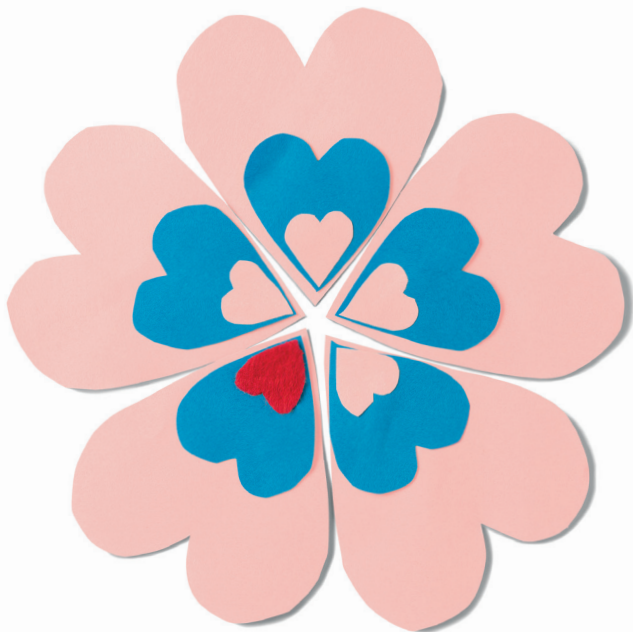




Understanding your child's heart

Pulmonary atresia with intact ventricular septum



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You can go directly to the coloured section to read about your child's heart condition



About this booklet

This booklet is for parents of children with pulmonary atresia where the ventricular septum is intact. There is a separate condition called 'pulmonary atresia with a ventricular septal defect'. If your child has that condition, it would be more helpful for you to read our booklet *Understanding your child's heart: Pulmonary atresia with a ventricular septal defect*. See page 30 for information on how to order the booklet.

This booklet explains:

- what pulmonary atresia with intact ventricular septum is and how it is diagnosed
- how pulmonary atresia with intact ventricular septum is treated
- the benefits and risks of treatments
- how to cope as a parent of a child with pulmonary atresia with intact ventricular septum, and
- where to go for more support.

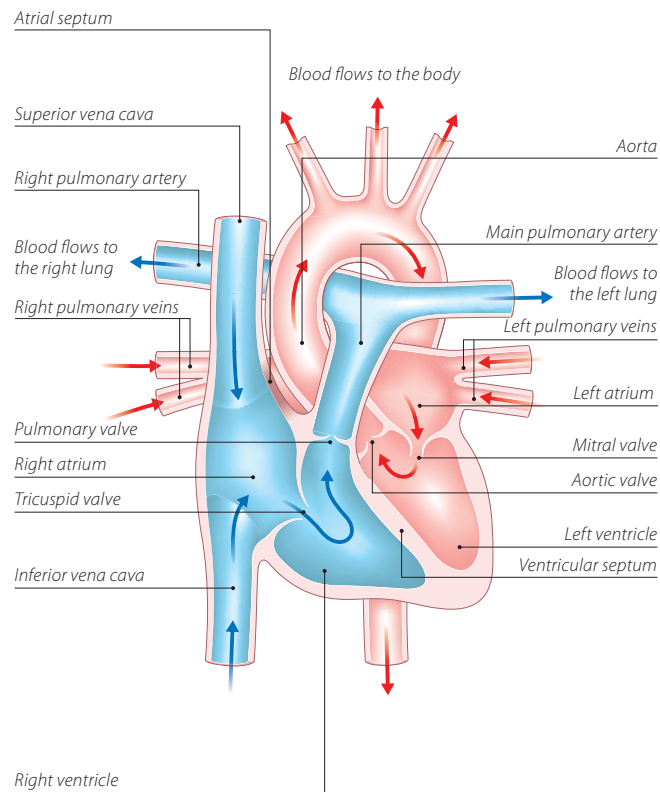
This booklet does not replace the advice that doctors or nurses may give you, but it should help you to understand what they tell you.

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?

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. ***Pulmonary atresia with intact ventricular septum*** is a very serious type.

What causes congenital heart disease?

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.)

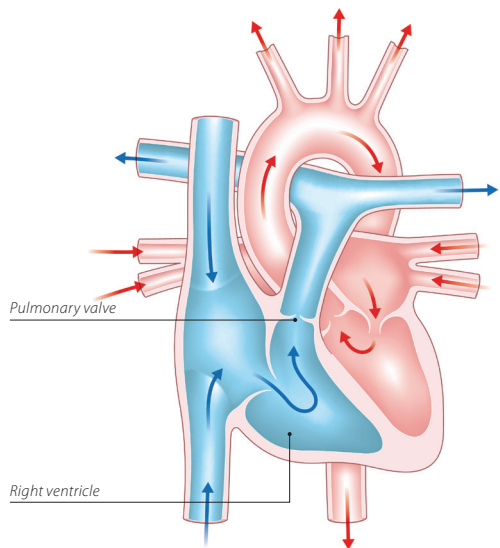
Why me? Why my child?

