Congenital heart disease

Introduction

Congenital heart disease is a general term for a range of birth defects that affect the normal workings of the heart.

The term congenital means the condition is present at birth.

Congenital heart disease is one of the most common types of birth defect, affecting up to 9 in every 1,000 babies.

Why it happens

In most cases, no obvious cause of congenital heart disease is identified. However, there are some things known to increase the risk of the condition, including:

Down's syndrome – a genetic disorder that affects a baby's normal physical development and causes learning difficulties

the mother having certain infections, such as rubella, during pregnancy

the mother having poorly controlled type 1 diabetes or type 2 diabetes

More and more cases of congenital heart disease are diagnosed before a baby is born during a routine ultrasound scan, although it's not always possible to detect more complicated heart defects in this way.

Signs and symptoms

The condition can have a number of symptoms, including:

rapid heartbeat

rapid breathing

excessive sweating

extreme tiredness and fatigue

a blue tinge to the skin (cyanosis)

tiredness and rapid breathing when a baby is feeding

These problems are sometimes noticeable soon after birth, although mild defects may not cause any problems until later in life.

Types of congenital heart disease

There are many types of congenital heart disease. Some of the more common defects include:

septal defects – where there is a hole between two of the heart's chambers (commonly referred to as "hole in the heart")

coarctation of the aorta – where the artery called the aorta is narrower than normal

pulmonary valve stenosis – where the pulmonary valve, which controls the flow of blood out of the lower right chamber of the heart to the lungs, is narrower than normal

transposition of the great arteries – where the pulmonary and aortic valves and the arteries they are connected to have swapped positions

Treating congenital heart disease

The treatment for congenital heart disease usually depends on the defect you or your child has.

Mild defects, such as holes in the heart, often don't need to be treated, as they may improve on their own and may not cause any further problems.

If the defect is significant and is causing problems, surgery is usually required. Modern surgical techniques can often restore most or all of the heart's normal function, and nowadays about 80% of children with congenital heart disease will survive into adulthood.

However, people with congenital heart disease often do need treatment over their life and therefore require specialist review during childhood and adulthood.

This is because people with complex heart problems can develop further problems with their heart rhythm or valves over time.

Your baby's screening programme

Everything you need to know about your baby's routine screening, including hearing and eyesight tests, and weight and height checks

Congenital heart disease refers to a range of possible heart defects.

The following defects are described below:

aortic valve stenosis

coarctation of the aorta

Ebstein's anomaly

patent ductus arteriosus

pulmonary valve stenosis

septal defects – including atrial septal defects and ventricle septal defects

single ventricle defects – including tricuspid atresia and hypoplastic left heart syndrome

tetralogy of Fallot

total anomalous pulmonary venous connection

transposition of the great arteries

truncus arteriosus

Aortic valve stenosis

Aortic valve stenosis is an uncommon and serious type of congenital heart defect. It accounts for around 5% of cases of congenital heart disease.

In aortic valve stenosis, the aortic valve that controls the flow of blood out of the main pumping chamber of the heart (the left ventricle) to the body's main artery (the aorta) is narrowed. This affects the flow of oxygen-rich blood away

from the heart towards the rest of the body and means the muscle thickens because the pump has to work harder.

Coarctation of the aorta

Coarctation of the aorta (CoA) is where the main artery (the aorta) has a narrowing, which means that less blood can flow through it.

CoA accounts for around 10% of cases of congenital heart disease. It can occur by itself or in combination with other types of heart defects, most commonly a ventricular septal defect or a type of defect known as a patent ductus arteriosus (see below).

In around half of all cases, the narrowing can be severe and will require treatment shortly after birth.

Ebstein's anomaly

Ebstein's anomaly is where the valve on the right side of the heart (the tricuspid valve), which separates the chambers called the right atrium and right ventricle, does not develop properly. This means blood can flow the wrong way within the heart.

Ebstein's anomaly can occur on its own, but it often occurs along with an atrial septal defect (see below).

It's estimated that Ebstein's anomaly accounts for less than 1% of congenital heart disease cases.

Patent ductus arteriosus

Patent ductus arteriosus (PDA) is a rare type of congenital heart disease, affecting around 5 in every 100,000 babies. It is where a connection between the main body artery and lung artery (the ductus arteriosus) doesn't completely close after birth as it's supposed to.

