



Hypoplastic left heart syndrome



WHAT IS HYPOPLASTIC LEFT HEART SYNDROME?

HLHS is a congenital heart condition. This means that before you were born there was a problem with the development in the structure of your heart. HLHS is a set of congenital heart abnormalities on the left side of your heart.

When you were born, your main pumping chamber (left ventricle) was small and under developed (hypoplastic). Your mitral and/or aortic valve was either very narrow or blocked or not formed at all. Your aorta, your biggest artery, was small and under developed (hypoplastic).

TREATMENTS

These problems made it difficult for your heart to pump oxygen-rich blood around your body. Before you were born your mum gave you all the oxygen you needed. Blood went round the blockages in your heart due to a hole (foramen ovale), and a tube (ductus arteriosus) that are always in the heart of a newborn baby. They close a few days after birth, so you had medicine (prostaglandin) to keep them open until you were well enough to have your first operation.

THINGS TO TALK ABOUT

To reduce your risk of getting endocarditis:

- Keep your teeth and mouth clean and have regular check-ups with a dentist
- Avoid body piercing and tattooing
- Never inject recreational drugs

SURGERY

In the first week of your life you will have had your first heart operation, either the Hybrid procedure, which is done for very small babies, or more commonly the Norwood procedure. This operation links the one heart pump that you have to a blood vessel that can take oxygen-rich blood around your body. Then a tube (a shunt) takes a small amount of blood to your lungs to pick up oxygen. You will also have had the hole between the top two chambers of your heart (atrial septal defect) made permanent (a septostomy).

At around six months old, you will have had your second operation. The cavo-pulmonary connection, sometimes called a Glenn shunt or a hemi-Fontan, connects the vein carrying blood back from your head and neck (superior vena cava) to the blood vessels that lead to your lungs (pulmonary arteries). The small tube (shunt) put in during your first operation would have to be removed.

The third and final operation was the Fontan procedure or a TCPC (total cavo-pulmonary

connection). This connected your main vein carrying blood from your body (inferior vena cava) onto your pulmonary arteries. Sometimes a small hole (fenestration) is made in the new connection acting as a pressure valve that protects your lungs. As you grow older this hole will either close itself or will be closed during a cardiac catheterisation when you no longer need it.

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AFTER SURGERY

Even though you have had lots of operations your heart will never be able to work normally. You will need regular check-ups with your cardiac team, tests to check your heart function, medications to keep your heart in balance and you may need further small operations/interventions to keep your heart working well. You will also need to learn to balance your levels of physical activity.

There is support available to help you cope as you go through life. Whatever type of treatment you have had for your heart, you will need regular check-ups in a cardiac clinic throughout your life.

Revealing the facts about your condition

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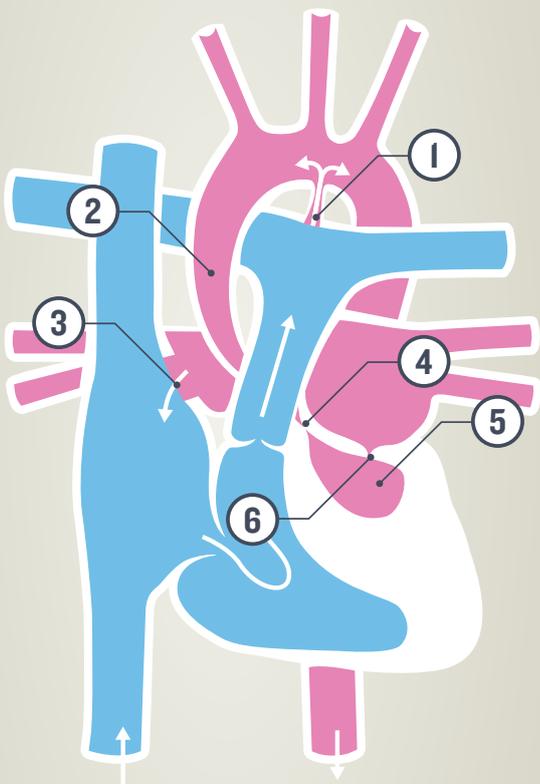
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YOUR HEART

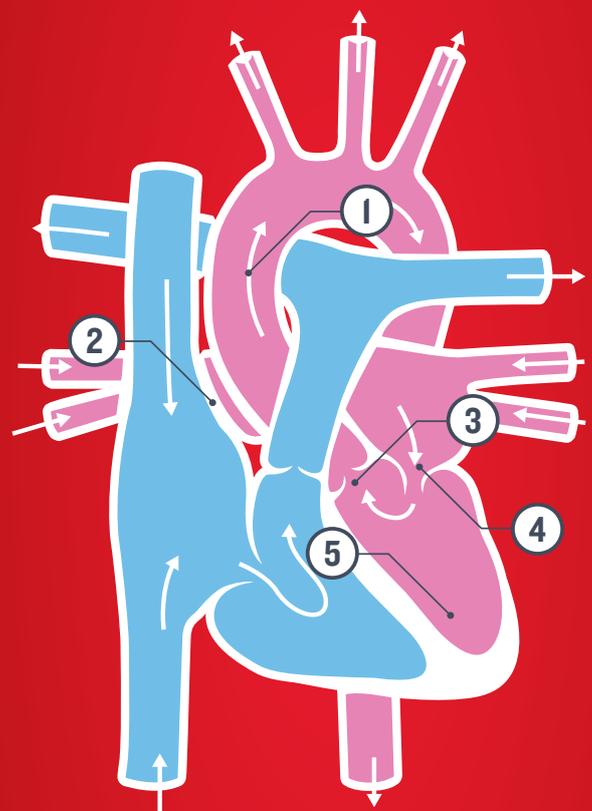
Find out more about your heart:

yheart.net / chfed.org.uk / lhm.org.uk



- ① patent ductus arteriosus /the duct
- ② small aorta
- ③ atrial septal defect (ASD)
- ④ blocked/narrow or unformed aortic valve
- ⑤ hypoplastic left ventricle
- ⑥ blocked/narrow or unformed mitral valve.

THE HEART



- ① aorta
- ② atrial septum
- ③ aortic valve
- ④ mitral valve
- ⑤ left ventricle.