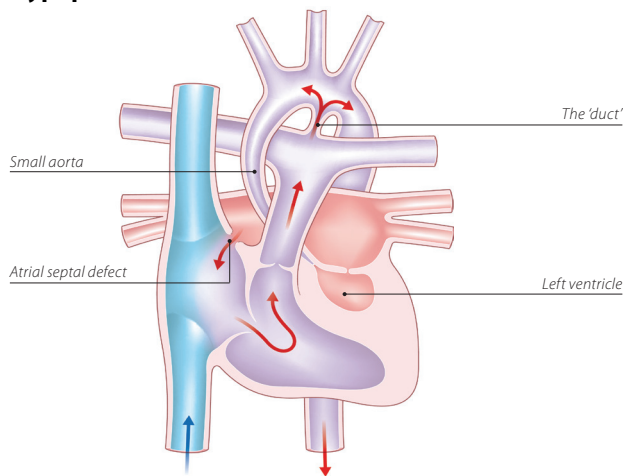
About 80 in every 100 babies survive this first stage of surgery. There is a small risk that your baby may have

## Norwood procedure stage 1



brain damage or internal bleeding. Kidney damage can also occur, but this usually recovers with treatment.

## Hypoplastic left heart

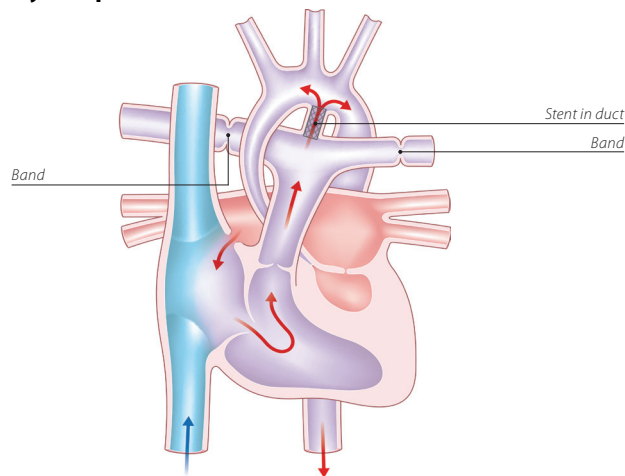


### The hybrid procedure

This is a new technique which involves a combination of surgery and catheter treatment. It is used for some babies – particularly those who are very small or very ill – who may not be suitable for the Norwood procedure.

The hybrid procedure helps to improve the baby's circulation while allowing them to grow before they have more major surgery. It also helps to protect the lungs by reducing the amount of blood being delivered to them. And it keeps the duct open. If the hybrid procedure is suitable for

## Hybrid procedure



your baby, your paediatric cardiologist will discuss it with you in more detail.

Your baby will be given a general anaesthetic. The surgeon or cardiologist will place an expandable metal mesh tube – called a **stent** – inside the duct, to stop it from closing. (See the illustration above). A hole is also created between the right atrium and left atrium. This means that blood can flow into the aorta to be delivered to the rest of the body. Also, small bands are placed around the right and left pulmonary arteries, to reduce the amount of blood flowing to the lungs.

This helps to protect the lungs. After the surgery, your baby will have a scar down the middle of his or her chest.

### What are the risks of the hybrid procedure?

This is a relatively new procedure and the technique is still being evaluated. Your paediatric cardiologist will discuss this with you in more detail.

### Further surgery

Normally, babies with hypoplastic left heart will need two further major operations as they grow. The exact nature and timing of any further surgery will depend on your child's progress.

The type of surgery most commonly carried out is a **cavopulmonary shunt**, which involves connecting the superior vena cava directly to the pulmonary arteries. Further surgery after this usually involves redirecting the blood flow from the inferior vena cava to the pulmonary artery. This is called a **total cavopulmonary connection**, or **TCPC** for short. For more information on these treatments, see our booklet *Understanding your child's heart: Single ventricle circulation*.

