



The Leeds
Teaching Hospitals
NHS Trust

Tetralogy of Fallot

Information for patients



Yorkshire and Humber
Congenital Heart Disease
Operational Delivery Network

LEEDS CONGENITAL
HEARTS

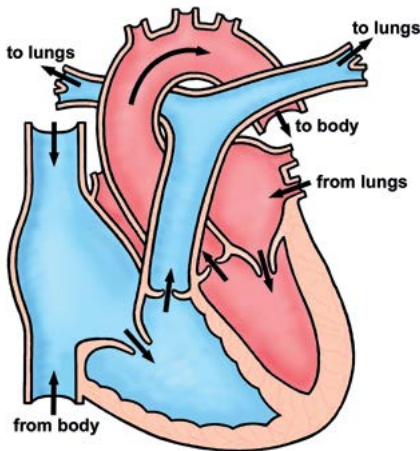
This leaflet aims to give you an overview of one of the most common congenital heart conditions called Tetralogy of Fallot.

Tetralogy of Fallot

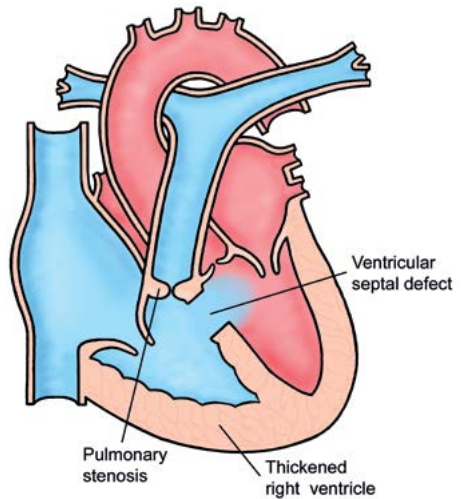
Tetralogy of Fallot is a heart condition in which there are two main problems;

1. There is a narrowing of the pulmonary valve which lets blood pass from the heart to the lungs.
2. There is a large hole between the two main pumping chambers (ventricles) of the heart. This is called a ventricular septal defect or VSD, meaning blue blood mixes with red blood.

Normal Heart



Tetralogy of Fallot



Treatment in childhood

Patients with Tetralogy of Fallot usually have major surgery during childhood to close the hole (VSD) by sewing a patch over it and opening up the narrowed pulmonary valve.

This operation is often referred to as “corrective” surgery, but it never makes the heart completely normal. Virtually all patients who have had surgery for Tetralogy of Fallot repair have an abnormal pulmonary valve and may develop other complications.

Long-term follow-up

Regular review in the outpatients department is very important even if you feel well to allow monitoring of your condition and allow us to treat any problems before they become severe and harder to treat.

Issues related to this particular condition include:

Heart rhythm abnormalities

Some people with Tetralogy of Fallot develop abnormal heart rhythms. These can cause the heart to beat too quickly or too slowly, causing light-headedness, dizziness and even collapse. It is very important to let us know if you suffer from these symptoms as they can be serious and may need some tests and treatment.

Treatment of heart rhythm problems is often with medication, but sometimes a pacemaker may be suggested, or a special type of pacemaker called an implantable cardioverter defibrillator (ICD).

Pulmonary valve abnormalities

After your operation, we will monitor your heart in the outpatients department, with regular echocardiograms (heart scans). This allows us to look at the function of your heart and to check if the pulmonary valve is functioning adequately. Some patients have pulmonary valves that “leak” which makes the right side of the heart stretch and ultimately work harder. If this continues, the heart will tire. If the leak is not causing any issues it may be that the pulmonary valve simply needs monitoring or it may be that the pulmonary valve needs to be replaced. For some people this will mean another open-heart operation. Some people are suitable for a keyhole valve replacement which is done using tubes passed through a blood vessel at the top of your leg. Your cardiologist will discuss this with you in more depth if you require further treatment.

How will this heart condition affect my life?

After a successful operation in childhood, you should not be limited in what you can and cannot do in life.

Exercise

Exercise and being generally active has many health benefits and we would encourage you to participate and enjoy sports and activities. We usually recommend that you avoid sports or activities which involve really hard sustained exercise (like marathon running) or those that are played at a highly competitive level as this can cause strain on the heart.

Very heavy weight lifting can also put strain on the heart so is best avoided.

Having children of your own

If you are planning a family it is important that you discuss this with your cardiologist beforehand, so they can provide you with information and support you throughout the pregnancy.

There are two main points that you need to know:

- If you have been born with Tetralogy of Fallot (this relates to both men and women), you have a small increased risk of having a child with congenital heart disease. This risk is approximately 3-5% risk (approximately 1 in 20) compared to less than 1% risk (1 in 100) if you do not have Congenital Heart Disease. Due to this increased risk, a detailed scan of the unborn baby's heart can be performed at approximately 18-20 weeks, to assess for any problem in the heart.
- For women who wish to get pregnant, it is important you discuss this with the cardiologist, as they may wish to assess how your heart will cope and if any medication you are taking can affect the baby's development. The majority of women after Tetralogy of Fallot repair cope well in pregnancy.

Endocarditis

All patients with Tetralogy of Fallot are at risk of infection in the heart (endocarditis). Endocarditis may be caused by infections of the teeth or gums. It is important to visit the dentist regularly. **If you have had a valve replacement, you require antibiotic cover for invasive dental procedures.** Please ask your doctor or specialist nurse if this applies to you. Due to the increased risk of infection we would also advise against body piercing and tattoos.

Insurance

It can be difficult for people who have congenital heart disease to get life insurance. There are some more sympathetic insurers who can be identified and contacted through the Somerville Heart Foundation. We would recommend you seek advice from a specialist insurance advisor before applying for life insurance.

Travel

The majority of people can and do fly/travel long distances around the world. If you are unsure, ask at your outpatient appointment. The most important point to remember is to ensure you declare your heart condition when booking travel insurance.

Tetralogy of Fallot - YouTube

<https://www.youtube.com/watch?v=8cRYkbm43Is&list=PLoTRklWm7TS-s-mHjgQuZhit77SPNGG89&index=4>



Contact us

For clinical queries, please contact the ACHD Specialist Nurses on **0113 392 8154** or leedsth-tr.achdnurse@nhs.net

Further Support and Advice

The Somerville Heart Foundation

- www.sfhearts.org.uk
- Helpline: 0300 015 1998



For young people and adults with congenital heart disease.

Join as a 'friend' to access their benefits including advice around benefits, employment, pensions, will writing and insurance. They also have a counselling service and support groups.

British Heart Foundation

- www.bhf.org.uk
 - Teen Heart for 13-18 year olds
 - One Beat for 18-30 year olds



The Children's Heart Surgery Fund

- www.chsf.org.uk



Our fantastic local charity who do loads to support both children and adults being cared for by Leeds Congenital Heart Unit.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



© The Leeds Teaching Hospitals NHS Trust • 1st edition (Ver 1.0)
Developed by: Hannah Swift - Adult Congenital Heart Disease Nurse
Specialist
Produced by: Medical Illustration Services • MID code: 20220707_021/MH

LN005377
Publication date
07/2024
Review date
07/2027