This means extra blood is pumped into the arteries of the lungs, forcing the heart and lungs to work harder.

Pulmonary valve stenosis

Pulmonary valve stenosis is a defect where the pulmonary valve, which controls the flow of blood out of the right heart pumping chamber (the right ventricle) to the lungs, is narrower than normal. This means the right heart pump has to work harder to push blood through the narrowed valve to get to the lungs.

Pulmonary valve stenosis accounts for around 10% of cases of congenital heart disease.

Septal defects

A septal defect is where there is an abnormality in the wall (septum) between the main chambers of the heart. The two main types of septal defect are outlined below.

Atrial septal defects

An atrial septal defect (ASD) is where there is a hole between the two filling chambers of the heart (the atria). It's a common type of congenital heart defect, affecting about 200 in every 100,000 babies.

When there is an ASD extra blood flows into the right side of the heart, causing it to stretch and enlarge.

Ventricular septal defects

A ventricular septal defect (VSD) is also a common form of congenital heart disease, affecting around 200 in every 100,000 babies. It occurs when there is a hole between the two pumping chambers of the heart (the left and right ventricles).

This means extra blood flow goes to the lungs and the left side of the heart, causing high pressure in the lungs and a stretch on the left-sided pumping chamber. Small holes often close by themselves eventually, but larger holes need to be closed by surgery.

Single ventricle defects

A single ventricle defect is where only one of the pumping chambers (ventricles) develops properly. Some of the more common single ventricle defects are described below.

Hypoplastic left heart syndrome

Hypoplastic left heart syndrome (HLHS) is a rare type of congenital heart disease where the left side of the heart doesn't develop properly and is too small. This means not enough oxygenated blood can get through to the body.

Without treatment HLHS can be fatal within a few weeks of birth, but nowadays complex heart operations can be performed to try to change this.

Tricuspid atresia

Tricuspid atresia is where the tricuspid heart valve has not formed properly. The tricuspid valve separates the filling chamber (atrium) and pumping chamber (ventricle) on the right side of the heart. As there is no blood flow into the right pumping chamber, the pump does not develop and is too small.

It is estimated that 10 babies in every 100,000 are affected by tricuspid atresia.

Tetralogy of Fallot

Tetralogy of Fallot is a combination of several defects, affecting about 30 in every 100,000 babies.

The defects making up tetralogy of Fallot are:

ventricular septal defect – a hole between the left and right ventricle

pulmonary stenosis – narrowing of the pulmonary valve

right ventricular hypertrophy – where the heart muscle is thick

displaced aorta – where the aorta is not in its usual position coming out of the heart

Because of this combination of defects, oxygenated and non-oxygenated blood mixes, causing the overall oxygen in the blood to be lower than normal.

Total anomalous pulmonary venous connection (TAPVC)

Total anomalous pulmonary venous connection (TAPVC) occurs when veins taking oxygenated blood from the lungs to the heart are connected in the wrong place. They connect to the right side of the heart when they should be connected to the left side. Sometimes veins are also narrowed, and the condition can be fatal within a month after birth.

TAPVC is an uncommon type of congenital heart disease, affecting around 7 in every 100,000 babies.

Transposition of the great arteries

Transposition of the great arteries is relatively common, accounting for around 5% of cases of congenital heart disease.

It is where the pulmonary (lung artery) and main body artery (the aorta) are connected to the wrong pumping chamber. This leads to blood low in oxygen being pumped around the body.

Truncus arteriosus

Truncus arteriosus is an uncommon type of congenital heart disease, affecting around 5 in every 100,000 babies.

It is where the development of the two main arteries (the pulmonary and aorta) does not happen properly and remains a single vessel.

This results in too much blood being sent to the lungs which, over time, can cause breathing difficulties and damaged blood vessels inside the lungs.

The condition is usually fatal within a year of birth if not treated.

Symptoms of congenital heart disease

Congenital heart disease can have a range of symptoms, as the condition refers to several different types of heart defect.

General signs of congenital heart disease can include:

excessive sweating

extreme tiredness and fatigue

poor feeding

rapid heartbeat

rapid breathing

shortness of breath

chest pain

a blue tinge to the skin (cyanosis)

clubbed fingernails

In more severe cases, these problems may develop shortly after birth. However, symptoms sometimes don't develop until the teenage years or early adulthood.

