# Information sheet



### TERMS PARENTS HAVE ASKED TO BE EXPLAINED

Please contact CHF and let us know if there are additional terms or abbreviations we should add to this list:

**Ablation:** an electric current or radiofrequency energy can be used via a catheter to destroy the extra pathways in the heart which cause tachycardia.

#### Absent pulmonary valve syndrome:

the pulmonary valve is not formed properly, there is a hole between the ventricles and the pulmonary arteries are much wider than they should be.

**Amniocentesis:** withdrawing amniotic fluid from the uterus during pregnancy. This can test for some abnormalities of the chromosomes and genes.

Analgesic: medicine given to stop pain.

**Aneurysm:** the wall of an artery or a ventricle balloons and becomes stretched and weak.

**Angiogram**: an x-ray of the heart assisted by a liquid introduced through a catheter.

Anomalous pulmonary venous drainage: the pulmonary veins carry red blood from the lungs to the right side of the heart instead of the left side.

Anticoagulant: a medicine such as Warfarin given to stop blood clots forming.

**Aorta**: main artery which carries blood from the heart to the body.

**Aortic stenosis:** a narrowing which restricts red blood from moving from the left ventricle into the aorta.

**Aortic valve**: The valve between the left ventricle and the aorta.

Apnoea: lack of breathing.

APVC/R/D (anomalous pulmonary venous connection/return/drainage): some or all of the veins bringing red blood from the lungs to the heart are not connected into the left atrium.

**Arrhythmia**: out of rhythm - the heart is beating too fast, too slowly, or irregularly.

**Arterial Switch:** Reattaching the aorta and the pulmonary artery the right way around when a baby is born with transposition of the great arteries (TGA).

Aspirin: used to prevent blood clots.

Atresia: blocked or missing.

Atria: plural of atrium. The left atrium pumps oxygenated blood into the left ventricle. The right atrium pumps deoxygenated blood into the right ventricle from where it is pumped into the left ventricle.

Atrial septal defect (ASD): a hole in the wall between the atria.

Atrial septostomy: making a hole between the two atrial chambers.

Atrioventricular septal defect (AVSD): a hole between the atria (atrial septal defect, or ASD), a hole between the ventricles (ventricular septal defect or VSD) and a single valve instead of a tricuspid valve and a mitral valve.

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Atrium: an upper chamber of the heart where blood collects before passing to the ventricle.

**Balloon dilatation**: using a tube (catheter) to reach the narrow part of the heart and making it bigger by inflating a balloon on the end of the catheter.

**Balloon septostomy:** a tube (catheter) is put into the heart and a balloon inflated on the end of it to make a hole, or increase the size of a hole, in the wall (septum) of the heart.

**Banding**: Making the pulmonary artery narrower with a band to reduce blood flow to the lungs.

**Bicuspid:** (of a valve) having two cusps, or leaflets.

**Biopsy:** removal of a small piece of tissue for examination.

**Blue blood**: blood which is returning from the body to the heart and so pumped to the lungs, where it will pick up oxygen and become red blood.

Bradycardia: slow heart beat.

**BT shunt**: taking blood from an arm artery to the lungs.

**Bypass**: using a machine to bypass the heart and lungs during surgery.

Candida: a fungal infection.

**Cannula:** a tube for introducing eg IV drugs.

Cardiac: relating to the heart.

**Cardiac catheter**: a tube which is put into the heart via a vein. It is used to help diagnosis, by measuring pressures very accurately, or can treat a problem such as widening an artery, or closing a hole.

**Cardiologist**: doctor specialising in heart.

**Cardiomyopathy:** weakness of the heart muscle.

**Catheter:** a long fine tube which is threaded through a vein and into the heart. Here it can test pressures or widen valves and block some kinds of hole.

**Chest splinted open**: when there is strong reason to suppose that further surgery is needed the opening in the chest is not closed.

**Chest drains**: tubes often left in after heart surgery to drain away fluid.

**Chylothorax:** fatty fluid leaks into the chest.

**CT (cerebral topography) scan**: scan of the brain.

**Coarctation of the aorta**: narrowing in the aorta - the artery taking blood from the heart to the body.

**Congenital:** describes a condition which is present at birth.

**Corrective:** treatment/procedure to return blood circulation to normal.

**Corrected transposition:** the pulmonary artery and the aorta are around the wrong way, but this has been 'corrected' by the fact that the ventricles are also around the wrong way.

**CPAP (constant positive airway pressure):** keeping small airways open, especially before completely off ventilation.

**Cyanosed**: there is not enough oxygen in the blood, causing the skin to look blue in some children.

**Dextrocardia:** the heart is on the right, rather than the left, side of the chest.

**Digoxin:** a medicine given to increase the strength, or slow down the rate, of the contraction of the heart.

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**Dilated cardiomyopathy**: a condition in which the heart becomes enlarged and weak, sometimes because of a virus.

**Dismorphic features:** unusual features sometimes associated with a syndrome.

**Diuretic medicines**: these medicines help the kidneys pass more water, so reducing excess fluid in the organs, especially the lungs.

