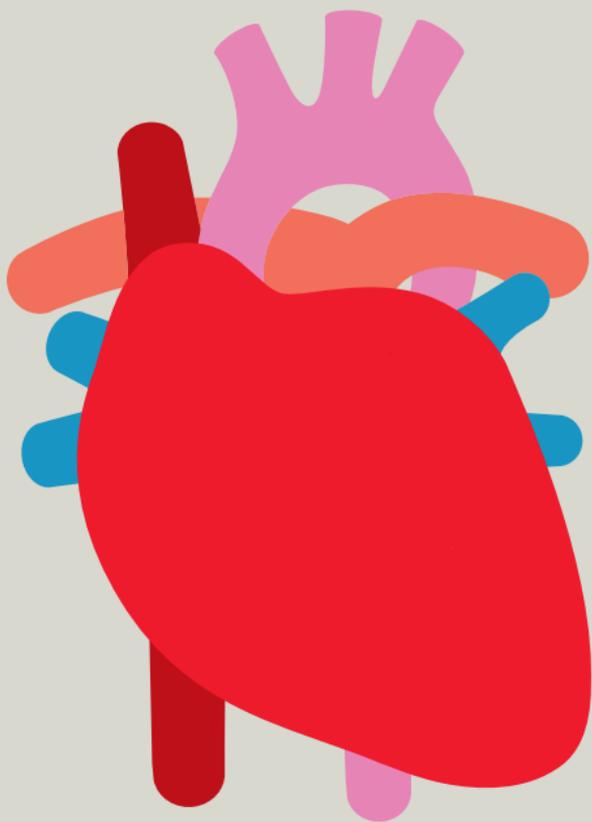




Understanding your child's heart

Complete and partial atrioventricular septal defect

7



**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

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 complete and partial atrioventricular septal defect is and how it is diagnosed
- how complete and partial atrioventricular 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.

Contents

What is a congenital heart condition?	2
What causes a congenital heart condition?	3
What is an atrioventricular septal defect?	7
What are the symptoms of an atrioventricular septal defect?	9
What other conditions are associated with an atrioventricular septal defect?	10
How is an atrioventricular septal defect diagnosed?	11
How is an atrioventricular septal defect treated?	12
Surgery	13
What happens as my child grows up?	17
What is the risk of having another child with a congenital heart condition?	18
Coping with everyday life	19
The medical terms and what they mean	20
References & acknowledgments	22

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.

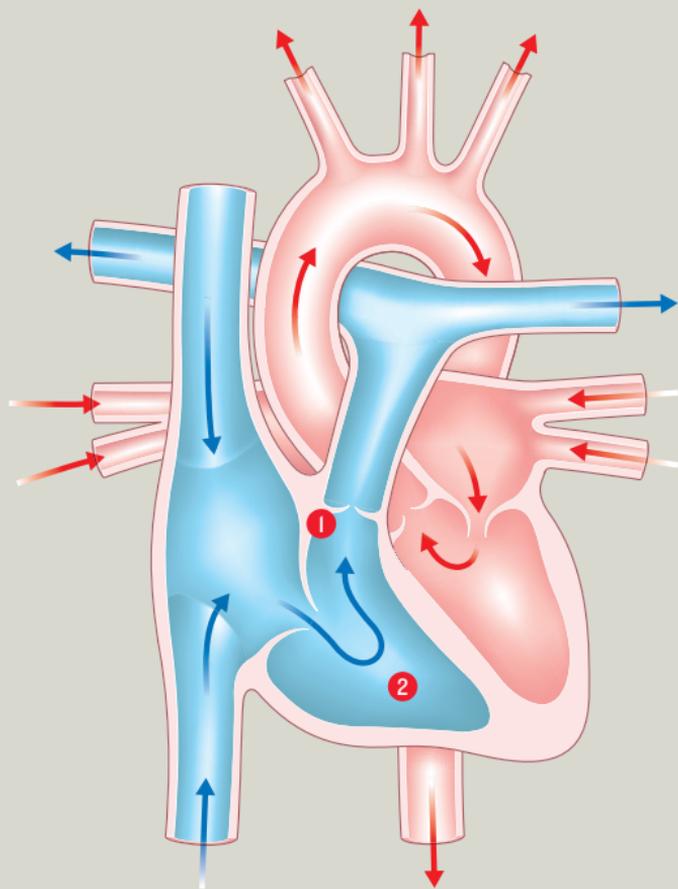
Each day 12 babies are diagnosed with a **congenital** heart defect in the UK. We continue to support research to improve the understanding, diagnosis and treatment of **congenital** heart conditions. For more information into our pioneering research visit [bhf.org.uk/research](https://www.bhf.org.uk/research)

What causes a congenital heart condition?