Complications

Children and adults with congenital heart disease can also develop a range of further problems, such as:

problems with growth and development

repeated respiratory tract infections (RTIs) – infections of the sinuses, throat, airways or lungs

heart infection (endocarditis)

pulmonary hypertension – raised blood pressure within the blood vessels that supply the lungs (pulmonary arteries)

heart failure – where the heart is unable to pump enough blood around the body at the right pressure

Causes of congenital heart disease

Congenital heart disease is caused when something disrupts the normal development of the heart.

It's thought most cases of congenital heart disease occur when something affects the heart's development during about week five of pregnancy. This is when the heart is developing from a simple tube-like structure into a shape more like a fully developed heart.

While some things are known to increase the risk of congenital heart disease, no obvious cause is identified in most cases.

Increased risk

There are a number of things that can increase the chances of a child having congenital heart disease. Some of these are described below.

See types of congenital heart disease for more information about the different heart defects mentioned below.

Genetic conditions

Several genetic health conditions that a baby inherits from one or both parents can cause congenital heart disease.

Down's syndrome is the most widely known genetic condition that can cause congenital heart disease. Children with Down's syndrome are born with a range of disabilities as the result of a genetic abnormality.

About half of all children with Down's syndrome have congenital heart disease. In 90% of cases, this is a type of septal defect.

Other genetic conditions associated with congenital heart disease include:

Turner syndrome – a genetic condition that only affects females. It is estimated that 25% of children with Turner syndrome will be born with congenital heart disease, which is usually a type of obstruction defect.

Noonan syndrome – a genetic disorder that can cause a wide range of potential symptoms. Around 80% of children with Noonan syndrome will be born with congenital heart disease. In about half of all cases, this will be pulmonary stenosis.

Maternal diabetes

Women with diabetes are five times more likely to give birth to a baby with congenital heart disease than women who do not have diabetes. It is estimated that 3 to 6% of women with diabetes who become pregnant will give birth to a baby with a heart defect, most commonly transposition of the great arteries.

This increased risk only applies to type 1 diabetes and type 2 diabetes. It does not apply to gestational diabetes, which can develop during pregnancy and usually goes away once the baby is born.

The increased risk is thought to be caused by the high levels of the hormone insulin in the blood, which may interfere with the normal development of a foetus.

Alcohol

If a pregnant woman drinks too much alcohol during pregnancy, it can have a poisonous effect on the tissue of the foetus. This is known as foetal alcohol syndrome.

It is estimated that as many as half of all children with foetal alcohol syndrome will have congenital heart disease, most commonly an atrial septal defect.

The Department of Health recommends that pregnant women should not drink alcohol. If you choose to drink, you should not drink more than one or two units of alcohol once or twice a week to minimise the risk to your unborn baby.

See Can I drink alcohol if I'm pregnant? for more information about alcohol and pregnancy.

Rubella

Rubella (German measles) is an infectious condition caused by a virus. Rubella is not usually a serious infection for adults or children. However, it can have a devastating effect on an unborn baby if a mother develops a rubella infection during the first 8 to 10 weeks of pregnancy.

A rubella infection can cause multiple birth defects, including congenital heart disease. All women of childbearing age should be vaccinated against rubella. The vaccine is now given as part of the routine childhood vaccination schedule. Contact your DOCTOR for advice if you're not sure whether you have been vaccinated against rubella.

Flu

Women who get flu during the first trimester (three months) of pregnancy are twice as likely to give birth to a baby with congenital heart disease than the general population. The reasons for this are unclear.

The flu vaccine is recommended for all pregnant women.

Medications

There are several medications linked to an increased risk of a baby being born with congenital heart disease. These include:

certain anti-seizure medications, such as benzodiazepines and lithium

certain acne medications, such as isotretinoin and topical retinoids (see treating acne for more information)

ibuprofen

Women who take the painkiller ibuprofen during the first trimester of their pregnancy are twice as likely to give birth to a baby with congenital heart disease than the general population.

Paracetamol is a safer alternative, although ideally you should avoid taking any medicines while you are pregnant, particularly during the first three months of pregnancy.

