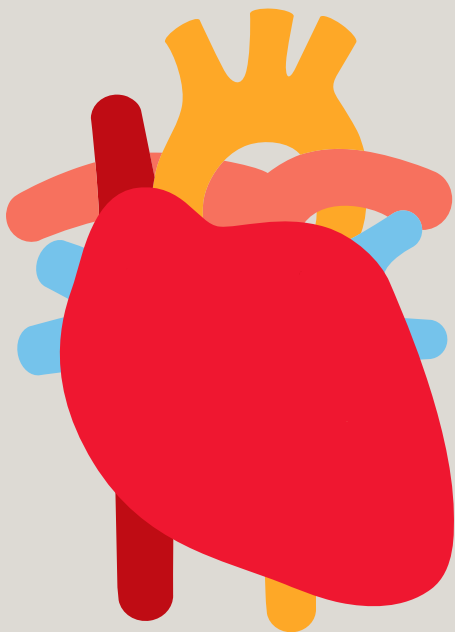




Understanding your child's heart

Large ventricular septal defect

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**FIGHT
FOR EVERY
HEARTBEAT**

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About this book

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

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

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

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

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What is a congenital heart condition?

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

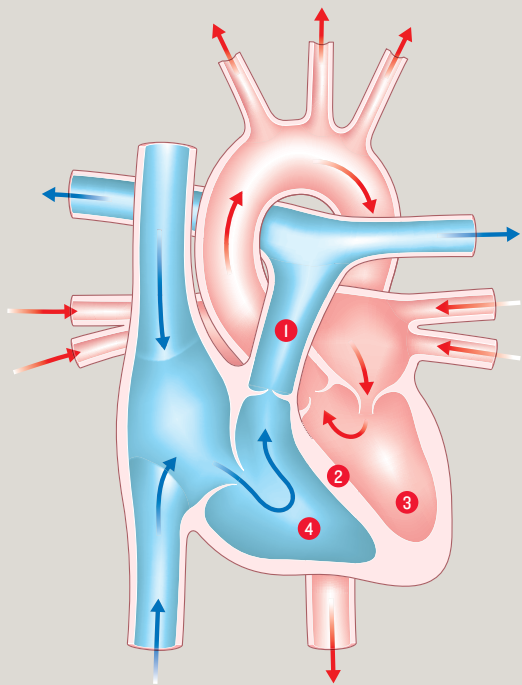
Each day 12 babies are diagnosed with a **congenital** heart defect in the UK. We continue to support research to improve the understanding, diagnosis and treatment of **congenital** heart conditions. For more information into our pioneering research visit [bhf.org.uk/research](https://www.bhf.org.uk/research)

What causes a congenital heart condition?

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

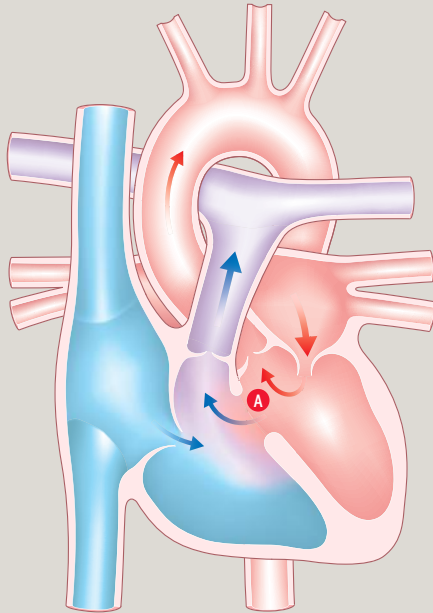
At the moment we don't fully understand why a baby's heart doesn't develop normally. But sometimes a **congenital** heart condition can be part of a syndrome which the baby is born with. *(A syndrome is a group of symptoms that commonly appear together as part of a condition).*

Normal heart



- | | |
|----------------------|-------------------|
| 1 Pulmonary artery | 3 Left ventricle |
| 2 Ventricular septum | 4 Right ventricle |

Large ventricular septal defect



A Ventricular septal defect

What is a large ventricular septal defect?

A **ventricular septal defect (VSD)** is a hole in the ventricular septum, which is the wall between the two ventricles – the lower pumping chambers of the heart. VSDs can happen in any part of the **ventricular septum**. They can be small or large, and can sometimes occur more than once. This booklet explains large **VSDs**.

In a normal heart, the left side works under high pressure to pump blood through the aorta to the brain and the rest of the body. The pressure is lower in the right side which pumps blood to the lungs.

If your child has a **VSD**, their blood flows through the hole from the left to the right side. If the **VSD** is large, it means that a large volume of blood flows to the lungs. A large **VSD** also causes high blood pressure in the **pulmonary** arteries (*pulmonary hypertension*). The high flow of blood to the lungs

can make your baby breathless. It also causes the heart muscle to become enlarged as it has to work much harder than normal. Sadly this can lead to heart failure. If left untreated for a long time, pulmonary hypertension can be very serious, as it can permanently damage the lungs.

