



Heart  
Foundation

Heart information

# Children with heart problems



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# Your heart

Your heart is a vital organ. It is a muscle that pumps blood to all parts of your body. The blood pumped by your heart provides your body with the oxygen and nutrients it needs to function.

## Structure

### Heart chambers

Your heart has a right and a left side separated by a wall called a 'septum'. Each side has a small collecting chamber called an 'atrium', which leads into a large pumping chamber called a 'ventricle'. There are four chambers: the left atrium and right atrium (upper chambers), and the left ventricle and right ventricle (lower chambers).

### Heart valves

Heart valves are like one-way doors that guard the entrance and exit of your heart's chambers. They make sure that blood flows only in the right direction between the four chambers of your heart.

Your heart has four heart valves:

- the 'tricuspid valve', on the right side of the heart, which lets the blood flow from the right atrium to the right ventricle
- the 'mitral valve', on the left side of the heart, which lets the blood flow from the left atrium to the left ventricle
- the 'pulmonary valve', on the right side of the heart, which lets blood flow from the right ventricle to the pulmonary artery (the blood vessel that carries blood from the heart to the lungs)
- the 'aortic valve', on the left side of the heart, which lets the blood flow from the left ventricle to the aorta.

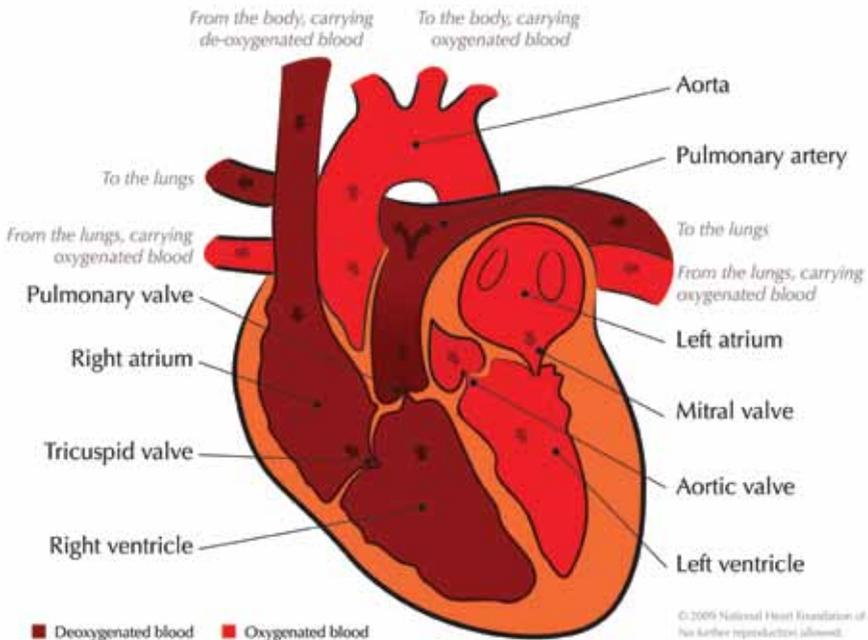
## How your heart pumps blood

The right side of your heart collects blood on its return from the rest of your body. The blood entering the right side of your heart is low in oxygen. This is because oxygen is removed from your blood as it circulates through your body's organs and tissues.

Your heart pumps the blood from the right side of your heart to your lungs so it can receive more oxygen.

Once it has received oxygen, the blood returns directly to the left side of your heart, which then pumps it out again to all parts of your body through the aorta.

### Blood flow through heart



## Development

A baby's heart develops between the third and seventh weeks of pregnancy. Hearts start as a hollow tube that grows. As the tube becomes longer, it is forced to bend and rotate. The left and right atria form at the entry end of the tube, and the right and left ventricles form from the middle section. Walls divide the chambers and the valves form. The exit end of the original hollow tube divides into two channels, which become the pulmonary artery and the aorta.

Two months into pregnancy, the baby's heart is functioning and looks like a small adult heart.