See Can I take ibuprofen when I'm pregnant? and Can I take paracetamol during pregnancy? for more information and advice.

Speak to your DOCTOR or pharmacist if you are unsure which medications should be avoided during pregnancy.

Phenylketonuria (PKU)

Phenylketonuria (PKU) is a rare genetic condition present from birth. In PKU the body cannot break down a chemical called phenylalanine, which builds up in the blood and brain. This can cause symptoms such as learning and behavioural difficulties.

PKU can usually be controlled by sticking to a low protein diet. Pregnant mothers with PKU who do not do this are six times more likely to give birth to a baby with congenital heart disease than the general population.

Organic solvents

Women who are exposed to organic solvents are three times more likely to give birth to a baby with congenital heart disease than the general population.

Organic solvents are chemicals found in a wide range of products and substances such as paint, nail polish and glue.

Diagnosing congenital heart disease

In most cases, congenital heart disease is diagnosed during pregnancy. However, a diagnosis may sometimes only be confirmed after the birth.

Diagnosis during pregnancy

Congenital heart disease can be diagnosed during pregnancy with a procedure called foetal echocardiography.

Foetal echocardiography uses an ultrasound scanner to build up a picture of an unborn baby's heart. The procedure should be carried out during routine antenatal examinations, usually some time between week 18 and week 20 of pregnancy.

However, it is not always possible to detect heart defects, particularly mild ones, using foetal echocardiography.

Diagnosis after the birth

It is sometimes possible to diagnose a baby shortly after birth if it has some of the characteristic symptoms of congenital heart disease, such as a blue tinge to the skin (cyanosis).

However, some defects don't cause any noticeable symptoms for several months or even years.

See symptoms of congenital heart disease for more information about things to look out for in yourself or your child.

See your DOCTOR if you or your child shows signs of the condition. Further testing can usually help confirm or disprove a diagnosis.

Further testing

Further tests that may be used to diagnose congenital heart disease are described below.

Echocardiography

Echocardiography is a type of ultrasound scan, which means it uses high frequency sound waves to create an image of the heart.

It may be used to check the inside of the heart. Sometimes, problems with the heart that were missed during foetal echocardiography can be detected as a child develops.

Electrocardiogram

An electrocardiogram is a test that measures the electrical activity of the heart. Electrodes are placed on the skin around the heart and are connected to a

computer. The computer analyses the electrical signals produced by the heart to assess how well it is beating.

Chest X-ray

A chest X-ray of the heart and lungs can be used to check whether there is an excess amount of blood in the lungs or whether the heart is larger than normal. Both may be signs of heart disease.

Pulse oximetry

Pulse oximetry is a test that measures the amount of oxygen present in the blood.

The test involves placing a special sensor on the fingertip, ear or toe that sends out light waves. A computer is connected to the sensor and measures how the light waves are absorbed.

Oxygen can affect how the light waves are absorbed, so by analysing the results the computer can quickly determine how much oxygen is present in the blood.

Cardiac catheterisation

Cardiac catheterisation is a useful way of obtaining more information about exactly how the blood is being pumped through the heart.

During this procedure, a small flexible tube called a catheter is inserted into a blood vessel, usually in the groin or arm. The tube is moved up into the heart, guided by X-rays or MRI scanners.

The end of the tube contains a tiny blood pressure monitor, which can be used to take blood pressure readings in different parts of the heart.

A coloured dye that shows up on X-rays can also be injected into the tube. The dye can be studied as it moves through the heart, enabling medical staff to see how well each chamber of the heart is working.

The procedure is painless, as it is performed under a local anaesthetic.

Coping with a diagnosis

Being told that you or your child has a complex and lifelong condition such as congenital heart disease can be a confusing and frightening experience, even if their condition is relatively mild.

It's natural to want to find out as much as possible about congenital heart disease, including the available treatments, and how it can affect your life.

Below is a list of charities and support groups you may find useful:

The Children's Heart Federation – a charity dedicated to helping people affected by congenital heart disease

The Down's Heart Group – a charity offering support and information on heart conditions associated with Down's syndrome

Healthtalkonline.org – a website with a range of stories about children with different types of congenital heart disease, including interviews with their parents

You may also want to find out what help is available for parents who care for children with complex conditions. Find out more about parent caring.

