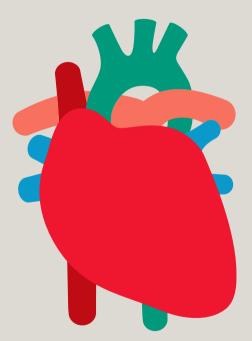




Understanding your child's heart

Patent ductus arteriosus





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 patent ductus arteriosus is and how it is diagnosed
- how patent ductus arteriosus 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.

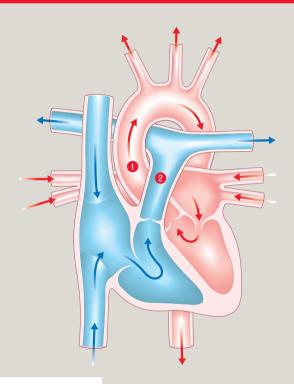
Each day 12 babies are diagnosed with a **congenital** heart defect in the UK. We continue to support research to improve the understanding, diagnosis and treatment of **congenital** heart conditions. For more information into our pioneering research visit **bhf.org.uk/research**

What causes a congenital heart condition?

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

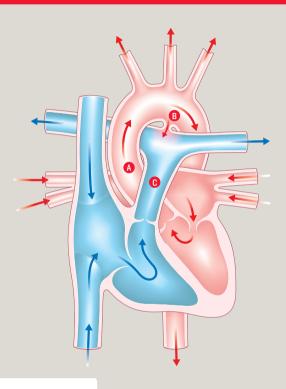
At the moment we don't fully understand why a baby's heart doesn't develop normally. But sometimes a congenital heart condition can be part of a syndrome which the baby is born with. (A syndrome is a group of symptoms that commonly appear together as part of a condition).

Normal heart



- AortaPulmonary artery

Patent ductus arteriosus



- Aorta
- B The duct
- Pulmonary artery

What is patent ductus arteriosus?

The ductus arteriosus is a short blood vessel connecting the two main arteries of the heart – the aorta and the pulmonary artery.

Before a baby is born the **duct** allows blood to bypass their lungs. After the baby is born and the lungs fill with air, the **duct** is no longer needed – it usually closes by itself within the first week after birth. Sometimes the duct fails to close by itself and remains open (*patent*). This is called patent **ductus arteriosus** or PDA.

PDA causes too much blood to be delivered to the lungs. This may only cause mild symptoms in young children (such as breathlessness) but if left untreated over a period of many years it can lead to permanent damage to the heart and lungs. This could become life-threatening as your child reaches adulthood, so it is important that large ducts are

treated when your child is young and before any damage is caused.

If the **duct** is small there is a very small risk of damage. But there is is also a risk that a serious infection could occur inside the **duct** later in your child's life, so it is recommended that even small ducts are closed.

Premature babies

PDA is common in premature babies and is more likely to cause symptoms. If it is difficult to wean your baby off the life support machine, your doctor will usually recommend using medication to try and close the **duct**. If this fails, or if medication is not considered appropriate, your child will need to have an operation to close the duct.

How is patent ductus arteriosus diagnosed?

Because babies and young children often don't show any symptoms, PDA may not be found until they are older. It's not unusual for PDA to be diagnosed in older children, teenagers or even in adults.

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.

How is patent ductus arteriosus treated?

PDA is treated with:

- keyhole surgery, or
- open-heart surgery.

Most ducts are small (only a couple of millimeters or so wide) and can be safely closed using a 'keyhole' treatment. If your child has a larger duct they may need open-heart surgery.

Keyhole surgery for patent ductus arteriosus

For this surgery, your child will be given a general anaesthetic. A small thin tube called a catheter will be inserted into a vein at the top of their leg. X-rays are used to guide the **catheter** to the right position in the heart. Once the **catheter** is in the right position a small stainless steel coil (like the spring of pen) is threaded along the catheter and placed inside the duct to seal it closed. If the duct is large, a plug, (shaped like a tiny cork) made of fine wire, will be used instead of the steel coil. The catheter will then be removed. Both the steel coil and the plug are designed to stay in position permanently.

The PDA does not always close completely as soon as the coil or plug is inserted. Sometimes it takes a few weeks for the body's own tissue to grow around it as part of the healing process and seal it completely. Your child will be able to return to normal activities within a few days. They will need to attend the outpatient department a few weeks later for a check-up.

What are the risks associated with keyhole surgery?

Keyhole surgery is very successful and usually there are no major complications. There is a small risk that the closure device will not completely close the duct. If there is only a very small space left around the device it may heal up on its own, but if not it is can be necessary to have further surgery one or two years later.

There is a very small risk that the closure device may move out of position. If your child has a steel coil this is not usually serious – it is often possible to remove it using a keyhole technique and to put a larger coil in. If your child has a plug, and it moves out of position, a bigger operation may be needed to remove it.

There is a very small risk that the device may become infected. Unfortunately, this is a very serious complication and would almost certainly require open-heart surgery to remove the device.

Open-heart surgery for patent ductus arteriosus

If your child has a larger PDA they may need open-heart surgery. If your baby has this surgery, they will be given a general anaesthetic. The surgeon will make a cut in their chest to get access to their heart. They will then will tie the **duct** to close it, and your child's chest will be stitched closed. Your child will need to stay in hospital for a few days following the operation, and then return to the outpatient's department a few weeks later for a check-up. Most children return to normal activities a few weeks after surgery. Your child will have a scar along the side of their chest afterwards.

What are the risks of open-heart surgery?

The good news is open-heart surgery to close a PDA is usually very successful and carries a very low risk of fatality. The majority of children survive the surgery without any major complications.

There is a small risk that the duct may not completely close, even after surgery. If this is the case it is almost always possible to complete further treatment using the keyhole method, rather than a second open-heart surgery.

Premature babies with patent ductus arteriosus

Sadly, there is a higher risk of premature babies with PDA passing away shortly after birth, compared to babies with PDA who were not born premature. This is rarely as a direct result of PDA or its treatment, and may be caused by other problems related to their prematurity.

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.

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.

Cardiologist A consultant specialising in heart disease.

Catheter A fine, hollow tube.

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.

Pulmonary To do with the lungs.

Pulmonary artery The blood vessel that takes blood to the lungs.

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



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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