CONDITION

Cyanotic heart disease

Cyanotic heart disease describes heart conditions that leave the blood carrying too little oxygen.

WHAT IT IS
Heart conditions causing too little oxygen in circulating blood

BODY SYSTEM
Heart and circulation

MAIN SYMPTOMS
Blue-grey lips or skin, breathlessness, tiredness, poor feeding

WHAT CAUSES IT
Congenital heart differences, sometimes later circulation changes

HOW IT IS DIAGNOSED
Echocardiogram, with catheterization or MRI when needed

MAIN TREATMENT
Heart procedures, surgery, medicines, and lifelong follow-up

CAN IT BE CURED?
Sometimes - repair improves flow; monitoring often continues

IS IT AN EMERGENCY?
Sometimes - sudden deeper blueness, breathing trouble, or collapse

LONG-TERM OUTLOOK
Often good after repair, but lifelong specialist follow-up remains

Overview

Cyanotic heart disease is a general term for heart conditions that cause too little oxygen to reach the body. It is usually related to a heart difference present from birth, called a congenital heart defect.

These conditions may allow oxygen-poor blood to bypass the lungs or mix with oxygen-rich blood. Some reduce blood flow to the lungs. This can give the lips, tongue, skin, or nail beds a blue-grey colour, known as cyanosis.

Examples include tetralogy of Fallot, transposition of the great arteries, pulmonary atresia, tricuspid atresia, and some forms of single-ventricle heart disease. Cyanosis can also develop later if severe high blood pressure in the lung arteries reverses blood flow through a previously non-cyanotic defect. This is called Eisenmenger syndrome.

Some babies become seriously unwell soon after birth, while milder or occasional cyanosis may not be recognized until later. Modern procedures and surgery allow many people to live well into adulthood, although ongoing specialist care is usually needed.

Blue or grey skin does not always mean a heart condition. Cold temperatures, lung conditions, circulation problems, and other medical issues can also change skin colour.

Symptoms

Cyanosis may appear on the lips, tongue, inside of the mouth, or nail beds. On darker skin, it may look grey, pale, or ashen rather than blue. Changes inside the mouth may be easier to see.

A baby with a cyanotic heart condition may have:

Older children and adults may have breathlessness, tiredness, limited stamina, dizziness, fainting, chest discomfort, or a racing or irregular heartbeat.

Some children with tetralogy of Fallot have sudden episodes of deeper cyanosis, rapid breathing, distress, or limpness. These are called cyanotic spells or "tet spells." Older children may instinctively squat because this can temporarily improve blood flow to the lungs.

Long-term low oxygen can cause clubbing, in which the ends of the fingers or toes broaden and the nails curve. The body may also make extra red blood cells to carry oxygen.

Symptoms cannot show which heart condition is present or how severe it is.

- Blue-grey lips, tongue, or skin
- Fast or difficult breathing
- Poor feeding or tiring during feeds
- Sweating, sleepiness, or poor weight gain

Causes and risk factors

Most cyanotic heart conditions result from differences in how the heart, valves, or major blood vessels developed before birth. The exact cause is often unknown.

Some are linked to genetic or chromosome changes, although many affected babies have no known genetic condition or family history.

Factors associated with congenital heart defects include certain infections during pregnancy, poorly controlled diabetes, exposure to some medicines or substances, and having a close relative with a congenital heart defect. A risk factor does not mean that a parent caused the

condition.

Cyanosis can develop later if an unrepaired connection in the heart or major blood vessels leads to very high pressure in the lung arteries. Blood flow may then reverse, carrying oxygen-poor blood into the body and causing Eisenmenger syndrome.

Diagnosis

Severe conditions are often detected during pregnancy or soon after birth. A pregnancy ultrasound may show a possible heart difference, and a fetal echocardiogram can examine the baby's heart in more detail.

After birth, pulse oximetry measures oxygen using a sensor on the hand or foot. Newborn screening identifies some critical congenital heart defects before symptoms appear, but it does not detect every condition.

An echocardiogram is the main test used to examine heart structure and blood flow. It uses sound waves and does not involve radiation.

Other tests may include:

During catheterization, a thin tube is passed through a blood vessel to the heart. Treatment can sometimes be performed during the same procedure.

- An electrocardiogram, or ECG, to record electrical activity
- A chest X-ray to examine heart size and the lungs
- Blood tests to check red blood cells, iron, and organ function
- Cardiac MRI or CT for detailed images
- Cardiac catheterization to measure pressures and oxygen levels

Treatment and management

Treatment depends on the heart structure, oxygen level, symptoms, age, and overall health. Care is usually coordinated by a congenital heart specialist.

A critically unwell newborn may need breathing support and medicines to stabilize circulation. Some receive medicine that temporarily keeps the ductus arteriosus, a fetal blood vessel, open until a procedure or operation is possible.

Catheter procedures can open a narrowed valve or blood vessel, enlarge a connection, or place a stent. Surgery may repair the heart or redirect blood flow. Some people need one operation;

those with complex or single-ventricle hearts may need several staged operations. When full repair is not possible, surgery may improve oxygen levels and reduce strain.

Medicines may manage fluid build-up, abnormal rhythms, blood clots, or high pressure in the lung arteries. Oxygen helps in some situations but may have limited benefit if blood is bypassing the lungs.

