

Repaired Atrioventricular Septal Defect (AVSD)

Information for patients



Yorkshire and Humber
Congenital Heart Disease
Operational Delivery Network

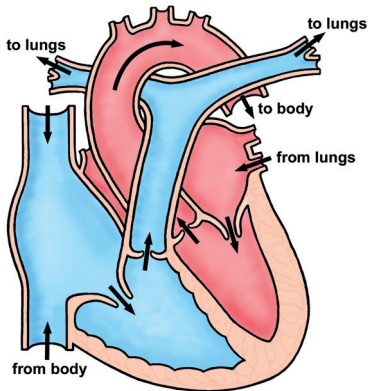
LEEDS CONGENITAL
HEARTS

This leaflet aims to give you information about atrioventricular septal defects (AVSD) and their long-term management.

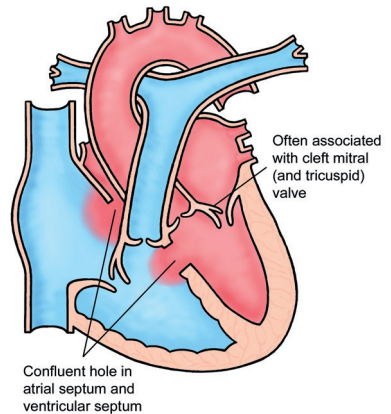
Repaired Atrioventricular Septal Defect (AVSD)

You were born with a complicated hole in the middle of your heart involving the wall between the two collecting chambers (atria), the wall between the two pumping chambers (ventricles), and one or two of the heart valves. You have had an operation to repair the hole and the valve(s) in childhood. Although your heart has been repaired, and you may feel very well, we recommend long term follow up so we can watch out for certain problems.

Normal Heart



Atrio-Ventricular Septal Defect



Leaking valves

Despite successful repair, there is often some leak on one or more of the heart valves. In some cases, the leak worsens and may require another operation to fix it. If it is needed, this is very likely to be an open-heart operation.

Narrowed valves

In some patients a narrowing can develop in one of the valves, which occasionally requires another operation to fix it. If it is needed, this is likely to be an open-heart operation.

Palpitations

Because you have had previous heart surgery, you will have some scars in your heart. You have a slightly higher chance than normal of developing heart rhythm problems in later life.

Children/Pregnancy/Contraception

Whether you are a man or woman there is a higher risk than usual of your children being born with a similar heart condition. If you are planning a pregnancy, we can talk to you about this in more detail. We would recommend having a detailed look at the baby's heart by ultrasound before they are born to assess for any possible problems. If you are a woman then we also need to make sure your heart will cope with being pregnant and therefore we would like to see you before you become pregnant.

For most women with a repaired AVSD, all methods of contraception are fine but please speak to your doctor or specialist nurse for more advice.

Exercise

Regular exercise is encouraged. It is good for your general health and wellbeing and beneficial for your heart and circulation. Activities such as walking, cycling, and swimming are ideal and it is important to warm up. We would not usually restrict your physical activities. If you have problems with leaky valves or heart rhythm you may have a reduced exercise capacity and you will need to modify your activities to cope with your symptoms. Your cardiologist will tell you if you need to restrict any physical activity.

Endocarditis

All patients who have had heart surgery are at risk of a serious infection in the heart (endocarditis). It is important to have good dental hygiene and you should visit the dentist every every 12 months. **Some people require antibiotics before invasive dental treatment.** 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 with congenital heart disease to get some types of insurance. Travel insurance may be more expensive and people who have congenital heart disease often struggle to get any type of life insurance. There are some more sympathetic insurers who can be identified and contacted through the Somerville Heart Foundation.

We would recommend seeking advice from a specialist insurance advisor before applying for life insurance.

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



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