**Double inlet ventricle**: DIRV – Double Inlet Right Ventricle. DILV – Double Inlet Left Ventricle. There is one large ventricle into which both atria empty their blood through either one or two valves, and usually a second smaller ventricle.

**Double outlet ventricle:** DORV – Double Outlet Right Ventricle. DOLV – Double Outlet Left Ventricle. One ventricle pumps blood into both the aorta and pulmonary artery, although there may be a second smaller ventricle.

**Duocal:** a food supplement to help children gain weight faster.

Dysplastic: doesn't work properly.

**Ebstein's anomaly:** the tricuspid valve is abnormal and is low down in the right ventricle, so limiting its size.

**ECG:** short for electrocardiogram - for measuring the electrical activity of the heart.

**Echo:** short for echocardiogram - an image of the heart created by using high frequency sound waves.

**ECMO:** a by-pass machine which can be used to support the heart so that it can be rested after surgery, or during a viral illness for example.

**EEG**: a print-out of the electrical activity in the brain.

Endocarditis: an infection of the lining of

the heart.

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Fallots: see tetralogy of Fallot.

FISH (fluorescence in situ hybridisation): a way of identifying gene microdeletions such as 22q11.2

**Fontan:** a procedure which changes a circulation in the heart so that theleft side takes on the pumping workof the right side.

**Foramen ovale:** a small between theright and left atrium.

**Gastrostomy:** making an opening into the stomach so that food can bepassed directly into it.

Glenn shunt: The

superior vena cava, bringing blood back to the right side of the heart, is connected to a pulmonary artery, so taking blood directly to the lungs, and bypassing the right ventricle.Bi-directional Glenn connects into both the left and right pulmonary arteries.

Heart block: Electric impulses between the top and bottom of the heart are partlyblocked so that the heart rate is slower than usual.

**Heart failure:** heart failing to keep upwith the demands of it.

**Heart murmur:** a murmur is a sound made by blood moving round the heart:

sometimes but not always this could be caused by a heart defect.

**Heparin**: a drug given directly into a vein which thins the blood when there is a danger of clotting (an anticoagulant).

**HDU:** high dependency unit - unit where a child receives more care than they can be given on the ward.

**Homograft**: putting in human tissue - such as a valve or artery.

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**Hyper:** too much, as in hyperactive or hypertension.

**Hypertrophic cardiomyopathy:** the heart muscle becomes so thick that it can interfere with its proper functioning.

Hypo: too little

**Hypoplastic right ventricle**: the right ventricle has not developed properly so it is small.

**Hypotonia:** floppiness due to lack of muscle tone.

**INR (international normalisation ratio) test**: a blood test to measure how fast the blood clots, used to adjust the amount of anticoagulant prescribed. Normal is 1 whereas 3 would mean it takes 3 times as long as normal to clot.

**IV antibiotics**: antibiotics directly into the blood stream.

**IV drugs**: drugs given directly into the blood stream.

**Kidney dialysis**: used to take impurities from the blood when the kidneys are not working properly.

**MAPCAs**: Multi aorto-pulmonary arteries. A number of additional arteries come from the aorta and supply the lungs with blood.

**Maxijul:** a food supplement to help a baby gain weight faster.

**Meningitis**: an infection of the lining of the brain.

**Mitral valve stenosis**: the mitral valve in the heart opens to let oxygenated blood to pass into the left ventricle, and then closes as it is pumped into the aorta and so around the body. Stenosis means that it is narrow, and therefore not allowing enough blood through, and causing a backflow to the lungs. **Mosaicism:** a chromosomal error thatonly occurs in some of the cells in the body.

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**Murmur:** the sound of blood flowing in he heart and vessels.

#### Mustard procedure: (not

commonly used these days) this redirects the flow of blood to the atria and leaves the left ventricle pumping to the lungs, and the right to the body, for children who have transposition of the great arteries (TGA).

Nasal cannula: a cap with attachednasal prongs to deliver oxygen.

#### NG tube: a naso-

gastric tube - for feeding the child through the nose directly into the stomach.

NICU: a neonatal intensive care unit.

Oliguria: lack of urine.

**Pacemaker**: a small battery placed under the skin and joined to the heart by pacing wires, which measure the pulse and corrects too fast or too slow rhythms.

Pacing box: when the pulse rate is veryirregular or slow an external pacemakercan be used to regulate the heart by attaching it to temporary pacing wires often put in place after heart surgery in case they should be needed.

**Pacing wire**: there is often a problem with heart rhythm after heart surgery, so a pacing wire is left in place just in case itis needed.

**PAPVC:** partial form of anomalous pulmonary venous connection.

**Parachute mitral valve:** valve is attached to one instead of two muscles in the left ventricle.

#### PDA (patent or persistent ductus

**arteriosus)**: a passage used for circulation before the baby is born remains open, instead of closing shortly after birth. This causes red blood to return from the aorta back to the lungs.

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PICU: Paediatric Intensive Care Unit

**PEG (Percutaneous Endoscopic Gastrostomy):** a surgical procedure to place a tube into the stomach for direct feeding.

**Pericardial effusion**: fluid collects in the pericardial sac - the outer covering of the heart -which can be drawn off using a needle, or drained using diuretics.

