

## Information for patients, parents or carers

# Brugada Syndrome

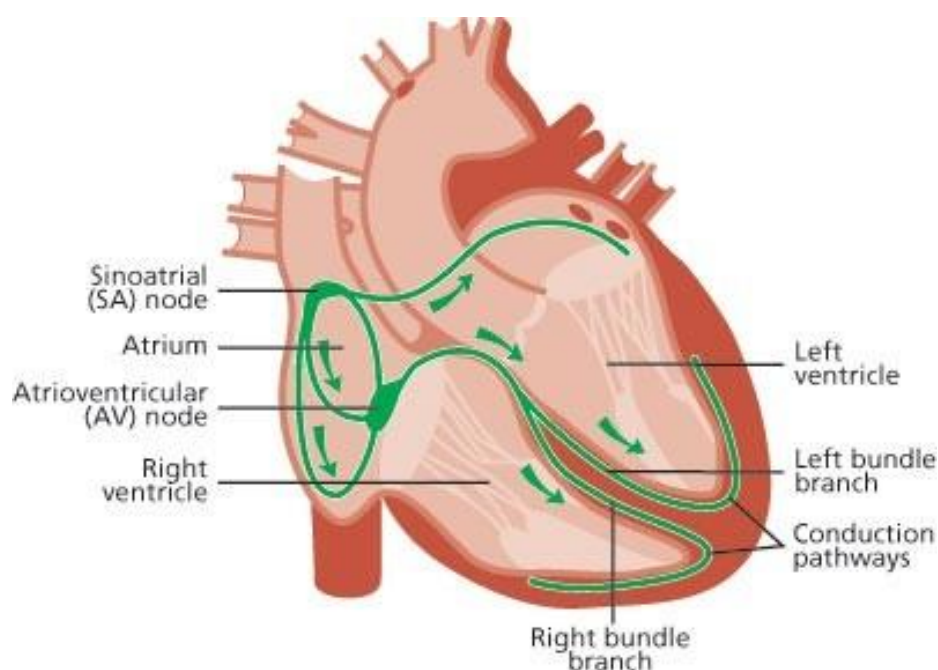
## Introduction

Brugada syndrome is an Inherited Cardiac Condition (ICC), which means that it was passed down in the genes from a person's parents. People with this condition have differences in the structure of their heart muscle cells when compared to other people, which affect the way that electrical messages travel through their heart. This information sheet explains the condition, what causes it and where to get help.

## The normal heart

The heart is a special kind of muscle which acts as a pump to keep blood moving. The pumping action of the heart muscle is triggered by electrical messages which travel through the walls of the heart, causing them to squeeze the blood out and around the body.

Each electrical message starts at the sinoatrial (SA) node in the heart. It travels through the walls of the top sections of the heart (the left and right atria), causing them to squeeze blood downwards into the bottom sections of the heart (the left and right ventricles). As the message travels through the bottom sections, it causes them to squeeze and pump blood out of the heart.



## **What is Brugada Syndrome?**

This condition can put affected individuals at an increased risk of developing an abnormal heart rhythm, known as an arrhythmia.

This means that the electrical messages passing through the ventricles may become dangerously fast (ventricular tachycardia) or may become disorganised and lose their usual pattern (ventricular fibrillation). These arrhythmias can stop the heart pumping properly. If left untreated, these arrhythmias can cause loss of consciousness and may even be fatal.

## **Signs and symptoms**

People with Brugada syndrome do not always show symptoms so it can remain undiagnosed, or it may be found accidentally when they see a doctor or nurse about another condition.

Some people may be sent for cardiac screening after a close relative is diagnosed with Brugada syndrome. If someone does have symptoms, they are likely to include fainting spells (syncope) or a feeling of fluttering in your chest (heart palpitations).

Unfortunately, in some cases, Brugada syndrome may cause sudden death in undiagnosed individuals. It is important that the condition is found early so that doctors can identify and treat those patients who have a higher risk of developing dangerous heart rhythms.

Patients with a diagnosis of Brugada syndrome should have an appointment with a specialist cardiologist, who can work out whether or not treatment is needed.

## **How is Brugada syndrome diagnosed?**

An electrocardiogram (ECG) is one of the main tests for Brugada syndrome. It measures electrical activity within the heart through sticky sensor pads put on your child's chest. Some people with Brugada syndrome have a very typical pattern on their ECG at rest, and this is enough to make a diagnosis. In other individuals, an ECG may not show the typical abnormalities, and a different test called an ajmaline provocation test might be suggested.