An unborn baby depends on its mother's body to provide oxygen and nutrients to supply its growing tissues and remove waste products. The umbilical cord has blood vessels that go in and out of the baby's body, and are connected to the mother by the placenta.

A baby's lungs are not used until after it is born, so some of the baby's blood flow bypasses its lungs while it is in the womb. During this period, there is a hole in the wall between the two upper chambers of the baby's heart, known as the *foramen ovale* (oval hole). The hole lets blood flow straight from the right atrium to the left atrium. When a baby is born, this hole usually closes over.

A unborn baby has a special blood vessel called *ductus arteriosus*. It is a small connection that lets blood bypass the lungs by shunting it from the pulmonary artery straight into the aorta and through to the entire body. After a baby is born, this connection usually closes within a few days.

## What are heart problems?

Heart problems can stop a heart from working properly. There is a range of different heart problems and your child might have one or more of them. Some of the more common problems are outlined below.

### Congenital heart defects

A congenital heart defect is a heart problem that a baby is born with. It can include abnormal development of the heart, the heart valves, major arteries, or a combination of these problems.

Congenital heart defects are caused by a problem in the heart's development during the first few weeks of pregnancy. Usually the exact cause of the problem is not known, but often it is just a chance event in the complex development of the baby's heart. Sometimes infections and drugs cause a heart defect. For example, German measles (Rubella) and other viruses can damage the heart as it develops. If a woman takes certain medicines, smokes or drinks too much alcohol early in pregnancy, this can also cause heart and other problems.

A baby is generally well protected from outside influences and fright when it is in the womb. Accidents and threatened miscarriages do not cause congenital heart defects. A family history of health problems is only a small risk. It is unusual to have more than one child in a family with congenital heart defects.

Almost one baby in 100 is born with a heart defect, so it is quite common. Many defects are minor and most can be corrected with medicines or surgery.

## Heart murmurs

A heart murmur is a murmuring sound that can be heard with a stethoscope when listening to the heartbeat. Murmurs are caused by turbulence in the flow of blood through the heart valves.

Murmurs in normal hearts are called 'innocent'. Many young children have innocent murmurs. They can be heard when the heart has to pump a bit harder, such as during a fever. Innocent murmurs usually disappear with time and are not serious.

However, murmurs can be a sign of heart defects, such as a valve problem or an abnormal opening in the wall between the left and right sides of the heart (sometimes called a 'hole in the heart').

If your doctor thinks your child has a heart murmur, it is important that your child sees a cardiologist to find out which type of murmur they have.

## Congestive heart failure

Congestive heart failure is a condition in which the heart cannot pump enough blood to meet the body's demands. This is usually due to a congenital heart defect. Congestive heart failure causes fluid to build up in your child's lungs and the rest of their body.

Congestive heart failure doesn't mean that your child's heart will stop beating, it means it is not beating efficiently. Their heart is actually beating very hard to make up for the problem.

Medicines and some lifestyle changes, such as regular, gentle physical activity and avoiding adding salt to food, can help your child's heart beat better and reduce fluid build up (see pages 11–12).

## Endocarditis

Endocarditis (also called 'infective' or 'bacterial' endocarditis) is a serious bacterial infection that affects the inner lining of the heart or the heart valves. There are many ways to get endocarditis, including dental work, surgery, urinary infections, infected cuts and bad throat infections.

People with heart problems are much more likely to get endocarditis than other people, so it's important that you try to prevent your child getting it.

To reduce your child's risk of getting endocarditis, your doctor will prescribe antibiotics for them to take before having dental work or surgery. You should also take your child to the doctor for treatment straight away if they get chest infections or infected sores.

If your child gets endocarditis, they will need to take antibiotics and stay in hospital for a few weeks to help them recover.

## Arrhythmias

Arrhythmias are a disturbed rhythm of the heartbeat and are caused by changes in the heart's electrical system.