**Portage:** a service operated by some local authorities whereby advice and support is given to mothers to improve the progress of children with disabilities.

**Prophylactic**: describes a medicine or procedure intended to prevent illness.

**Prostine:** a drug given to keep the fetal circulation passages open in the heart.

Pulmonary: to do with the lungs.

**Pulmonary artery**: the blood vessel which takes blood from the heart to the lungs.

**Pulmonary Atresia:** blood cannot be pumped to the lungs from the right ventricle through the pulmonary artery, which is blocked or missing.

...with intact septum: there is no hole in the septum which could allow blood to reach the lungs.

**Pulmonary hypertension:** high pressure of blood moving into the lungs.

**Pulmonary stenosis**: a narrowing between the right ventricle and the lung artery.

**Pulmonary vein stenosis (PVS):** a narrowing of the veins that bring oxygenated blood from the lungs to the left atrium.

**Ross Procedure:** replacing the child's aortic valve with his or her own pulmonary valve.

**RSV**: a virus that causes bronchiolitis.

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**Red blood:** blood which has picked upoxygen from the lungs and travels through the left side of the heart to be pumped around the body.

Respiration rate: breathing rate.

**Sats:** short for saturation levels (of oxygen in the blood).

#### Scimitar Syndrome: the

vein from theright lung connects to the inferior venacava instead of the left ventricle. The vein is shaped like a scimitar sword. Usually the right lung is underdeveloped.

SCBU: special care baby unit.

Septostomy: making a hole in the septum, the wall, between the left andright chambers of the heart. SHO: senior house officer – a grade ofdoctor.

**Shunt**: a natural or artificially created passageway between two parts of theheart.

Simian crease: a single crease as compared to two creases in a normal palm.

**Situs inversus**: a mirror image arrangement of the organs, so that theheart and stomach are on the right andthe liver and spleen on the left.

**Spell**: (particularly with Tetralogy of Fallot) the child becomes bluer,

breathless and limp for a period of time.

Stenosis: Narrowing.

**Stent:** a short, metal mesh tube. Using balloon dilation this is expanded into a narrow artery to hold it open.

Sternum: the breast bone.

Sub: below

Supra: above

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Sub-aortic stenosis: a narrowing below the aortic valve. Supravalvular mitral ring: a narrowing above the mitral valve.

**Supraventricular tachycardia**: SVT. A very fast heart beat.

**Surfactant:** coating that protects the lungs.

**Syndrome:** a collection of characteristics that fall together. There are about 150 syndromes that include a heart defect.

Tachycardia: fast heart beat.

**Taussig-Bing Anomaly** A Double Outlet Right Ventricle with VSD lying under the pulmonary artery.

**TAPVC/D/R** (Total Anomalous Pulmonary Venus Connection /Drainage/Return): the veins bringing red blood from the lungs are abnormally connected.

**Tetralogy of fallot**: four defects found together: a ventricular septal defect, pulmonary stenosis, over-riding aorta and right ventricular hypertrophy.

#### **TCPC:** Total cavo pulmonary

**connection** - a surgical procedure that connects blood returning from the body directly to the pulmonary arteries, bypassing the right side of the heart.

**TOE (Transoesophageal echo):** an echocardiogram that is carried out from inside the oesophagus.

**TPN (Total Parenteral Nutrition):** all the nutrients needed are put directly into a vein.

Trachea: windpipe.

**Tracheotomy**: a hole cut into the windpipe to help breathing.

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#### Transposition of the great

arteries: thebig arteries, which should be taking blue blood from the heart to the lungs, and red blood from the heart to the body, are round the wrong way. This means that deoxygenated blood goes back to the body, and oxygenated blood from the lungs is directed back into the lungs.

**Tricuspid atresia**: the tricuspid valve isabsent.

**Tricuspid valve**: the valve between the right atrium and right ventricle which hasthree cusps.

**Truncus arteriosus**: there is one singleartery arising from the heart which then divides into the lung artery and the bodyartery. There is in addition, a large hole between the two pumping chambers.

**Tube feed**: the baby's feed is given through a tube in the nose directly into the stomach - this is so that breathless babies can get enough food.

**Valvotomy:** cutting the valve, sometimesremoving it altogether.

Ventricles: pumping chambers of the heart - left ventricle pumps blood roundthe body and the right ventricle pumps blood to lungs.

Ventricular Septal Defect (VSD): a hole between the two ventricles - the pumping chambers of the heart.

mouth thatslows the time it takes blood to clot (anticoagulant).

Please contact CHF if you have amendments or changes to suggest so that we can keep our information sheets relevant and up-to-date.

Evidence, and sources of information for this CHF information sheet ran be obtained Africtiute for Health & Care Excellence. Structural Heart Defects Overview Londor. NICE, 2017. Excellence at: https:// pathways.nice.org.uk/pathways/structural-heart-defects

 NHS Choices. Congenital Heart Disease. London: NHS;
2017. Available at:
www.nhs.uk/conditions/congenital-heart-disease/pages/ Introduction.aspx

Warfarin: medicine given by