This test uses a medicine called ajmaline (which is introduced via a drip in the patient's arm) to provoke the typical ECG changes. In patients who do not have Brugada syndrome, ajmaline will not have any significant effect on the ECG. The ajmaline test is widely used by specialist cardiologists around the world to help diagnose Brugada syndrome in teenagers and adults. It is a very safe test and complications are rare. Common and mild side effects generally only last for a few minutes these include a metallic taste in the mouth, a warm flush, tingling sensation on the skin, a sensation of needing to pass urine, nausea, headaches or dizziness and blurred visions. Very rarely (less than 0.1% to 1% of cases) ajmaline can cause a very fast and potentially life-threatening heart rhythm. If this occurs a doctor or nurse will quickly correct this abnormal rhythm with medication or if required a shock to the heart (with a defibrillator or cardioversion).

## **Treatment**

Although Brugada syndrome can be dangerous for some, most people with this condition will not need any treatment and have a low risk of developing abnormal and dangerous heart rhythms. However, there are some important things that can be done to help reduce this further.

Medicines can sometimes increase the risk of abnormal heart rhythms in people who have Brugada syndrome. Cardiologists will therefore advise patients to avoid these drugs. A family doctor (GP) should be made aware that there are certain medications that should not be prescribed for

patients with Brugada syndrome. A regularly updated list of these medicines can be found at <https://www.brugadadrugs.org/>. Alternative medications are widely available, so health problems can still be treated.

A high temperature or fever can cause ECG changes in patients with Brugada syndrome. Therefore, affected individuals are advised to control fevers very carefully by taking regular paracetamol and ibuprofen. If this does not work, people with Brugada syndrome should go to their local hospital to have an ECG to make sure they are safe.

In people with cardiac symptoms and when the doctor thinks they have a higher risk of a dangerous heart rhythm, treatment with a device called an implantable cardioverter-defibrillator (ICD) may be recommended. An ICD is a small generator about the size of a matchbox, connected to some thin wires, that are all put inside the body while the patient is asleep under a general anaesthetic. The ends of the wires sit inside the heart and monitor the heart rhythm constantly. If the ICD detects a dangerous heart rhythm, it can automatically deliver a pulse of electricity to 'reset' the heart. The vast majority of patients with Brugada syndrome do not require an ICD.

Children and young people diagnosed with Brugada syndrome will need regular life-long monitoring. As Brugada syndrome is an inherited condition, immediate family members of any affected individual will require clinical screening at a specialist cardiology centre.

It is not always possible to use genetic testing to diagnose Brugada syndrome, because we do not know all the genes that can cause the condition. Clinical screening with ECGs and ajmaline testing is the recommended means of diagnosis.

If your child is diagnosed with Brugada you will receive an Emergency Health Care Plan (EHCP), this is an official document that gives information about their condition, events that might occur and how healthcare professionals should act to ensure the best possible outcomes for your child. You will be given a written copy and sent an electronic version to handover/show to healthcare professionals. For further information please contact your child's Specialist Cardiac Rhythm Nurse.

## **For further information**

### **Contact details**

Paediatric Rhythm and ICC Nurse Specialist: 0191 213 9633

Children's Cardiac Nurse Specialist: 0191 213 7344 Email address: [nuth.ccns@nhs.net](mailto:nuth.ccns@nhs.net)

The cardiac nurse specialists are around 09.00am to 5.00pm Monday to Friday. If there is no answer please leave a voicemail, and they will endeavour to return your call within 24 hours. If urgent, please contact ward 23, Freeman Hospital for advice.

Ward 23 Freeman Hospital: 0191 2137023 (24 hours)

PALS (Patient Advice and Liaison Service) for help, advice and information about NHS services. You can contact them on freephone 0800 032 02 02, email [pals@nhct.nhs.uk](mailto:pals@nhct.nhs.uk).

<https://www.northumbria.nhs.uk/patients-and-visitors/share-your-feedback/patient-and-advice-liaison-service-pals#9882d87e>

## Useful websites

Brugada Drugs website contains up to date information on drugs that individuals diagnosed with Brugada should avoid. Visit their website at [www.brugadadrugs.org](http://www.brugadadrugs.org)

The Arrhythmia Alliance supports anyone affected by a heart rhythm problem. Visit their website at [www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk)

CRY (Cardiac Risk in the Young) is another organisation offering advice and support to families of children with heart problems. Visit their website at [www.c-r-y.org.uk](http://www.c-r-y.org.uk)

SADS UK offers support and advice about heart conditions that can lead to sudden unexpected death. Visit their website at [www.sadsuk.org](http://www.sadsuk.org)

The British Heart Foundation is the main organisation in the UK offering advice and support to anyone affected by heart disease. Visit their website at [www.bhf.org.uk](http://www.bhf.org.uk)

If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS website at [www.nhs.uk](http://www.nhs.uk)

If you would like to find accessibility information for our hospitals, please visit [www.accessable.co.uk](http://www.accessable.co.uk)

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