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

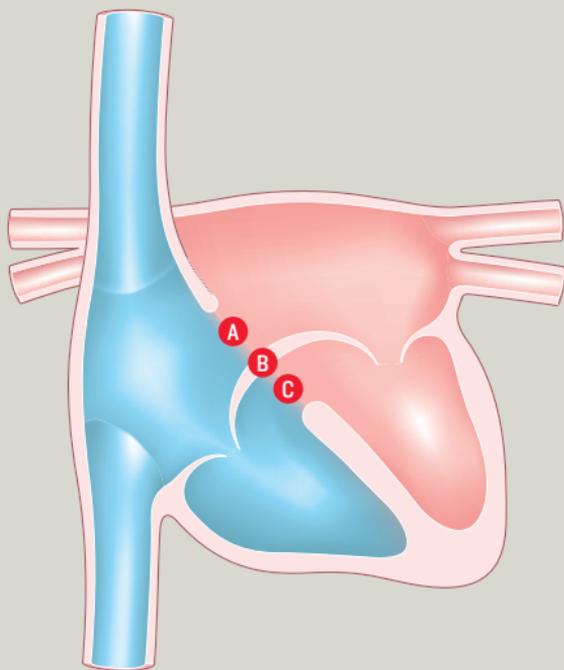
At the moment we don't fully understand why a baby's heart doesn't develop normally. But sometimes a **congenital** heart condition can be part of a syndrome which the baby is born with. *(A syndrome is a group of symptoms that commonly appear together as part of a condition).*

Normal heart



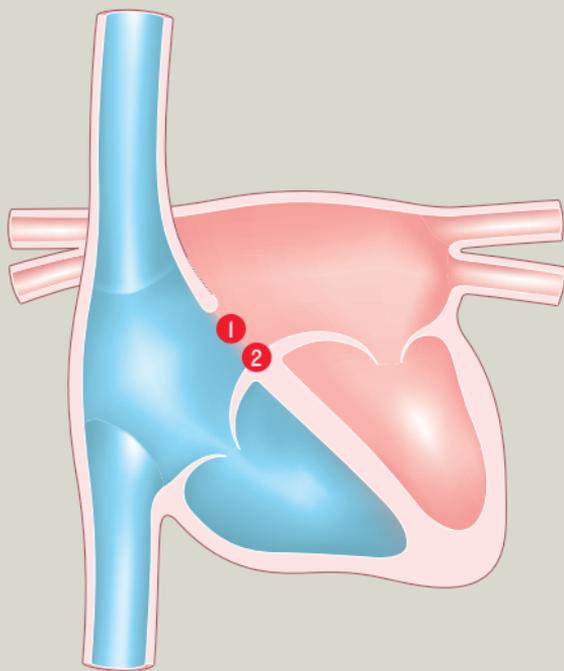
- 1 Pulmonary valve
- 2 Right ventricle

Complete atrioventricular septal defect



- A** Hole between atria
- B** Common valve
- C** Hole between ventricles

Partial atrioventricular septal defect



- 1 Hole between atria
- 2 Common valve

What is an atrioventricular septal defect?

There are two types of atrioventricular septal defect (AVSD) – complete and partial. Both are described in this booklet.

- A complete AVSD consists of a complicated hole between the right and the left side of the heart. The hole is in the centre of the heart, effectively producing two holes – one between the atria, and the other between the **ventricles**.
(See the illustration on page 5).
- A partial AVSD is very similar but there is no hole between the **ventricles**.
(See the illustration on page 6).

Normally, there are separate right and left-sided inlet valves – the tricuspid valve on the right side, and the mitral valve on the left. In children with either a complete or partial AVSD, the middle part of the two valves is shared between the left and right sides of the heart. This is often called a common valve.

Normally the valves open to allow the **ventricles** to fill with blood and then they close to allow all the blood to be pumped out through the two main arteries leaving the heart. The abnormal valves may not be 'watertight', so when they close, some blood may leak backwards from the **ventricles** into the atria (*regurgitation*).

In some children, either the right or the left side of the heart may be underdeveloped. This is known as an unbalanced AVSD. If this is severe, your child will require complicated surgery and their longer-term outlook would be more uncertain. AVSD may be associated with many other heart conditions, which can affect the treatment available and the outcome for your child.

