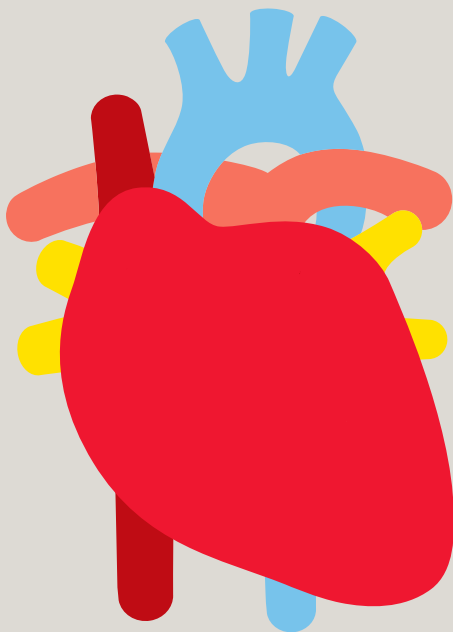




Understanding your child's heart

Atrial 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 atrial septal defect is and how it is diagnosed
- how atrial 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



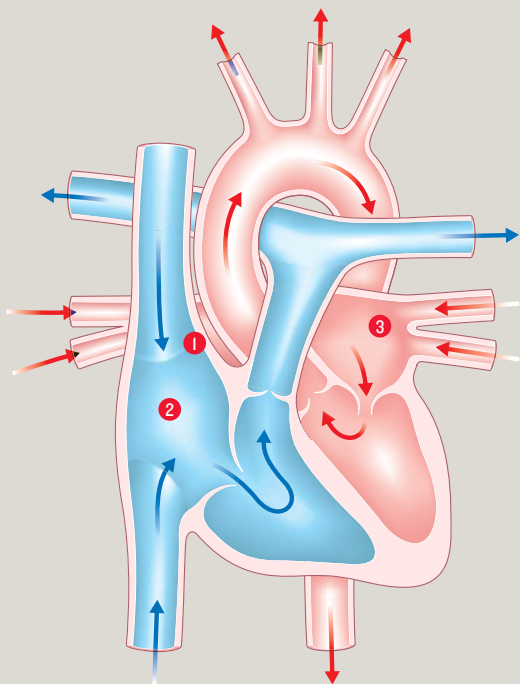


What causes a congenital heart condition?

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

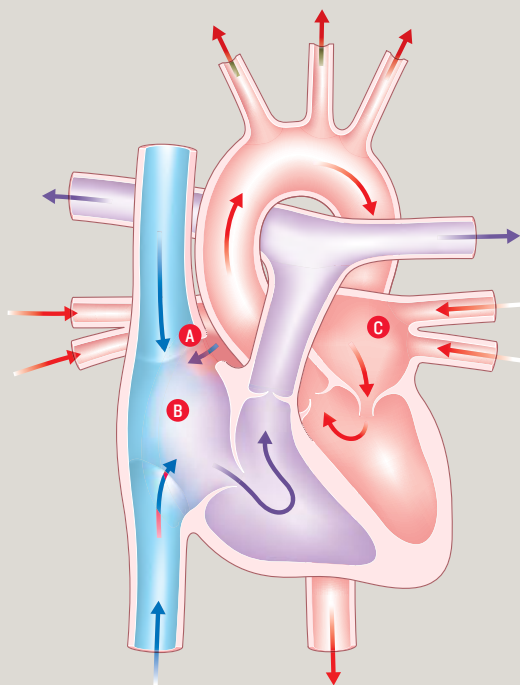
At the moment we don't fully understand why a baby's heart doesn't develop normally. But sometimes a congenital heart condition can be part of a syndrome which the baby is born with. *(A syndrome is a group of symptoms that commonly appear together as part of a condition).*

Normal heart



- 1 Atrial septum
- 2 Right atrium
- 3 Left atrium

Atrial septal defect




- A** Atrial septal defect
- B** Right atrium
- C** Left atrium




What is an atrial septal defect?

An atrial septal defect (*ASD*) is a hole between the two upper chambers (*atria*) of the heart. Because pressure in the left side of the heart is much higher, the ASD allows blood from the left atrium to pass to the right atrium.



Some ASDs are very small and may never cause any problems or require treatment. However, a large ASD can result in the right side of your child's heart being overloaded with blood.



ASD may only cause mild symptoms, such as breathlessness when being active. However, if a large ASD is left untreated, over a period of many years it can eventually lead to permanent damage to your child's heart and sometimes to their lungs.



How is an atrial septal defect diagnosed?

Usually, the only test that is needed to make the diagnosis is an **echocardiogram**. This is an ultrasound scan of the heart. It won't hurt your baby at all.

Because babies and young children often show no symptoms, ASD may not be found until they are older, sometimes even in teenage and adult years.







How is an atrial septal defect treated?

ASD is treated with:

- keyhole surgery, or
- open-heart surgery.





