

Aortic Stenosis in children

Information for parents and carers



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This leaflet provides information for parents and carers about aortic stenosis in children and the management and treatment of this condition.

Aortic stenosis is a narrowing of the aortic valve. This valve lets blood flow from the heart to the artery feeding the body with blood (the aorta).

Almost all children with aortic stenosis will need major heart surgery at some stage in their life, but the age at which surgery is necessary is very variable.

If the valve is severely narrowed treatment may be necessary within the first few weeks of life, but if the narrowing is mild, treatment may not be necessary until later in life.

The timing of treatment depends on how badly narrowed the valve is, how it changes as time goes by (it almost always gets worse with increasing age), and how well the heart is coping with the extra work of pumping blood through the narrow valve.

Image of a normal heart

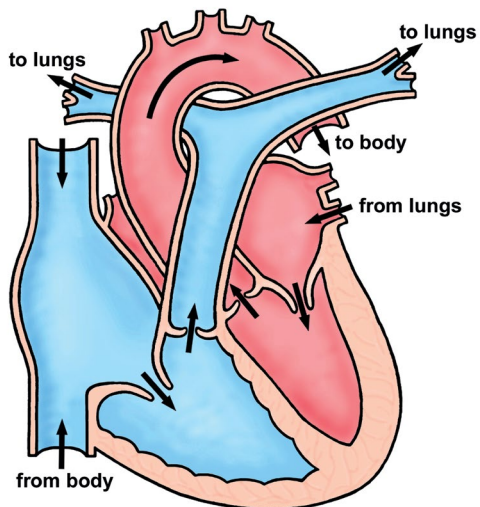
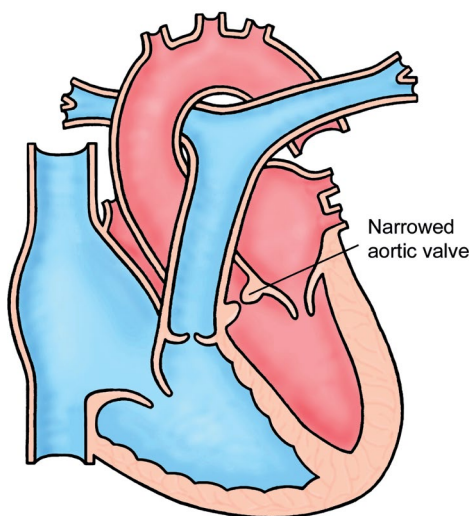


Image of a heart with Aortic Stenosis



When the aortic valve is narrow the muscle of the main pumping chamber of the left side of the heart (the left ventricle) has to work harder than normal and the muscle gets thickened, just like other muscles in the body if they are worked hard. If the valve is only mildly narrowed the heart copes very well, but if the narrowing is very severe the heart cannot pump normally and this can limit how much exercise a child can manage and can even cause death if it is not treated.

Tests

Usually only simple tests such as an ultrasound scan of the heart ("echocardiogram") and electrical recordings of the heart's activity (electrocardiogram or ECG) are needed to make a diagnosis.

Treatment

Most children with aortic stenosis will need an operation to replace the valve at some stage in their life, but avoiding this during childhood if possible is the best option as valves do not grow and repeated operations would be needed to put a larger valve in place. When the valve is badly narrowed in childhood, we can often help to delay valve replacement by stretching the narrow valve open with a balloon (called "balloon valvuloplasty").

This is done under general anaesthetic and involves passing a long tube with a collapsed balloon on the end of it (a balloon catheter) into the artery at the top of the leg (or the arm in babies) and feeding it up into the heart and across the narrow valve. Using Xray pictures, the balloon is positioned in the narrow valve and is blown up, stretching the valve open.

This never makes the valve normal and it is not always successful, but in many cases it can reduce the severity of the narrowing so surgery can be delayed until the child is older, possibly an adult. However, it can also make the valve leak which may necessitate valve replacement. Sometimes balloon valvuloplasty can be repeated as the patient grows to further delay the need to replace the valve. Usually only one night's stay in hospital is necessary after the balloon procedure.

If the valve cannot be stretched open using a balloon, open heart surgery will be needed. This involves opening the chest and the function of the heart and lungs are taken over by a machine so the surgeon can open the heart and cut the narrow valve open (called a "valvotomy") or replace the valve. Usually about a week's stay in hospital is necessary after this surgery.

If the valve needs to be replaced, there are two main options:

1) Metal Valve Replacement

To replace the aortic valve with an artificial metal one, because they last longer. Following a metal valve replacement, a drug called warfarin, will need to be taken to reduce the risk of a blood clot forming across the metal valve.

2) Ross Procedure

Surgery to replace the valve using an animal or human tissue valve. This is called the Ross Procedure. The pulmonary valve replaces the narrowed aortic valve, then a 'tissue valve' (usually from a pig, or a human valve) is used to replace the pulmonary valve. This video explains more about this operation.

Ross procedure - YouTube

<https://www.youtube.com/watch?v=4I5BqJR4BGc>



All treatment for aortic stenosis has potentially serious risks for the patient. If your child requires surgery or treatment in the catheter lab, the surgeon or cardiologist will talk to you about this in detail.

General advice for the future

Regular check-ups in the outpatient clinic are very important even if the patient appears perfectly well.

Unless the valve is only slightly narrowed, it is usually best to avoid competitive sporting activities. In most cases PE at school can continued to be enjoyed but more intensive exercise should be avoided. Your cardiologist, specialist nurse, or physiotherapist will answer any questions you have about individual recommendations for your child.

Children with aortic stenosis will be at risk of infection in the heart (called endocarditis), both before and after treatment.

Such infections may be caused by infections of the teeth or gums. It is important to visit the dentist regularly (every 6-12 months) and to follow good dental hygiene.

Ear or body piercing and tattooing are best avoided as they also carry a small risk of infection which may spread to the heart.

For more information about endocarditis please see the link below:

**Infective endocarditis ... what to do to avoid it -
Leeds Teaching Hospitals NHS Trust ([leedsth.nhs.uk](https://www.leedsth.nhs.uk))**

**[https://www.leedsth.nhs.uk/patients/
resources/infective-endocarditis-
what-to-do-to-avoid-it/](https://www.leedsth.nhs.uk/patients/resources/infective-endocarditis-what-to-do-to-avoid-it/)**



Contact us

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