Sometimes, **VSDs** that are large very early in life can get smaller as a baby grows, so it is often worth watching and waiting for some months before making a decision to carry out surgery to close a **VSD**. We explain more about the surgery later on.

What are the symptoms of a large ventricular septal defect?

Babies with a **VSD** often appear perfectly well in the first week or so of life but, if the **VSD** is large, they may get gradually more short of breath over the first month or two after birth. Your baby may find it difficult to feed, as they are putting all their energy into breathing, and they may not put on weight as normal.

For more information on coping with feeding your baby, ask your midwife or **paediatric** liaison nurse.

What other conditions are associated with a large ventricular septal defect?

Most babies with a **VSD** don't have other abnormalities, but some do have additional heart or **chromosome** abnormalities. If that is the case, your child's **cardiologist** will talk this through with you. If your child is diagnosed with a **VSD** before birth, your doctor will talk to you about the option of having a test to find out if your baby has a chromosomal abnormality before they are born.

How is a large ventricular septal defect diagnosed?

Most VSDs are not diagnosed until after birth using an **echocardiogram**. This is an ultrasound scan of the heart and it won't hurt your baby at all.



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

How is a large ventricular septal defect treated?

If your baby is very breathless, medication may help their breathing, but it won't help to close the **VSD**. However, if the **VSD** gets smaller by itself, it's possible that your baby won't need any treatment at all.

It's always important to have regular outpatient reviews as a small number of children will develop new abnormalities as they get older – such as a leaking **aortic** valve, or narrowing of the outlet of the right **ventricle** or the left **ventricle**. If your baby does develop a new abnormality, they may need to have surgery.

If the **VSD** remains large, your baby will need surgery to close the **VSD** or, in some cases, a treatment called **pulmonary** artery banding. We describe both of these treatments below.

Surgery to close the large ventricular septal defect

Your baby will be given a general anaesthetic. A heart-lung machine is used to take over the function of the heart and lungs so that the heart can be stopped while the hole is closed. In most cases a patch of synthetic material is sewn over the hole. Your baby will need to stay in hospital for about a week after the operation. After the operation, they will have a scar in the centre of their chest along the breast bone.

What are the risks of surgery?

The good news is, surgery to repair a **VSD** is usually very successful and the fatality risks are very low. There are small risks of complications such as brain damage, kidney damage, damage to the heart's electrical system (*which may need treatment with a **pacemaker***), or serious lung infections such as pneumonia. Sometimes, a small **VSD** is left after surgery, but this doesn't usually cause a problem and further surgery is rarely needed.

Keyhole treatment is a relatively new procedure, so it is too early yet to give an accurate estimate of the risks involved in this type of treatment. At present this option is only available for older children, rather than babies.

Pulmonary artery banding

In some cases, it is not safe to repair the **VSD** so an operation called **pulmonary** artery banding is used. Your baby will have a general anaesthetic. This surgery involves placing a band around the **pulmonary** artery to narrow it. This is done without using the heart-lung machine and often leaves a scar at the side of the chest or in the centre, depending on the surgeon.

The band reduces the high blood flow to the lungs, improving your baby's breathing, and it also reduces the blood pressure in the **pulmonary** arteries, to help prevent lung damage.

Most babies who have had pulmonary artery banding will be suitable for further surgery to close the **VSD** at a later date.

What are the risks of pulmonary artery banding?

“About 96 out of every 100 babies survive **pulmonary** artery banding. However, they will all need further surgery at some stage.”

Getting the tightness of the band just right can be difficult. If it is not tight enough, your baby will still be breathless after the operation and sometimes a repeat operation is needed. If the band is too tight, your baby can appear blue. Either way, a repeat operation may be needed.

As your child grows, their **pulmonary** artery grows but the band stays the same size, so it becomes relatively tighter. If this happens they may become blue when they cry, but after a while they may appear blue all the time. In a small number of cases, the band may cause narrowing of the right and left

branches of the **pulmonary** artery. If this happens, your child may need to have further surgery. Fortunately, this can be done at the same time as the surgery to close the **VSD**.

What happens after surgery or pulmonary artery banding?

Whether your child has had surgery to close the **VSD**, or **pulmonary** artery banding, they may need to take medications for a short while after leaving the hospital.

After surgery, your child will need to have regular reviews in the outpatients department.

What happens as my child grows up?

The good news is, most children who have had a **VSD** repaired go on to lead completely normal, active lives.



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For more information and support about growing up with a heart condition, visit bhf.org.uk/heart-health/children-and-young-people

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

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

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

Coping with everyday life

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

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

The medical terms and what they mean

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

Cardiologist A consultant specialising in heart disease.

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.

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

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

Pacemaker An electrical device which stimulates contractions (beats) of the heart.

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.

Ventricle One of the two lower chambers of the heart.

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

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

VSD See ventricular septal defect.

References

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

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Notes



A series of 18 horizontal dotted lines for writing notes.

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



**British Heart
Foundation**

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

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

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

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

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

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