

A close-up photograph of a woman with dark hair and blonde highlights holding a baby. The baby is crying with its mouth wide open and eyes closed. The woman is looking at the baby with a concerned expression. The background is a blurred green, suggesting an outdoor setting.

**Supporting families where an individual with DS has heart problems**

**Penny Green - Press Officer (past Director)**

# Frequency of heart problems

- About 47% of babies with Down's Syndrome are born with a congenital heart
  - A small percentage of people develop heart problems later in life
  - These figures are reflected fairly uniformly across the world
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- Regardless of when they get the diagnosis, families need extra support
  - They need parent friendly information and support



It needs to be positive, but realistic and reflective of the family's situation / location



# Some heart related terms

Ventricular Septal Defect - VSD

Straddling Chordae

Stenosis

Tetralogy of Fallot

Cardiac Bypass

Persistent Ductus Arteriosus - PDA

Atresia

Atrial Septal Defect - ASD

Electrocardiogram

ECMO

Echocardiogram

Patent Foramen Ovale - PFO

Eisenmengers Syndrome

Cardiac Catheterisation

Partial AV Canal

AtrioVentricular Septal Defect - AVSD

Pulmonary Hypertension

# Good input is important

The internet and Social Media provide a great platform for families to find information and support, but it has its drawbacks too.

- It can be difficult to tell good information and websites from bad, especially when this is all very new to them.
- On social media people try to be supportive and offer advice and encouragement, but without a proper understanding of the different defects and other issues, families can be given unhelpful input which may be frightening or unrealistic.

If you are not careful it can be like trying to compare these

and that **DOESN'T WORK!**





# No two youngsters are the same

My little boy is 3 weeks old he has AVSD and has been in hospital as was struggling to breath. ECHO showed his heart is working over time, and he is loosing weight due to his body working harder. He's been put on.. Furosemide and spiro lacton.


Anyone had similar? And when will he start to gain weight? He is Breastfeeding xx

My princess had exactly the same meds and had to have formula and duocal to double the calorie intake. She got to 10lb by 4 month and had her op. She is 16 now and amazing. Hang in there it really does get easier. Xx

My son is now 17 and had avsd repaired at 3mths before surgery he was oxygen dependant and I did a combination of breast feeding and a special milk for him to put on weight. He was also on diuretics and digoxin until surgery

didn't really put on weight till after she had her surgery for a complete avsd when she was 9 months old. She had to work so hard keeping it together there were no spare calories for growing!

complete avsd repair at 3mths, he was on the same medication. unfortunately he developed pneumonia at a month old and ended up on oxygen 24/7 and being ng fed from then til surgery as he was just too poorly and tired due to heart failure. It's such a scary time, I really feel for you but once the surgery is done it will make such a difference! Good luck xx



## Atrioventricular Septal Defect (AVSD or AV Canal)

An AVSD is the most common congenital heart defect found in children with Down's Syndrome, accounting for 50% of the total.

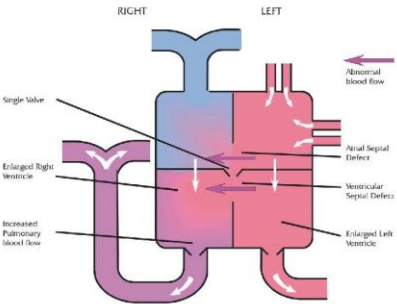


Diagram shows the heart looking at the patient:

In its complete form there is a hole in the wall between the top chambers (atria) and a hole in the wall between the bottom chambers (ventricles), and one common valve between the two atria and the two ventricles. In the partial forms there may not be a hole between the bottom chambers (ventricles) or the mitral and tricuspid valves may not be joined together, but either or both may leak, known as valve incompetence.

Because of the high pressure in the left ventricle (needed to pump the blood around the body), blood is forced through the holes in the septum (central heart wall) when the ventricle contracts, thus increasing the pressure in the right ventricle. This increased pressure (pulmonary hypertension) results in excess blood flow to the lungs.

**Symptoms**  
Some of the early symptoms which may be exhibited are difficulty in feeding, poor weight gain, fast irregular breathing and a degree of cyanosis (blueness) particularly noticeable around the mouth, fingers and toes. Clinical examination may show an enlarged heart and liver, and a diagnosis of 'heart failure' may be given. This is not as frightening as it sounds - it is in fact the medical term used to indicate that the heart is working inefficiently due to the demands the body is placing on it. Because of the flow of blood from one side to the other, the heart has to work harder than normal.

Not all children will exhibit symptoms early in life, and those that do will not necessarily show all of these.

- Individual sheets
- Simple diagrams
- Parent friendly language
- Info on main heart defects and normal heart
- Info on other topics, travel advice, teeth etc.

- All available to view or download on our website
- Also available on a CD





# Our Support

DHG provides support according to individual circumstance and need so that families are supported in the way that helps them most.

*“We contacted Down’s Heart Group just after \* was born after finding about the group on the internet. We were put in touch with another family who had a young lad with Down's Syndrome and a heart condition. Just knowing that there were others with similar experiences was a great help. The Down's Heart Group were a big help to us and I would like to thank them for their much needed and appreciated support - thank you.”*

Support can be by phone, email, social media or in person and provided regularly or on an ad hoc basis when needed.



# Why not work with us?

Don't waste your valuable time and money reproducing resources we already have and working on your own ...

Talk to us about how we can work together with your group to ensure your members whose youngsters have heart issues are fully and appropriately supported







# DHG contact information

[www.dhg.org.uk](http://www.dhg.org.uk)

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