There are many different kinds of arrhythmias (see below). Some may cause your child's heart to skip or add a beat now and again, but have no effect on their general health or ability to lead a normal life. Other arrhythmias are more serious and life-threatening. Untreated, they can affect the heart's pumping action, which can lead to dizzy spells, shortness of breath, faintness or serious heart problems.

Fortunately, many arrhythmias can be treated with medicines, surgery or other medical procedures, and lifestyle changes, such as avoiding vigorous or extreme physical activity.

- **Bradycardia** is when the heart beats too slowly. It may be successfully treated with an artificial pacemaker.
- **Tachycardia** is when the heart beats too fast. Tachycardia may not be serious, but may indicate a heart defect or disease. If your child gets tachycardia often or it is serious, they may need to take medicine to manage it.
- **Atrial fibrillation** is an irregular heartbeat that is caused by the heart's collecting chambers (atria) not contracting properly. Treatment usually involves taking medicine to stop blood clots forming.
- **Long QT syndrome** is a genetic (inherited) condition that affects the heart's electrical system. It can cause 'blackouts' and in some cases, cardiac arrest.



### Important note

If you think your child might have a heart problem, speak to your doctor. If your doctor thinks that there might be a problem, he or she may refer you to a cardiologist.

## How are heart problems diagnosed?

### Diagnosis

Some very serious congenital heart defects may be diagnosed by ultrasound during pregnancy. However, most are usually diagnosed during infancy, and others during childhood or even in adulthood, by some simple tests.

### Tests

To help them find out what is wrong with your child, the cardiologist will ask about your child's medical history, do a physical examination and usually arrange some tests, such as an electrocardiogram (ECG), a chest X-ray, an echocardiogram or cardiac catheterisation (see below).

After reviewing all of the information and test results, the cardiologist will talk with you about your child's health. If your child has a heart problem, the cardiologist will explain how to manage or treat the problem.

### ECG

An ECG is a test that shows doctors how the heart's electrical system is working. During an ECG, electrical leads are placed on your child's chest, arms and legs. These leads detect small electrical signals and produce a tracing on graph paper that illustrates the electrical impulses travelling through the heart muscle. ECGs are harmless and painless.

### Chest X-ray

Your doctor may take an X-ray of your child's chest so they can check the size and shape of your child's heart and lungs. A chest X-ray shows 'shadows' of the heart and lungs, not any internal detail of these organs.

## **Echocardiogram**

This is a routine test that uses ultrasound to give a picture of your child's heart, including its chambers and valves.

Echocardiograms are usually done in semi-darkness. Your child will need to stay very still so that the picture will be clear.

Like an ECG, an echocardiogram is also painless and harmless.

## **Cardiac catheterisation**

During a cardiac catheterisation, your child is given anaesthetic and then a very thin, flexible tube (catheter) is inserted into an artery or vein at the top of their leg or in one of their arms. The catheter is guided into your child's heart so that the cardiologist can check how well it is working.

Small blood samples are taken from the heart chambers through the catheter, so the cardiologist can check how much oxygen is in the blood. The pressure in different parts of your child's circulatory system is also checked.

During catheterisation, the doctor might perform a procedure called 'angiography'. With angiography, a dye is injected into the heart, and the flow of blood through the heart and arteries is checked and recorded using a special X-ray (an 'angiogram' – see picture on the right). When angiography is finished, the dye will safely pass through your child's kidneys and out of their body in urine.

Cardiac catheterisation usually takes a few hours, depending on what the heart problem is.

Some children may need to go to hospital the day before the catheterisation so the doctors and nurses can fully prepare them for it. An ECG, chest X-ray and blood test are also usually done before a cardiac catheterisation.

Your child will not be able to have anything to eat or drink before the catheterisation. They may need to have a general anaesthetic to have the test, but some children (including babies) may have the test with a local anaesthetic and other medicine (a sedative) to make them relax.