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.¹ 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 pulmonary atresia with intact ventricular septum?

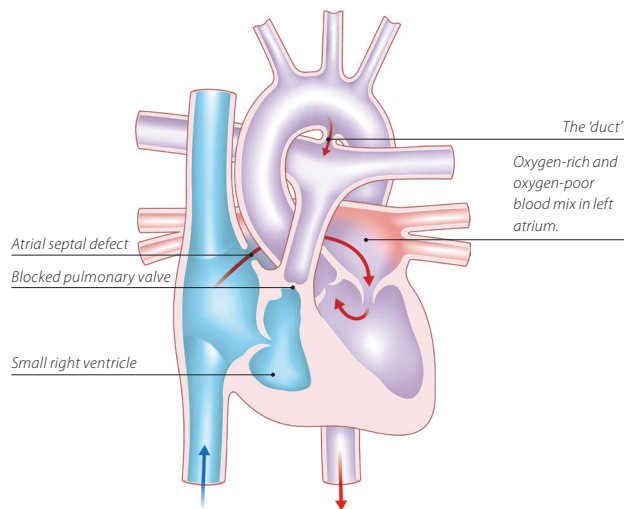
The normal heart



Pulmonary atresia with intact ventricular septum is a very serious type of congenital heart condition. There are two main abnormalities:

- The valve which allows blood to flow from the heart to

Pulmonary atresia with intact ventricular septum



the lungs – the pulmonary valve – is completely blocked. (See the illustration above.)

- The main pumping chamber on the right side – the right ventricle – has often not developed normally.

In some babies, the tricuspid valve – the valve which allows blood to flow into the right ventricle – may also be under-developed. In others there can be abnormalities of the coronary arteries (the arteries which supply the heart muscle with blood). These additional abnormalities can make treatment more difficult.

In the normal circulation, blood passes through the pulmonary artery to the lungs, to collect oxygen. In babies who have pulmonary atresia with intact ventricular septum, blood cannot pass to the lungs in this way. Instead, the blood passes from the aorta to the pulmonary artery through a connection called the ductus arteriosus – often called ‘the *duct*’. (See the illustration.) The duct is open while the baby is developing in the womb, but it usually closes shortly after birth. In a baby with pulmonary atresia with intact ventricular septum, it is vital that the duct stays open after birth if the baby is to survive. We explain more about the treatment to keep it open on the next page.

What are the symptoms of pulmonary atresia with intact ventricular septum?

The low level of oxygen in your baby’s blood can make him or her appear blue, especially around the lips, tongue, mouth and hands.

What other conditions are associated with pulmonary atresia with intact ventricular septum?

In some rare cases, babies who have pulmonary atresia with intact ventricular septum may have chromosome abnormalities which might affect their outlook. If your child does have any other abnormalities, your paediatric cardiologist will discuss this with you.

How is pulmonary atresia with intact ventricular septum diagnosed?

In some cases, pulmonary atresia with intact ventricular septum may be detected before birth, but in other 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 pulmonary atresia with intact ventricular septum treated?

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**.

Drug treatment is not usually recommended for very long periods, so your baby may need surgery to treat his or her condition within the first few weeks of life. The type of surgery needed will depend on how well the right ventricle has developed and whether your child has any other abnormalities of the heart. Your paediatric cardiologist will discuss your child's condition with you.

The next stage of treatment will depend on how well your baby's right ventricle has developed. If the right ventricle has developed enough, the next procedure is likely to be a **valvotomy**. This is a procedure to open the blocked valve. We explain more about it on page 15.

If the right ventricle is still very small, opening the blocked valve will not allow enough blood to the lungs. So, instead of, or as well as, a valvotomy, your child may need an operation called a **shunt operation**, to provide blood flow to the lungs and to keep him or her alive. We explain more about this on page 16.

A small number of children are not suitable for any type of treatment and their life expectancy is very short. If this is the case for your child, see page 28 for information on where to go for more support.

Valvotomy

In some babies it may be possible to open the blocked valve using a procedure called a **valvotomy**. Sometimes this can be done using the catheter valvotomy procedure, or it can be done with surgery.

Catheter valvotomy

Under general anaesthetic, a catheter (a fine, hollow tube) is inserted into a vein at the top of your baby's leg. It is guided up the vein into the right side of the heart and put in position under the blocked valve. Once it is in position, the tip of the catheter is heated to burn a small hole in the valve. Using X-ray pictures for guidance, a small balloon is put through the hole which has been made in the valve. The balloon is inflated, stretching the valve open. The balloon is then deflated and removed.

After the catheter valvotomy, your baby will need to stay in hospital for a few days to a few weeks. You will have to take your child to the outpatients department to see the paediatric cardiologist for a check-up within a few weeks.

