

Tetralogy of Fallot (Fallot's tetralogy or ToF)

The aim of this factsheet is to explain what tetralogy of Fallot (ToF) is, what effect it will have on a child and how it can be treated.

What is ToF?

The name Fallot originated from the name of a doctor who spotted this particular type of heart defect. Tetralogy means fourfold – there are four defects found together.

These four defects are:

Pulmonary stenosis

Pulmonary means 'of the lungs' and stenosis means narrowing. Pulmonary stenosis is therefore a narrowing at or below the pulmonary valve. This means that blood has difficulty getting from the right ventricle into the pulmonary artery.

Ventricular septal defect (VSD)

Ventricular means 'of the ventricles' – the pumping chambers of the heart. Septal means 'of the septum' – the wall between the right and left ventricles of the heart. Defect means a hole. So a VSD is a hole in the wall between the ventricles. This means that blood can leak from one side to the other.

Over-riding aorta

The entrance to the aorta, which should only take red (oxygenated) blood around the body, lies over the VSD (the hole), allowing the right ventricle to pump some (deoxygenated) blood directly into it.

Fallot's Tetralogy

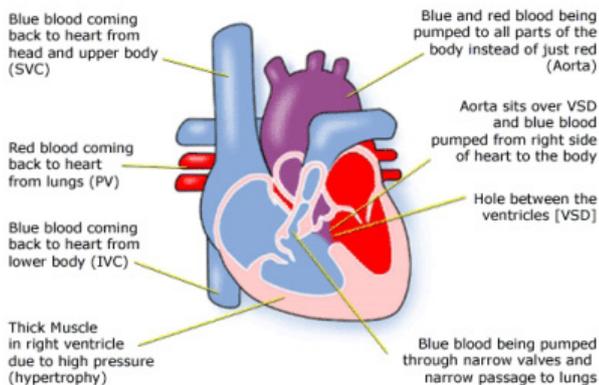


Fig 1. Tetralogy of Fallot

Normal Heart

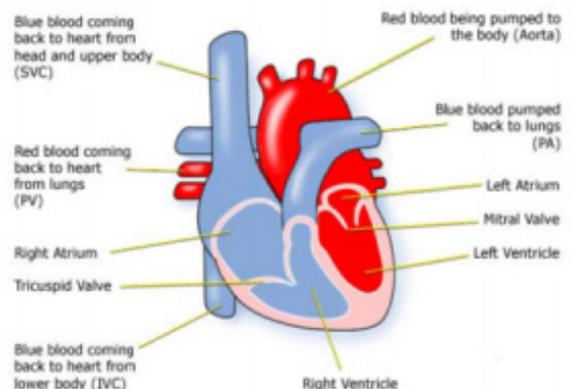


Fig 2. Normal heart

Right ventricular hypertrophy

The right ventricle becomes thickened (hypertrophy), as it forces blood into the narrowed pulmonary artery.

How is ToF diagnosed?

ToF can sometimes be seen on a scan during pregnancy. After birth the sound of blood moving through the pulmonary valve can be heard as a heart murmur. As your baby grows you may notice that he or she has a stronger blue tinge to the skin (cyanosed). After a few months he or she may start to have 'spells' – increased blueness and even loss of consciousness/fainting, particularly with activity or stress.

In order to diagnose this condition, these tests may be performed:

- pulse, blood pressure, temperature and number of breaths a baby takes a minute
- listening with a stethoscope for changes in heart sounds
- an oxygen saturation monitor to see how much oxygen is getting into the blood
- a chest x-ray to see the size and position of the heart
- an ECG (electrocardiogram) to check the electrical activity
- an ultrasound scan (echocardiogram) to see how the blood moves through the heart
- checks for chemical balance in blood and urine
- a cardiac catheterisation or MRI (Magnetic Resonance Imaging) test may be needed.

How does ToF affect my child?