The aim of both these surgeries is to close the ASD and stop blood from the left **atrium** of the heart passing to the right **atrium**. The type of treatment will depend on the size of the ASD and its exact position. Your child's **cardiologist** will talk to you about which type of surgery is best for your child.





Keyhole surgery for an atrial septal defect



Your child will be given a general anaesthetic. A small tube will be inserted into your child's food pipe (*oesophagus*) through their mouth. The doctors will use this tube to do a scan called a transoesophageal **echocardiogram** (*TOE*) to see the heart, and in particular the ASD, clearly. Then, a long thin tube called a **catheter** will be inserted into a vein at the top of their leg and guided to their heart. The ASD is closed using a special device, which is folded up and pushed through the **catheter** to the heart. Once it is in the correct position, the device is unfolded so that the ASD hole is closed. The **catheter** will then be removed. The device will stay inside your child's heart and become covered over by their own tissue during the healing process.

After the operation, you will need to take your child to the outpatient department to see the **cardiologist** for a check-up about a month later.



Your child will need to take aspirin for a few months after the treatment. This reduces the risk of a blood clot forming on the device while it is healing over.

What are the risks of keyhole surgery?

Keyhole treatment to repair an ASD is usually very successful and carries a very low risk of fatality. Most children will not experience any major complications. There is a small risk of bleeding around the heart and a small risk that the device could move out of place after the surgery. If this happens your child may need an operation to remove the device and to close the hole at the same time.

Sometimes the device might not completely close the hole. If this happens your child may need another operation to close the hole around the device. There is a very small risk that the device





could become infected and an operation would be needed to remove it.

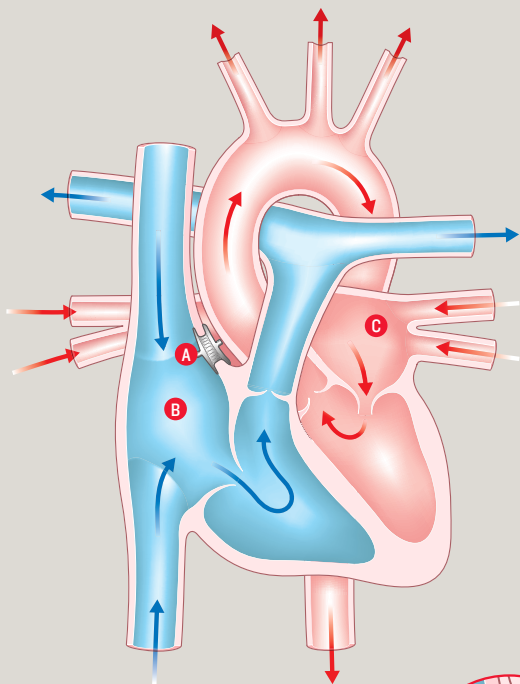
It's very rare, but there is also a very small risk of blood clots forming inside the heart during the surgery which could cause a stroke. The risk of dying as a result of this treatment is very small. Your doctor will talk you through all these risks before your child's treatment.

Headaches after ASD closure

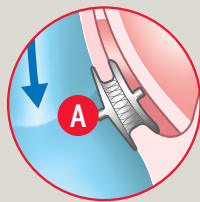
Some children who suffered from migraines in the past may find that their migraine is worse for a few months after keyhole closure of their ASD. However, some find that their migraine disappears after keyhole surgery. The reasons for this are not fully understood at the moment.



The heart with a closure device in place





- A** Closure device
- B** Right atrium
- C** Left atrium





Open-heart surgery for an atrial septal defect



Sometimes open-heart surgery is required to close the ASD. If your child has surgery, they will be given a general anaesthetic. The surgeon will make a cut in their breastbone to get access to their heart. Their heart will be stopped and a **'heart-lung machine'** will be used to take over the function of the heart and lungs. The surgeon will sew the ASD closed. They will start the heart beating again and the heart-lung machine will be turned off. Your child's chest will be sewn closed.

After the operation your child will have a scar, usually in the centre of the chest along their breastbone. They will need to stay in hospital for a few days and return to the out-patient department a few weeks later for a check-up.



What are the risks of open-heart surgery?

Open-heart surgery to repair ASD is usually very successful and the fatality risks are very low.

There are small risks of complications such as brain damage, kidney damage, or serious lung diseases such as pneumonia. Your child's doctor will talk you through all these risks before the operation.





What happens as my child grows up?

Most children will remain completely well and lead a normal, active life after treatment. There is no need to restrict your child's physical activity and no special precautions are necessary.



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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 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

- 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.

Atria Either of the two upper chambers of the heart.

Atrium One of the two upper chambers of the heart.

Cardiologist A consultant specialising in heart disease.

Catheter A fine, hollow tube.

Congenital From birth.

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

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

Ventricle One of the two lower chambers of the heart.



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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children and young people with a heart
condition, visit
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.

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