Treating congenital heart disease

The treatment for congenital heart disease depends on the specific defect your child has.

Mild defects don't usually need to be treated, although it is likely that you will have regular check-ups to monitor your health.

More severe defects usually require surgery and long-term surveillance of the heart throughout adult life by a congenital heart disease specialist.

In some cases, medications may be used to temporarily relieve symptoms or stabilise the condition before surgery.

These may include diuretics to remove fluid from the body and make breathing easier, and digoxin to slow your child's heartbeat and increase the strength at which the heart pumps.

Types of congenital heart disease

Treatment plans for the following types of congenital heart defect are described below:

aortic valve stenosis

coarctation of the aorta

Ebstein's anomaly

patent ductus arteriosus

pulmonary valve stenosis

septal defects – including atrial septal defects and ventricular septal defects

single ventricle defects – including tricuspid atresia and hypoplastic left heart syndrome

tetralogy of Fallot

total anomalous pulmonary venous connection

transposition of the great arteries

truncus arteriosus

See types of congenital heart disease for descriptions of these defects.

Aortic valve stenosis

The urgency for treatment depends on how narrow the valve is. Treatment may be needed immediately, or it could be delayed until your child develops symptoms.

If treatment is required, a procedure called a balloon valvuloplasty is often the recommended treatment option.

During this procedure a small tube (catheter) is passed through the blood vessels to the site of the narrowed valve. A balloon attached to the catheter is inflated, which helps widen the valve and relieve any blockage in blood flow.

If balloon valvuloplasty is ineffective or unsuitable, it is usually necessary to remove and replace the valve using open heart surgery. This is where the surgeon makes a cut in the chest to access the heart.

Replacement valves are usually made from animal or human tissue if used in children. Metal valves are used in adulthood.

Coarctation of the aorta

If your child has the more serious form of coarctation of the aorta that develops shortly after birth, surgery to restore the flow of blood through the aorta is usually recommended.

Several surgical techniques can be used, including:

removing the narrowed section of the aorta and reconnecting the two remaining ends

inserting a catheter into the aorta and widening it with a balloon or metal tube (stent)

removing sections of blood vessels from other parts of your child's body and using them to create a bypass around the site of the blockage (this is similar to a coronary artery bypass graft, which is used to treat heart disease)

If your child develops the less serious form of coarctation of the aorta in later life, the main goal of treatment will be to control their high blood pressure. This will usually involve using a combination of diet, exercise and, in some cases, medication.

Ebstein's anomaly

In many cases, Ebstein's anomaly is mild and does not require treatment. However, surgery to repair the abnormal tricuspid valve is usually recommended if the valve is very leaky.

If valve repair surgery is ineffective or unsuitable, a replacement valve may be implanted. If Ebstein's anomaly occurs along with an atrial septal defect (see below), the hole will be closed at the same time.

Patent ductus arteriosus

Many cases of patent ductus arteriosus (PDA) can be treated with medication shortly after birth.

Two types of medication have been shown to effectively stimulate the closure of the duct that is responsible for PDA. These are indomethacin and a special form of ibuprofen.

If PDA does not close with medication, the duct may be sealed with a coil or plug, which is implanted using a catheter.

Pulmonary valve stenosis

Mild pulmonary valve stenosis does not require treatment as it does not cause any symptoms or problems.

More severe cases of pulmonary valve stenosis usually require treatment, even if they cause few or no symptoms. This is because there is a high risk of heart failure in later life if it's not treated.

As with aortic valve stenosis, the main treatment for pulmonary valve stenosis is a balloon pulmonary valvuloplasty. However, if this is ineffective or the valve is not suitable for this treatment, surgery may be needed to open the valve (valvotomy).

Septal defects

The treatment of ventricular and atrial septal defects depends very much on the size of the hole. No treatment will be required if your child has a small septal defect that does not cause any symptoms or stretch on the heart. These types of septal defects have an excellent outcome and do not pose a threat to your child's health.

If your child has a larger ventricular septal defect, surgery is usually recommended to close the hole.

If there is a large atrial septal defect, this can be closed with an umbrella device inserted with a catheter. If the defect is too big or not suitable for the umbrella, surgery may be needed to close the hole.