Your cardiologist will explain what type of treatment is recommended for your child.

Babies can die at any stage of their treatment, but are at particular risk between their first and second operation. Sadly, a few babies may not be suitable for any further

surgery and will die very young. For support on coping as a parent with a child who is dying, see page 30. For support or helping a young child with the death of a brother or sister, see the BHF bereavement booklet *The small creature*. For information on how to order this booklet, see page 32.

## What happens as my child grows up?

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Hypoplastic left heart is a complex condition, and only about six out of ten children will survive all three stages of surgery. Although surgery can give a reasonable quality of life, it is not possible to correct the heart abnormality and we do not know how long children with this condition will live for. The longest survivors in the UK at present are in their teens. Heart transplantation may be an option for some patients, although this is rarely considered before adulthood.

Children with hypoplastic left heart are always limited to some extent in their physical activities, but specific restrictions on exercise are usually not necessary. It is usually best to allow children with this condition to join in with their friends' activities, including some sport at school, and for them to judge for themselves what they are able to do.

Whatever type of treatment your child has for hypoplastic left heart, regular check-ups with a cardiologist are very important – not just in childhood but as he or she grows older too.

## 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 specialist centre for children with congenital heart disease (paediatric cardiac centre).

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 (some general hospitals have paediatricians who have had special training in cardiology). This means that your child will be looked after locally, but will go to the specialist centre for specialised treatment. (See page 26 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 26.)

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 22). 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 hypoplastic left heart 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

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

### **Little hearts matter**

11 Greenfield Crescent, Edgbaston, Birmingham,  
West Midlands, B15 3AU  
Phone: 0121 455 8982. Website: [www.lhm.org.uk](http://www.lhm.org.uk)

### **Action for Sick Children**

32b Buxton Road, High Lane, Stockport SK6 8BH  
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)

### **Grown Up Congenital Heart Patients Association**

Saracen's House, 25 St Margaret's Green, Ipswich IP4 2BN  
Phone: 0800 854759. Website: [www.guch.org.uk](http://www.guch.org.uk)

### **www.yheart.net**

A website for young people with heart conditions.

### **Child Death Helpline**

Offers support and befriending for those affected by child death  
Phone: 0800 282 986. Website: [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

## **Compassionate Friends**

For parents who have lost a child and of any age, including adult children.

Phone: 0845 123 2304. Website: [www.tcf.org.uk](http://www.tcf.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](http://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](http://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.



## Other resources

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### 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/congenital](http://bhf.org.uk/congenital) or call the Heart Helpline on 0300 330 3311 (local rate number).

### Children with congenital heart disease (DVD)

Three families share their experiences from diagnosis to treatment, and staff at the Evelina Children's Hospital offer guidance on parents' common concerns.

### The small creature

This beautiful, award winning resource is to help children under 11 years who are bereaved.

### 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.

### To order any of our resources

- call the BHF Orderline on 0870 600 6566
- email [orderline@bhf.org.uk](mailto:orderline@bhf.org.uk) or
- visit [bhf.org.uk/publications](http://bhf.org.uk/publications)

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

For information on other BHF booklets and DVDs ask for a copy of *Our heart health catalogue*.

## References

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1. Petersen S, Peto V, Rayner M. 2003. *Congenital Heart Disease Statistics 2003*. Oxford: British Heart Foundation Health Promotion Research Group.
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

Paediatric nurse

Paediatrician

Social worker

Surgeon

Others

## Hospital visits

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

Date	Time	With	Where

## 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>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>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> below.
<b>ductus arteriosus</b>	A natural connection between the aorta and the pulmonary artery. Also called the 'duct'.
<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>heart-lung machine</b>	A machine that pumps blood around the body while the heart is stopped during an operation.
<b>paediatric</b>	To do with paediatrics – the study of children's diseases.
<b>ventilator</b>	A machine that helps your child breathe.
<b>ventricle</b>	One of the two lower chambers of the heart.

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## 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

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# 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)

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