**Coronary angiogram**

## How are heart problems treated?

Many children with small heart problems don't need to have an operation and can live well without any treatment. Other children may need to take medicines to manage their heart problem. If your child's heart problem is serious, they may need to have an operation.

### Medicines

Your doctor might recommend that your child takes medicines to treat or manage their heart problem. Some commonly prescribed medicines are outlined below.

**Digoxin** is a medicine that improves the heart's pumping power. It is given in a precise dose according to your child's weight.

**Diuretics** increase urine output to help get rid of extra fluid in the body and lungs because of a heart problem. This medicine can also sometimes increase the loss of body salts, such as potassium. You can manage this by giving your child more high potassium foods, such as oranges and bananas, or potassium supplements. Talk to your doctor first if you have any questions.

**ACE inhibitors** are used to widen ('dilate') blood vessels and reduce strain on the heart. They work by inhibiting the production of chemicals in the body that constrict blood vessels. ACE inhibitors lower blood pressure and help the heart to work better.

### Cardiac catheterisation

As well as being used to help diagnose heart problems, cardiac catheterisation is now also used to treat certain heart problems. For example, a catheter with an inflatable balloon attached can be guided into a narrowed artery or valve, the balloon inflated and the narrowed part stretched open. This procedure is called 'angioplasty'.

After the narrowed artery or valve is stretched open, sometimes a small, expandable metal tube called a 'stent' may be inserted and left in place to keep the artery or valve open. Special



Catheter

materials, coils or plugs may also be inserted and are used to close abnormal arteries or holes in arteries.

Some operations may be avoided through the use of these procedures.

If your child needs to have any of these procedures, they will be sleepy for a few hours but can usually go home later that day or the next day.

## Cardiac surgery

If your child needs to have an operation, the cardiologist and cardiac surgeon will talk with you about it and explain exactly what will happen.

Usually children will need to have some tests before an operation. They may also need to go into hospital a couple of days before the operation to prepare, and stay there for a few days afterwards to recover, depending on the operation.

Try to reassure your child. Tell them that the doctors and nurses will look after them and that you will visit a lot of the time. Encourage your child to take their favourite toy to hospital and give them honest and reassuring answers to any questions they may have.

Some heart operations are done while the heart is still beating. For other operations (open heart surgery), the blood needs to be removed from the heart so it is empty. If your child needs open heart surgery, a heart-lung machine (cardiopulmonary bypass) will take over pumping blood around your child's body during the operation.

If your child has had a major operation, it is normal for them to stay in an intensive care ward for at least 24 hours, sometimes longer. You will be able to sit with your child, but may have to wait outside while doctors and nurses check on them. When the doctor thinks your child is ready, they will be moved to a general ward.

Surgery may completely cure some heart problems. Your child may need more than one operation to correct their heart problem as they, and their heart, grows.

### Remember

Advancing surgical techniques now mean that the majority of children with heart problems can enjoy a normal lifestyle, including going to school and playing sports.





## What other health issues should I consider?

### Immunisation

Immunisation is very important for children with heart problems.

You should make sure that your child has injections at the standard, recommended times to protect them against infections. If you want to postpone immunisation, for example, if your child is sick, talk with your doctor first.

### Feeding

Generally, babies with heart problems should be fed like other babies, either by breast or bottle. We recommend breastfeeding because breast milk is a complete food and helps to protect your baby against infection. However, you shouldn't feel guilty about bottle-feeding your baby if you can't breastfeed.

Your baby may get tired quickly from feeding, so you may need to feed them smaller amounts more frequently.

If your baby is sick or weak after surgery, he or she may need to be fed by a tube inserted through the nose into the stomach. If you are breastfeeding your baby, you can express milk to feed your baby this way. Hospital staff will help you if this is needed.

Your baby may gain weight more slowly than other babies, but as long as they seem happy and sleep well, don't worry. If your baby is having trouble gaining weight, your doctor may refer you to a dietitian.

### Other illnesses

Children with heart problems are at no particular increased risk of common childhood illnesses, such as chickenpox. If you are worried or have any questions about your child's health, talk with your doctor.