What are the symptoms of an atrioventricular septal defect?

Children with a complete AVSD often gradually become breathless over the first month or so after birth.

Children with a partial AVSD usually remain well.

What other conditions are associated with an atrioventricular septal defect?

The most common are chromosomal abnormalities which are often associated with learning difficulties. Down's Syndrome is the most common example. If your baby has been diagnosed with an AVSD before birth, your doctor will talk you through the option of having a test to check for chromosomal abnormality.



i

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 an atrioventricular septal defect diagnosed?

Many cases can be diagnosed while the baby is still in the womb, but some are not detected until after birth using an **echocardiogram**. This is an ultrasound scan of the heart and it won't hurt your baby at all.

How is an atrioventricular septal defect treated?

Most babies with an AVSD don't need immediate treatment, but babies who become breathless may be given medicines to help improve their symptoms until surgery is carried out.

Surgery

Babies with a complete AVSD will usually need major surgery to repair the defect when they are about three to six months old. In babies with partial AVSD the operation is usually not necessary until they are a few years old.

The operations are carried out under general anaesthetic. The heart is stopped and the function of the heart and lungs is taken over by a **'heart-lung machine'** which makes sure that blood is still pumped around your baby's body. During the operation, the surgeon will close the hole(s) in the heart. The common valve will also be divided into separate right and left parts. Once the heart is repaired, it is restarted. After the operation, your baby will have a scar in the centre of their chest, along the breast bone. If your baby has additional heart abnormalities, surgery may be much more complicated. Your **cardiologist** will talk this through with you.

What are the risks of surgery?

The good news is, surgery to repair a complete or partial AVSD is usually very successful and the fatality risks are very low. For both groups there are other serious but uncommon risks including brain damage, kidney damage or lung complications such as pneumonia. It is important to understand the risks of the operation for your child.

The valve on the left side (*the mitral valve*) always leaks to some extent after the holes have been closed. This is called mitral regurgitation. If the mitral valve slightly leaks no further surgery may be needed. However, if it leaks a lot further surgery will be needed. Where possible the valve is repaired, but in some cases it may need to be replaced. This can be very difficult in young children and it carries further risks.

There is also a small risk that the heart's electrical system may be damaged during the operation. If this happens, your child's heart rate will be slower than normal and a further procedure may be needed to implant a **pacemaker** to make their heart beat faster.

Further surgery

Although the operation is often called a 'repair' or 'corrective surgery', it never makes the heart completely normal. If your child has a replacement valve, they will outgrow the replacement valve, and will need it replaced again with a larger one. The age at which this surgery needs to be done varies from one child to another.

What happens after surgery?

Most children need to stay in hospital for about a week after the major repair operation, although if there are complications they may need to stay longer. Your child may be prescribed some medicines after leaving hospital, but they will probably need to take these only for a month or so.

What happens as my child grows up?

Most children with repaired AVSD will lead normal, active lives after their operation. Your child's **cardiologist** will tell you if they should avoid any specific forms of exercise.

After the operation you will need to take your child for regular visits to the outpatients clinic, to make sure that the mitral regurgitation does not become worse over time. After repair of the AVSD a small number of children can develop narrowing below the aortic valve. This is known as subaortic stenosis and it may need further surgery later.

What is the risk of having another child with 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.

Atrium One of the two upper chambers of the heart.

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.

Heart-lung machine A machine that pumps blood around the body while the heart is stopped during an operation.

Pacemaker A device that is implanted in the chest to stimulate the heart to beat.

Pulmonary To do with the lungs.

Ventricle One of the two lower chambers of the heart.

ventricular septal defect A hole in the wall between the two ventricles of the heart. Also called VSD.

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.

Acknowledgements

The British Heart Foundation would like to thank all the healthcare professionals involved in the updating of these booklets. Particular thanks are due to:

- Dr James Gnanapragasam, Consultant Paediatric Cardiologist, Southampton General Hospital
- Dr Aaron Bell, Consultant Paediatric Cardiologist, Evelina Children's Hospital

Notes



A series of 18 horizontal dotted lines for writing notes, evenly spaced and extending across the width of the page.

Notes



A series of 20 horizontal dotted lines for writing notes, arranged in a vertical column.

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.

Text FIGHT to 70080 to donate £3

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

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.

© British Heart Foundation 2016, a registered charity in England and Wales (225971) and Scotland (SC039426).

C7/0916