Follow-up may include oxygen measurements, blood tests, imaging, exercise testing, and rhythm monitoring. People with persistent cyanosis need assessment of iron levels. Extra red blood cells are often a normal response to low oxygen and should not automatically be treated by removing blood.

Good dental care matters because mouth bacteria can sometimes infect the heart lining or valves. Antibiotics like amoxicillin or doxycycline before dental work are recommended only for certain high-risk conditions and procedures.

Complications

Complication risks depend on the defect, previous operations, oxygen level, and pressure in the lungs.

Long-term low oxygen may cause excess red blood cells, headaches, dizziness, fatigue, or problems concentrating. Dehydration and iron deficiency can make these symptoms worse.

Other possible complications include:

Brain abscess, a pocket of infection in the brain, is uncommon but serious. A new severe headache, fever, seizure, weakness, or confusion needs urgent assessment.

Previous surgery does not remove every future risk. Valves, artificial materials, and rerouted circulation can develop problems many years after treatment.

- Abnormal heart rhythms
- Heart failure
- High blood pressure in the lung arteries
- Blood clots or stroke
- Infection of the heart lining or valves
- Delayed growth or development
- Kidney, liver, or other organ problems

Prevention

Most congenital heart differences cannot be reliably prevented and are not caused by something a parent knowingly did.

Before and during pregnancy, controlling diabetes, avoiding smoking and alcohol, and reviewing medicines with a healthcare professional can reduce some risks. Rubella vaccination before pregnancy can prevent an infection that may damage a developing baby's heart.

Do not stop prescribed medicine because of pregnancy without medical advice. Stopping treatment can also carry risks.

If you or a close relative has a congenital heart defect or known genetic condition, genetic counselling can explain inheritance and testing options, although it cannot predict or prevent every condition.

For people with cyanotic heart disease, regular follow-up, dental care, prescribed treatment, vaccinations, and early attention to infections or changing symptoms can help prevent complications.

Living with it and what to expect

The long-term course varies. Some children have a successful repair and grow with few limits. Others continue to have low oxygen or need further procedures, surgery, medicines, or rhythm treatment.

Growth, feeding, learning, and physical development may need extra support. Many children attend regular school and take part in suitable activities. Exercise advice should reflect the specific condition and recent test results.

Adults who had childhood surgery still need lifelong congenital heart care. Surgery may improve circulation without making the heart anatomically normal. Valve problems, rhythm changes, or reduced heart function can appear decades later, even without symptoms.

Routine appointments allow the care team to compare oxygen levels, heart function, exercise ability, and blood results over time. Missing follow-up for several years can allow gradual changes to go unnoticed.

People with persistent cyanosis may have reduced energy and exercise tolerance. Staying hydrated is important, particularly during illness or hot weather. Advice about flying, high altitude, work, competitive sport, and anaesthesia should be tailored to the person's circulation.

Pregnancy increases strain on the heart. Some people with repaired conditions can have a

successful pregnancy with specialist planning. Pregnancy may be high risk or unsafe with severe cyanosis, poor heart function, or Eisenmenger syndrome. Assessment by an adult congenital heart and high-risk pregnancy team should happen before pregnancy when possible.

When to get medical help

Arrange routine review for a gradual decline in exercise ability, increasing tiredness, new swelling, more frequent palpitations, poor growth, feeding difficulties, or a change from the usual cyanosis.

Contact the congenital heart team promptly if oxygen readings are repeatedly below the person's usual range, even if they seem comfortable. Some complex circulations have lower expected levels, so comparison with the established baseline matters.

Seek urgent medical help for:

Call emergency services for severe breathing difficulty, collapse, a seizure, sudden weakness on one side, inability to wake, or a cyanotic spell that does not quickly settle. A newborn or child who suddenly becomes deeply blue, limp, or unresponsive also needs emergency care.

- New or clearly worsening blue-grey colour
- Breathing that is harder or faster than usual
- A sustained racing or irregular heartbeat
- New chest pain, severe headache, fever, or marked weakness
- A baby who cannot feed, is unusually sleepy, or has fewer wet nappies

Common questions

Is cyanotic heart disease the same as congenital heart disease?

No. Congenital heart disease includes all structural heart differences present from birth. Only some cause low blood oxygen and cyanosis.

Can cyanotic heart disease be cured?

Some defects can be fully repaired. Complex conditions may be improved rather than completely corrected. Lifelong heart follow-up is often needed after surgery.

Why are the lips or fingers blue?

The colour appears when circulating blood contains less oxygen than usual. It may be most

noticeable in the lips, tongue, mouth, or nail beds.

Can someone with cyanotic heart disease exercise?

Many people can remain active, but safe intensity differs between conditions. A congenital heart specialist can recommend suitable activities using symptoms and test results.

Does every baby with a critical heart defect look blue?

No. Cyanosis may be subtle, and some critical defects do not cause visible blueness. Newborn examination and pulse-oximetry screening are therefore important.

Will my child need more surgery later?

Some repaired defects need no further surgery for many years. Others require staged operations or later treatment for valves, blood vessels, or abnormal rhythms. Regular imaging helps identify when another procedure may be useful.

Sources

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