Some children with heart problems get more chest infections than other children. If your child gets a chest infection, we recommend that they see a doctor.

## Dental health

Good mouth hygiene and dental care are important, especially for children at risk of developing infective endocarditis.

We recommend that you regularly take your child for dental check ups.

If your child needs dental treatment, the dentist and doctor may recommend that your child takes antibiotics one hour before the treatment, especially if the treatment may cause the gums to bleed.

### Remember

Make sure that your dentist knows your child has a heart problem.

## How will this affect me and the rest of my family?

If you are told that your child has a heart problem, it is normal to have a range of different feelings.

You may feel shocked and numb, and find it hard to take in what the doctor is telling you. You may also feel like it is not real, or find it hard to concentrate and make decisions.

Anger – at relatives, the hospital staff, friends and the situation – is a very normal feeling. Sadness is also a very normal feeling and crying is a natural way to release it.

Some parents feel guilty and think that they are to blame for their child's heart problem. Usually there isn't a clear reason why a child has a heart problem, although it is normal to want to know why.

Don't feel guilty about or fight any of these feelings. Talk with your partner, doctor, community or religious leader, social worker or friend to help you work through them and cope better.

Adjusting to your child's heart problem may be hard for you, but it can also be hard for the rest of your family. It can strain your relationship with your partner and family.

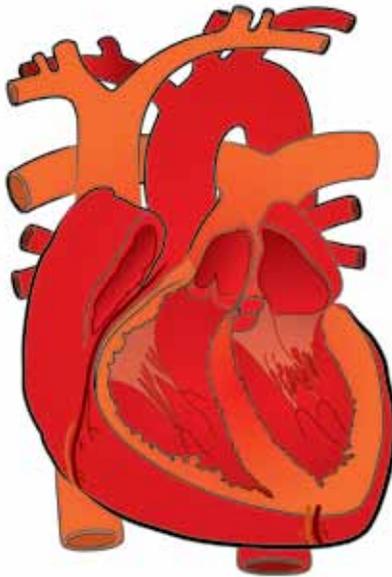
You might argue more with, or feel distant from, your partner. It's important that you keep talking to each other about how you feel. Talking with someone else, such as a counsellor, psychologist or support group, might help you and your partner cope better.

Other children may show that they are having trouble coping with the situation by changing their behaviour. They may seek attention, become irritable, complain that they feel ill, or start wetting the bed or sucking their thumb again. Try to spend time with your other children and make sure that you talk to them about their brother's or sister's heart problem and its treatment.

Talking to other parents of children with heart problems may also help you to cope better. There are support groups created by and for parents like you throughout Australia (see pages 17–18).

Record your child's heart problem on the illustration below. Your doctor can help.

### **My child's heart problem**



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## Where can I get help?

### Medical help

Don't be afraid to ask your doctor and nurses questions. They are happy to help.

### Social workers

You can talk to a social worker about how you feel and any problems you have. Often just talking to someone can make you feel better.

Social workers can give you a variety of help, including emotional support and advice on practical matters, such as benefits, allowances and accommodation.

### Travel

If you have to travel a long way from home to your nearest heart specialist, you can claim for some of your travel costs.

Arrangements for travel support vary from state to state, so ask your doctor, hospital staff or social worker for more information.

### Carer entitlements

If your child needs a lot of extra care, you may be entitled to Carer Allowance (Child), Carer Payment or a Health Care Card.

Carer Allowance (Child) helps parents or carers care for children with a disability or severe medical condition at home. It replaces the former Child Disability Allowance. Carer Allowance (Child) may be paid on top of Carer Payment.

Carer Payment is a payment for carers who, because of the demands of their caring role, can't work to support themselves.

A Health Care Card entitles you to reduced cost medicines for your child, as well as a limited number of other concessions.

