

## Information for patients, parents or carers

# Long QT Syndrome (LQTS)

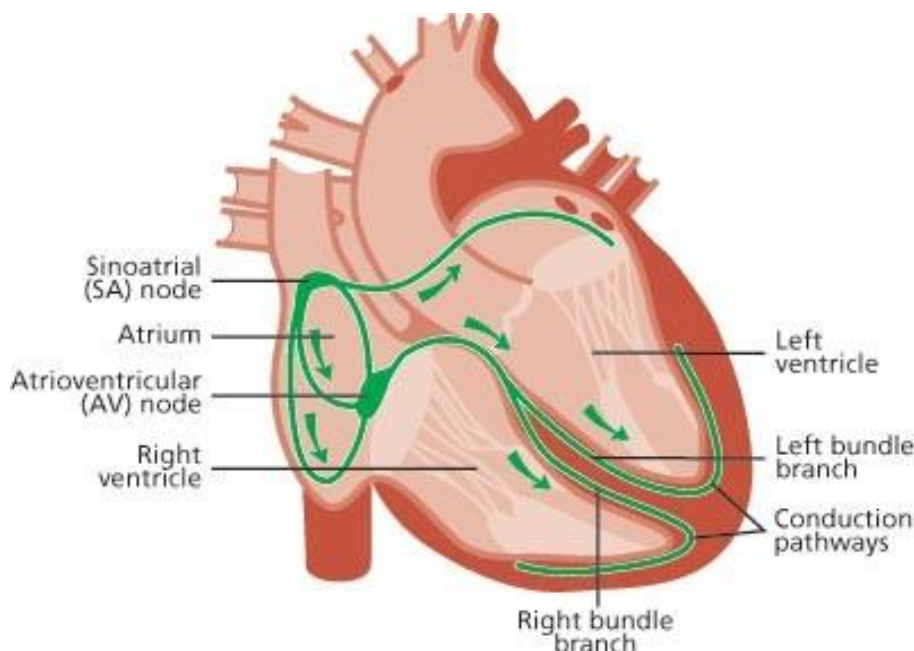
## Introduction

LQTS is a disturbance of the heart's electrical system, causing an abnormality of the heartbeat, or rhythm of the heart in apparently healthy people. This information leaflet is designed for patients, parents or carers and to give information on Long QT, diagnosis and management plan.

## 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 LQTS

Ions are charged atoms which allow electrical signals to flow in and out of cells through special channels and help your body function normally. LQTS is a disease caused by your ion channels not working properly. There are different kinds of ions, including potassium and sodium, which are important for keeping the electrical system of your heart working properly.

The electrical system controls your heart by telling it when to squeeze and relax to pump blood. Between each heartbeat, the electrical system recharges. If you have LQTS, your heart takes longer than usual to recharge between beats.

This is because the channels are not letting the ions in or out of your cells well enough, which causes a delay. When seen on an ECG test (which records the electrical activity of your heart), this delay is called a prolonged QT interval.

## Signs and symptoms

The symptoms of LQTS vary from person to person. They can depend on the type of LQTS you have, your age and gender. Many people don't have any symptoms at all, but they can include:

- Blackouts
- Palpitations
- Seizures (caused by a reduced amount of oxygen getting to the brain because of abnormal heart rhythms).

## What causes LQTS?

LQTS is usually caused by a faulty gene inherited from your parents. Genes decide how the body works and what parts of you are like, such as eye colour or hair type. If you have the condition from birth, it's called congenital LQTS.

LQTS is sometimes caused by certain medications you're taking for other conditions. This is called acquired or drug-induced LQTS. Medications may include certain types of:

- Antibiotics
- Antihistamines
- Antidepressants
- Antipsychotics
- Anti-arrhythmic medicines

Diuretics Please discuss any new medication with the team looking after you.

## What are the risks of LQTS

If you have LQTS, you're at risk of having an abnormal heart rhythm. This can be triggered by:

- A slow heart rate during sleep
- A sudden noise or something that startles you
- Strenuous exercise (particularly swimming)
- Stress
- Certain medications

The abnormal heart rhythms you are at risk of having are:

- Torsades de pointes (a dangerously fast heart rate)
- Ventricular fibrillation (when the bottom chambers of your heart quiver instead of beat).

Your abnormal heart rhythm may return to normal but if it doesn't you're at risk of sudden cardiac arrest (when your heart stops pumping).

The causes and symptoms of LQTS depend on each person.

## **Diagnosing LQTS**

There are a few ways in which your consultant will find out if you have LQTS. They include:

- Discussion – because LQTS can be inherited, your consultant will ask questions about your family history. They may also ask you about any medications you have been taking.
- ECG - to monitor the electrical activity of your heart. This is the main way that LQTS is checked. You may be given a 24-hour Electrocardiograph (ECG) monitor to look at your heart for a longer period.
- Exercise ECG – sometimes LQTS doesn't show up on a standard ECG, so the test needs to be done more than once and in different ways like when you're exercising.

As LQTS is sometimes inherited, you may also be referred for genetic testing to screen for any faulty genes that are linked with the condition. Your immediate family members (such as your parents, siblings and your children) may also be invited for an assessment.

## **Treatment for LQTS**

If you have LQTS, you could be given medications like beta blockers to treat it. Beta blockers, such as propranolol or nadolol, help control irregular heartbeats and slow your heart rate to make arrhythmia's less likely.

If you are at risk of a life-threatening arrhythmia and you need more than just medication to manage this risk, you may need a pacemaker or Implantable Cardioverter Defibrillator (ICD) fitted. These are fitted to help control the rhythm and rate of your heart or help correct life-threatening heart rhythms.

Some people may need surgery to remove certain nerves that affect the heart to help reduce the chance of a sudden cardiac arrest. This is usually only for people who cannot take medication.

It is also important to treat any prolonged period of diarrhoea and vomiting as this can cause dehydration and the loss of potassium and sodium, which can increase the risk of arrhythmias. Re-hydration sachets contain a good balance of minerals as well as fluid to replace any losses. If this period of sickness continues, seek immediate medical advice. You may need to visit your local accident and emergency centre for rehydration, blood tests and an ECG.

When your child is diagnosed with LQTS you will receive a documentation called 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 give to healthcare professionals if you need medical care. 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**

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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