If you are at home rather than in hospital while your baby develops, your child will be under regular review. You, your GP and health visitor should have details of your baby's condition from the heart doctor (paediatric cardiologist).

If not, call the hospital at which your baby was treated and ask for the name of the paediatric cardiologist and their telephone number. Call and explain that you need the information so that you can understand what is expected and pass it on to, for example, your local accident and emergency department should your child have a sudden illness.

You should have the number of a cardiac liaison nurse or outreach nurse to call should you have questions or any fears about your baby's heart problem. Ask for this from the hospital if it has not been given to you.

You can get the number of a parent support group from the CHF helpline: 0808 808 5000.

How is ToF treated?

Shunt: Your child may need an operation to increase the blood flow to the lungs. This is usually done by diverting an artery, usually the one that takes blood to the left arm or right arm, to the lung (pulmonary) arteries (a BT shunt). This operation is carried out through the side of the chest and the heart doesn't have to be stopped.



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Further surgery will be required later.

Balloon dilation: Another way of increasing blood to the lungs is to use a balloon catheter. A balloon is inserted into the narrow part of the pulmonary artery, and then inflated, so stretching the pulmonary valve and part of the artery below it. This does not leave any scar. Your child will still need surgery later.

Open heart surgery: this surgery is intended to make the heart work normally. To do this the heart will need to be stopped and opened. A machine will have to take over the job that the heart normally does – the heart bypass machine.

The aim of the operation is to make the circulation of blood through the heart and lungs as near to normal as possible. A patch is put over the hole between the ventricles, and the narrow area around the pulmonary valve enlarged.

How will ToF affect my child?

Cases of ToF can be more complicated than this description can outline, so there cannot be guarantees of how well your child will do. Things to be aware of: it is not uncommon for a child to pick up an infection, such as a chest infection or infected wound, while undergoing treatment. Some children react badly to some kinds of medicines, be aware of potential side effects. The kind of surgery needed can sometimes cause a very fast pulse rate (called tachycardia), which is worth

monitoring and may require treatment.

Most children are completely well, active, and gaining weight a few days after surgery. After open heart surgery, your child will have a scar down the middle of the chest, and there will be small scars where drain tubes were used. These fade very rapidly in most children, but they will not go altogether. After the first year, the child will be monitored by a cardiologist.

Other conditions

ToF is sometimes part of a syndrome, such as Down's syndrome or 22q11 deletion syndrome. Some people put many of their children's health difficulties down to the heart defect and treatment alone, so their children can miss out on help they need with other illnesses caused by a syndrome. If your child continues to suffer from problems such as vomiting, delayed walking and/or speech, behavioural problems or frequent infections, ask your GP or cardiologist for a referral to a paediatrician.

In later years the most common resulting heart problems are:

- a very fast heart rate (SVT or VT) can develop, which may require medicine to keep the blood pressure stable
- the pulmonary arteries or valve may become narrowed or the valve may start to leak, requiring further intervention or surgery



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Children with heart conditions are more likely to have an infection called infective endocarditis. Although this is a difficult disease to treat, it is rare.

Read about infective endocarditis and how to prevent it in our factsheet 'infective endocarditis' – order by calling our freephone infoline **0808 808 5000** or download from our website

www.chfed.org.uk

These problems may not become serious until the teen years or adulthood, but if you monitor your child's health and keep records you will be able to discuss issues with your cardiologist as they arise.

Evidence

Evidence used for CHF Factsheet:
(Fallot's tetralogy or ToF) can be obtained at:

www.gosh.nhs.uk/medical-information/search-medical-conditions/tetralogy-fallot

<https://www.bhf.org.uk/~media/files/publications/children-and-young-people/c5understanding-your-childs-heart-tetralogy-of-fallot1208.pdf>

About this document

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If you spot any inaccuracies, omissions or errors please contact The Children's Heart Federation (CHF) on tel 0808 808 5000 and via email at info@chfed.org.uk



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