For more information, contact the Centrelink Disability, Sickness and Carers Information Line on 13 27 17 or go to [www.centrelink.gov.au](http://www.centrelink.gov.au). Parent support groups (see below) in your state/territory may also be able to help you.



## Parent support groups

HeartKids is a voluntary association formed by parents of children with heart problems. Members offer understanding and support to other families in the same situation.

HeartKids has branches in many areas and in all states of Australia. The groups coordinate meetings, make hospital visits, fundraise and produce newsletters. Contact details for HeartKids are listed below.

### **HeartKids Victoria, including Tasmania**

PO Box 803

Parkville VIC 3052

Phone: 03 9513 9030

Fax: 03 9345 6765

Email: [Heartkids@heartkids.org.au](mailto:Heartkids@heartkids.org.au)

Website: [www.heartkidsvic.org.au](http://www.heartkidsvic.org.au)

### **HeartKids New South Wales**

C/O The Heart Centre for Children

Children's Hospital Westmead

Locked Bag 4001

Westmead NSW 2145

Phone: 02 9294 0800

Fax: 02 4423 5812

Email: [mail@heartkidsnsw.org.au](mailto:mail@heartkidsnsw.org.au)

Website: [www.heartkidsnsw.org.au](http://www.heartkidsnsw.org.au)

### **HeartKids Queensland**

PO Box 118

Underwood QLD 4119

Phone: 07 3341 8145

Fax: 07 3341 5460

Email: [hospitalsupport@heartkidsqld.org.au](mailto:hospitalsupport@heartkidsqld.org.au)

Website: [www.heartkidsqld.org.au](http://www.heartkidsqld.org.au)

**HeartKids of South Australia**

PO Box 364

North Adelaide SA 5006

Phone: 0406 165 111

Email: [secretary@heartkidssa.org.au](mailto:secretary@heartkidssa.org.au)

Website: [www.heartkidssa.org.au](http://www.heartkidssa.org.au)

**HeartKids Northern Territory**

PO Box 848

Palmerston NT 0830

Website: [www.heartkids.org.au](http://www.heartkids.org.au)

**HeartKids Western Australia**

PO Box 1554

West Perth WA 6872

Phone: 9340 7996

Fax: 9340 7997

Email: [hkwa@heartkids.org.au](mailto:hkwa@heartkids.org.au)

Website: [www.heartkidswa.org.au](http://www.heartkidswa.org.au)

## Want to know more?

If you would like to know more about heart problems in children, or anything else we have discussed in this booklet, call our Health Information Service on 1300 36 27 87 (local call cost) and speak to one of our trained health professionals. You can also visit [www.heartfoundation.org.au](http://www.heartfoundation.org.au).



# Glossary

## **Aorta**

The main artery of the body. The aorta rises directly from the left ventricle (the main pumping chamber of the heart) and supplies oxygen-rich blood to all other arteries except the pulmonary artery.

## **Aortic valve**

The valve separating the left ventricle and aorta.

## **Arteries**

Blood vessels that carry oxygen-rich blood throughout the body. Arteries vary in diameter from 3 cm to arteries so small they can be seen only under a microscope (these small arteries are called 'arterioles').

## **Arterioles**

The smallest arteries in the body. Arterioles supply blood to the capillaries.

## **Atrial septum**

A wall of tissue separating the left atrium from the right atrium.

## **Atrium (plural = atria)**

One of the heart's two upper chambers that act as collecting chambers for blood before it passes to the ventricles.

## **Capillaries**

Very small blood vessels that form a network between the arterioles and veins. Oxygen and nutrients pass from blood, through capillary walls, to tissues. Carbon dioxide and waste products pass from tissues into capillaries and are taken away by blood.

## **Cardiovascular disease**

An umbrella term that refers to all heart and blood vessel diseases, and stroke.

### **Circulatory system**

An umbrella term for the heart and blood vessels (arteries and veins). The circulatory system has two parts: pulmonary circulation, which pumps blood to, around and from the lungs, and systemic circulation, which pumps blood around the rest of the body.

