Understanding your child’s heart

Common arterial trunk
(Truncus arteriosus)
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 common arterial trunk (truncus arteriosus) is and how it is diagnosed
- how common arterial trunk (truncus 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

Understanding your child’s heart

1 Aorta
2 Pulmonary artery
3 Ventricular septum
Common arterial trunk (Truncus arteriosus)

Aorta
Pulmonary artery
Single large artery (trunk)
Ventricular septal defect
What is a common arterial trunk?

Common arterial trunk is a serious **congenital** heart condition. There are two main abnormalities:

- The two main arteries (*the aorta* and *pulmonary artery*) which supply blood to the lungs, the brain and the rest of the body do not arise normally from the heart. Instead of leaving the heart as two separate arteries, there is a single large artery which then divides to form the *aorta* and the *pulmonary* artery.

- There is a large hole (*ventricular septal defect*, or *VSD*) between the two main pumping chambers (*ventricles*) of the heart (*see the illustration on page 5*).
Some babies with a common arterial trunk have additional abnormalities. In particular, the valve in the single artery of the heart may not function normally. There may also be a narrowing in either the aorta or the pulmonary arteries.

Sometimes, there can also be a chromosome abnormality – most often an abnormality called ‘22q11 deletion’. Babies born with 22q11 deletion may have learning difficulties and may also have difficulty fighting some infections. If your baby has a chromosomal abnormality such as 22q11 or any other type, your child’s cardiologist will talk to you about it.
What are the symptoms of a common arterial trunk?

Babies with a common arterial trunk usually look perfectly healthy when they are born, but will gradually become breathless over the first month or so after birth.

Some babies might also have other heart abnormalities which may cause them to become breathless or blue when they are only a few days old.
How is a common arterial trunk diagnosed?

In some cases, a common arterial trunk can be detected before birth, but in others it is not diagnosed until after a baby is born. Usually the only test that is needed to make the diagnosis is an echocardiogram. This is an ultrasound scan of the heart. It is very similar to the scans that are carried out during pregnancy and it doesn’t hurt your baby at all.
How is a common arterial trunk treated?

Your baby will need surgery very early in life to close the hole between the ventricles, and to separate the blood flowing to the lungs from the blood flowing to the rest of the body.

Your baby will be given a general anaesthetic. The heart is stopped and a heart-lung machine takes over the function of the heart and lungs. The right and left pulmonary arteries are disconnected from the single large artery and reconnected to the right ventricle using a tube with a valve inside it (see illustration on page 13). A human valve is usually used when they are available, but sometimes tubes and valves made of other material – such as cow or pig valves – are used instead. The hole between the ventricles is closed with a patch made of synthetic material. The heart is then restarted. After the surgery your child will have a scar down the centre of their chest.
Although this operation is often referred to as ‘corrective’ surgery, it doesn’t make the heart completely normal. The replaced valves will eventually become narrow or leak as they age, so your child may need further surgery at some point.

**What are the risks associated with the surgery?**

The good news is, most surgeries to repair a common arterial trunk are successful, but the risks will depend very much on the exact abnormalities present. All heart operations are serious and carry a small risk of death, or of major complications such as brain damage, kidney damage, or lung complications such as pneumonia.
It is important to understand the risks of the operation for your child. Your child’s surgeon will explain them to you before you give your consent for the surgery.

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

Common arterial trunk (Truncus arteriosus)

- **A** Pulmonary artery
- **B** Tube connecting right ventricle to pulmonary artery
- **C** Patch closing VSD
- **D** Right ventricle
What happens as my child grows up?

Although surgery can give your child a better quality of life, sadly it isn’t possible to completely correct the heart abnormality and we do not know how long children with this condition will live for.

Over time, the tube between the right ventricle and the pulmonary artery will need to be replaced. The timing of this will vary in every case and will depend on how well the tube and valve function with age. In children where the original single outlet valve (which acts as the aortic valve after surgery) does not function well, this valve will also need to be replaced periodically (every 10 to 15 years) throughout their life. This is usually done by open heart surgery, but some adults may be suitable for valve replacement by key hole catheter surgery.

Unfortunately, even many years after apparently successful surgery, new problems may arise which require further treatment. Such problems include
narrowing of the arteries in the lungs and the development of abnormal heart rhythms. These complications can usually be treated, but some can be serious and in rare cases they may even be fatal. It’s very important that your child is regularly reviewed by a cardiologist in an outpatients clinic, even if they appear well.

Children with a common arterial trunk are always limited to some extent in their physical activities, but specific restrictions on exercise are usually not necessary. It is usually best to allow children with this condition to join in with their friends’ activities, including some sport at school, and for them to judge for themselves what they are able to do.
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

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Aorta</strong></td>
<td>The main artery of the heart. It supplies oxygen-rich blood to the body.</td>
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<tr>
<td><strong>Atrium</strong></td>
<td>One of the two upper chambers of the heart.</td>
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<td><strong>Cardiologist</strong></td>
<td>A consultant specialising in heart disease.</td>
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<tr>
<td><strong>Chromosomes</strong></td>
<td>Found in the nucleus of every cell in the body, chromosomes contain the genes, or hereditary elements, which establish the characteristics of an individual.</td>
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<td><strong>Congenital</strong></td>
<td>From birth.</td>
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<td><strong>Echocardiogram</strong></td>
<td>An ultrasound scan used to produce pictures of the heart and blood vessels.</td>
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<tr>
<td><strong>Heart-lung machine</strong></td>
<td>A machine that pumps blood around the body while the heart is stopped during an operation.</td>
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<tr>
<td><strong>Pulmonary</strong></td>
<td>To do with the lungs.</td>
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<tr>
<td><strong>Ventricle</strong></td>
<td>One of the two lower chambers of the heart.</td>
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<tr>
<td><strong>Ventricular septal defect</strong></td>
<td>A hole in the wall between the two ventricles of the heart. Also called VSD.</td>
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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.

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.

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