Unlike open heart surgery, the catheter procedure does not cause any scarring and is associated with just a small bruise in the groin. Recovery is very quick. This procedure is undertaken in specialist units that treat congenital heart problems in children and adults.

Single ventricle defects

Tricuspid atresia and hypoplastic left heart syndrome are treated in much the same way.

Shortly after birth, your baby will be given an injection of medication called prostaglandin. This will encourage the mixing of oxygen-rich blood with oxygen-poor blood. The condition will then need to be treated using a three-stage procedure.

The first stage is usually performed during the first few days of life. An artificial passage known as a shunt is created between the heart and lungs so blood can enter the lungs. However, not all babies will need a shunt.

The second stage will be performed when your child is four to six months old. The surgeon will connect veins that carry oxygen-poor blood from the upper part of the body directly to your child's pulmonary valve. This will allow blood to be pumped into the lungs, where it can be filled with oxygen.

The final stage is usually performed when your child is 18 to 36 months old. It involves connecting the remaining veins to the pulmonary valve.

An effective alternative to this three-stage procedure is to carry out a heart transplant, where a healthy heart is taken from a donor and surgically implanted into your baby. However, heart transplant surgery is rarely carried out in these circumstances because of a shortage of donated hearts suitable for young babies.

Tetralogy of Fallot

Tetralogy of Fallot is treated using surgery. If your baby is born with severe symptoms, surgery may be recommended soon after birth.

If the symptoms are less severe, surgery will usually be carried out when your child is three to six months old.

During the operation, the surgeon will close the hole in the heart and open up the narrowing in the pulmonary valve.

Total anomalous pulmonary venous connection

Total anomalous pulmonary venous connection (TAPVC) is treated with surgery. During the procedure, the surgeon will reconnect the abnormally positioned veins into the right position in the left atrium.

The timing of surgery will usually depend on whether your child's pulmonary vein (the vein that connects the lungs and heart) is also obstructed.

If the pulmonary vein is obstructed, surgery will be performed after birth. If the vein is not obstructed, surgery can often be postponed until your child is a few weeks or months old.

Transposition of the great arteries

As with treatment for single ventricle defects, your baby will be given an injection of medication called prostaglandin shortly after birth. This will prevent the passage between the aortic and pulmonary valve (the ductus arteriosus) closing after birth.

Keeping the ductus arteriosus open means that oxygen-rich blood is able to mix with oxygen-poor blood, which should help relieve your baby's symptoms.

In some cases, it may also be necessary to use a catheter to create a temporary hole in the atrial septum (the wall that separates the two upper chambers of the heart) to further encourage the mixing of blood.

Once your baby's health has stabilised, it is likely surgery will be recommended. This should ideally be carried out during the first month of the baby's life. A surgical technique called arterial switch is used. This involves detaching the arteries and reattaching them in the correct position.

Truncus arteriosus

Once your baby is in a stable condition, surgery is used to treat truncus arteriosus. This is usually carried out within a few weeks after birth.

The abnormal blood vessel will be split in two to create two new blood vessels, and each one will be reconnected in the correct position.

Complications of congenital heart disease

Children and adults with congenital heart disease are at an increased risk of developing further problems.

Problems with development

Many children with congenital heart disease experience delays in their development. For example, they may take longer to start walking or talking. They may also have lifelong problems with physical co-ordination.

Some children with congenital heart disease also have learning difficulties. These are thought to be caused by a poor oxygen supply during early life, which affects the development of the brain.

Natural intelligence is usually unaffected, but some children often perform well below the academic level they would be expected to reach.

This is because of problems such as:

impaired memory

problems expressing themselves using language

problems understanding the language of others

low attention span and difficulty concentrating

poor planning abilities

poor impulse control – acting rashly without thinking about the possible consequences

Recent research has found that children who have had surgery for transposition of the great arteries have significant problems understanding a concept known as theory of mind (TOM).

TOM is the ability to understand other people's mental state and recognise that they may differ from your own. In other words, to recognise that everyone has their own set of desires, intentions, beliefs, emotions, perspective, likes and dislikes. In simple terms, TOM is the ability to see the world through another person's eyes.

An inability to recognise other people's mental states can lead to problems with social interaction and behaviour in later life.

Respiratory tract infections

The risk of developing respiratory tract infections (RTIs) is higher in people with congenital heart disease. RTIs are infections of the lungs and airways, such as pneumonia.