### **Congenital heart disease**

A heart disease or defect present from birth.

### **Congestive heart failure**

A condition in which the heart is unable to pump enough blood around the body, causing a build up of fluid in the lungs and other tissues.

### **Cyanosis**

When skin turns blue because of a lack of oxygen in the blood. Cyanosis is seen in some patients with congenital heart defects or congestive heart failure.

### **Diastole**

The movement of the heart relaxing so its chambers can refill with blood.

### ***Ductus arteriosus***

A special blood vessel in the foetus that lets blood bypass the lungs.

### **Electrocardiogram (ECG)**

A reading of the heart's electrical impulses taken from electrical leads placed on the chest and limbs. It can be used to diagnose a heart attack or abnormal heart rhythms (called 'arrhythmias' – see page 7).

### **Endocarditis**

See 'infective endocarditis'.

### **Endocardium**

The thin surface layer inside the heart.

### **Foetus**

An unborn baby.

### **Foramen ovale**

In a foetus, an oval hole in the atrial septum that lets blood bypass the lungs. The hole normally closes soon after birth.

### **Heart murmurs**

A swishing sound caused by blood flowing forwards or backwards in the heart abnormally. Many children with normal hearts have 'innocent' (soft) murmurs. Louder murmurs are usually caused by a heart valve disorder or a congenital heart defect.

### **Heart valves**

Valves let blood flow through the heart and prevent back flow. See 'aortic valve', 'mitral valve', 'pulmonary valve', 'tricuspid valve'.

### **Infective endocarditis**

An infection of the endocardium or parts of the heart, such as heart valves. It happens mainly in people who already have structural heart defects, such as congenital heart disease.

### **Mitral valve**

The valve between the left atrium and left ventricle.

### **Myocardium**

The strong muscular wall of the heart that is responsible for pumping blood.

### **Pericarditis**

Inflammation of the pericardium.

### **Pericardium**

The sac that encases and protects the heart. The pericardium normally contains a thin film of fluid.

### **Pulmonary valve**

The valve between the right ventricle and pulmonary artery.

### **Pulmonary veins**

Veins that carry blood from the lungs to the heart.

**Rheumatic heart disease**

A permanent effect of acute rheumatic fever, which is caused by an untreated bacterial throat infection. Rheumatic heart disease is when heart valves are permanently damaged. Getting acute rheumatic fever again can damage heart valves even more. Rheumatic heart disease and acute rheumatic fever are still serious problems in some Aboriginal and Torres Strait Islander communities.

**Septum**

The wall of muscle that separates the left and right sides of the heart.

**Sinus arrhythmia**

A normal irregularity of the heart beat, caused by breathing.

**Sphygmomanometer**

A machine used to measure blood pressure.

**Systole**

The movement of the heart contracting and pumping blood.

**Tricuspid valve**

The valve between the right atrium and right ventricle.

**Veins**

Blood vessels that return blood to the heart after it has nourished the tissues.

**Vena cavae (singular = vena cava)**

The large veins entering the right atrium.

**Ventricle**

One of the two pumping chambers of the heart. The right ventricle pumps blood from your body to your lungs so it can receive more oxygen, and the left ventricle pumps the oxygen-rich blood to the rest of your body.



For heart health information  
1300 36 27 87  
[www.heartfoundation.org.au](http://www.heartfoundation.org.au)

## Key things to remember about children with heart problems

Heart problems can stop a heart from working properly. There is a range of different heart problems and your child might have one or more of them.

Many children with small heart problems don't need to have an operation and can live well without any treatment. Other children may need to take medicines or have an operation to treat their heart problem.

It is important to make sure your child is immunised and has regular dental check ups to prevent other health problems.

Seek help.

- Don't be afraid to ask the doctors and nurses questions about your child's health.
- Speak to a social worker and Centrelink about the various support that is available to you, including counselling and financial and travel support.
- Parent support groups can also offer helpful advice.

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