Surgical valvotomy

In more complicated cases, the blocked pulmonary valve cannot be opened using the catheter technique described above, and open-heart surgery is needed. This operation, called **surgical valvotomy**, involves a general anaesthetic and a heart-lung machine to pump blood around the body

while the heart is stopped briefly and the valve is cut open. The heart is then re-started. After the operation, your child will have a scar down the middle of the chest, along the breast bone. For information about how long your child will need to stay in hospital after the operation, see *After the surgery*, on page 18.

What are the risks of valvotomy?

About 97 in every 100 children survive the catheter valvotomy, but the risk varies from one child to another². There is also a small risk of complications, such as bleeding around around the heart, or occasionally brain damage.

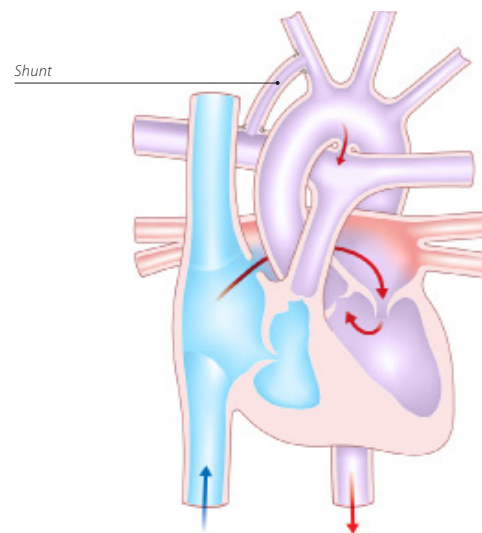
Surgical valvotomy is usually carried out in children with more complicated types of heart abnormalities, so the risks vary a great deal from one child to another. Your cardiologist will discuss this with you.

Shunt operation

In some cases, a valvotomy may not be possible or suitable, so a shunt operation may be carried out. This will not correct the heart problem, but it helps as a short-term measure to keep your baby alive until he or she can have further treatment.

A shunt allows more blood to flow to the lungs and makes the baby pinker. The operation involves placing a small tube made of synthetic material between a branch of the aorta and the pulmonary artery. (See the illustration on page 17.)

The surgery usually leaves a scar at the side of the chest rather than in the middle.



What are the risks of a shunt operation?

The risks associated with a shunt operation vary a great deal from one child to another. About 95 out of every 100 children with pulmonary atresia with intact ventricular septum who have a shunt operation survive the surgery. Your cardiologist will discuss this further with you.

After the surgery

The length of time children need to stay in hospital after a surgical valvotomy or a shunt operation varies. Many children recover quickly and may only need to stay for about a week. You will have to take your child to the outpatients department to see the paediatric cardiologist for a check-up a few weeks after the operation.

Further surgery

In some babies, the right ventricle remains very small. In these cases it is not possible to correct the heart abnormality, but there are operations which can help children to have a reasonable quality of life.

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.

What happens as my child grows up?

The long-term outlook for children who have pulmonary atresia with intact ventricular septum depends very much on which other abnormalities they have.

Children with a good result from a valvotomy may remain very well in adult life.

Children who have pulmonary atresia with intact ventricular septum are usually 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.

In the complex cases where the right ventricle has not developed, surgery can give a reasonable quality of life, but we do not know how long children with this condition will live for. The longest survivors at present are in their 30s. Heart transplantation may be an option for some patients, although this is rarely considered before adulthood.

Whatever type of treatment your child has for pulmonary atresia with intact ventricular septum, regular check-ups with a cardiologist are very important – not just in childhood, but throughout adult life too.

The specialist centre for congenital heart disease

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 24 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 24.)

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 20). 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

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

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

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. 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

Endocarditis

Everyone who has pulmonary atresia with intact ventricular septum 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?

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.³ 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.³

Support

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

Action for Sick Children

32b Buxton Road, High Lane, Stockport SK6 8BH
Phone: 0800 074 4519. Website: 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

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

www.yheart.net

A website for young people with heart conditions

About the British Heart Foundation

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

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.

Other resources

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 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.

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 or
- visit 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 the *Our heart health catalogue*.

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2. Specific procedures national data. The congenital heart disease website. London: The Information Centre. Accessed from: 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.

The medical terms and what they mean

aorta	The main artery of the heart. It supplies oxygen-rich blood to the body.
atrium	One of the two upper chambers of the heart.
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 below.
ductus arteriosus	A natural connection between the aorta and the pulmonary artery. Also called the 'duct'.
echocardiogram	An ultrasound scan used to produce pictures of the heart and blood vessels.
endocarditis	Infection of the lining of the heart or its valves.
genetic	To do with the information that is passed from parents to children through genes in sperm and eggs.

heart-lung machine	machine that pumps blood around the body while the heart is stopped during an operation.
paediatric	To do with paediatrics – the study of children's diseases.
pulmonary	To do with the lungs.
septum	The wall that keeps the right and left sides of the heart separate.
valvotomy	A surgical procedure to open a narrowed valve.
ventilator	A machine that helps your child breathe.
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 in the wall between the two ventricles of the heart. Also called VSD.

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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.

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- 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

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