Symptoms of an RTI can include:

a cough, which can be severe and bring up phlegm and mucus

wheezing

rapid breathing

chest tightness

Treatment for an RTI depends on the cause. For example, infections caused by bacteria can be treated with antibiotics.

Endocarditis

People with congenital heart disease also have an increased risk of developing endocarditis. This is an infection of the lining of the heart and valves, or both. If it's not treated, it can cause life-threatening damage to the heart.

Symptoms of endocarditis can include:

a high temperature (fever) of 38ºC (100.4ºF) or above

chills

loss of appetite

headache

muscle and joint pain

night sweats

shortness of breath

persistent cough

Endocarditis will need to be treated in hospital with injections of antibiotics.

The condition usually develops when an infection in another part of the body, such as on the skin or the gums, spreads through the blood into the heart.

As gum disease can potentially lead to endocarditis, it is very important to maintain excellent oral hygiene if you have congenital heart disease.

It is also usually recommended not to have any cosmetic procedure that involves piercing the skin, such as tattoos or body piercings.

Pulmonary hypertension

Some types of congenital heart disease can cause the blood pressure inside the arteries that connect the heart and lungs to be much higher than it should be. This is known as pulmonary hypertension.

Symptoms of pulmonary hypertension can include:

shortness of breath

extreme tiredness

dizziness

feeling faint

chest pain

a rapid heartbeat

A range of medications can be used to treat pulmonary hypertension. Read more about treating pulmonary hypertension.

Heart rhythm problems

It's relatively common for adults with a history of some types of congenital heart disease to develop an abnormal heartbeat. This is often a type of heart rhythm problem called atrial fibrillation or flutter.

With both of these heart rhythm problems, the heart may beat at more than 140 beats a minute. At rest, a normal heart rate is between 60 and 100 beats a minute.

Several treatment options are available for atrial fibrillation, including medications, surgery and an implanted device called a pacemaker.

Heart failure

Heart failure is where the heart cannot pump enough blood around the body to meet the body's needs. It can occur shortly after a baby with a severe congenital heart defect is born, or when a previously mild and untreated type of congenital heart disease gets worse in later life.

Symptoms of heart failure can include:

breathlessness when you're active or sometimes resting

extreme tiredness and weakness

swelling in the abdomen (tummy), legs, ankles and feet

Treatments for heart failure can include medication and the use of an implanted device such as a pacemaker.

Blood clots

Having a history of congenital heart disease can also increase the risk of a blood clot forming inside the heart and travelling up to the lungs or brain. This can lead to a:

pulmonary embolism – where the blood supply to the lungs is blocked

stroke – where the blood supply to the brain is blocked

Medications are often used to prevent, dissolve or remove blood clots.

Sudden cardiac death

There is a small but significant risk of people with a history of congenital heart disease experiencing a sudden cardiac death. It's estimated that 1 in every 1,000 adults with congenital heart disease will die suddenly in this way every year.

Identifying people at risk of sudden death is difficult. Some heart rhythm problems are known to have a high risk of this event. In these cases, a device called an implantable cardioverter defibrillator will be inserted. This is similar to a pacemaker and can deliver a pulse of electricity when required, which should stop your heart going into spasm.

However, many people have a sudden cardiac death without a rhythm problem being identified, so it is a concern for most people with congenital heart disease.

Preventing congenital heart disease

As so little is known about the causes of congenital heart disease, there is no guaranteed way of avoiding having a baby with the condition.

However, if you are pregnant, the following advice can help to reduce the risk:

ensure you are vaccinated against rubella and flu

avoid drinking alcohol or taking drugs

take 400 micrograms of folic acid supplement a day during the first trimester (first 12 weeks) of your pregnancy – this lowers your risk of giving birth to a child with congenital heart disease, as well as several other types of birth defect

check with your DOCTOR or pharmacist before you take any medication during pregnancy, including herbal remedies and medication that is available over the counter

avoid contact with people who are known to have an infection

if you have diabetes, make sure the condition is controlled

avoid exposure to organic solvents, such as those used in dry cleaning, paint thinners and nail polish remover

See vitamins and nutrition in pregnancy, infections in pregnancy and your antenatal care for more information and advice.