

# Long QT syndrome



Promoting better understanding, diagnosis, treatment and quality of life for those affected by heart rhythm disorders (cardiac arrhythmias)

# Glossary

**Arrhythmia** Heart rhythm disorder

**Cardiologist** A doctor who has specialised in the diagnosis and treatment of patients with a heart condition

**Electrocardiogram (ECG)** A 12 lead recording of the activity of the heart

**Implantable Cardioverter Defibrillator (ICD)**  
A small device containing a battery connected to your heart for monitoring and treating your heart rhythm

**Pacemaker** A small metal device implanted under the skin, which produces electrical impulses to treat an abnormal heart rhythm

**Syncope** A blackout/faint often due to a sudden lack of blood supply to the brain

## Important information

This booklet is intended for use by people who wish to understand more about Long QT syndrome. The information within this booklet comes from research and previous patients experiences. This booklet offers an explanation of the Long QT condition.

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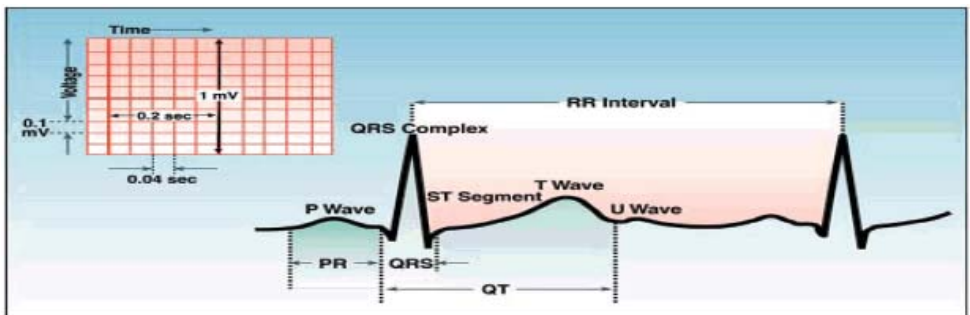
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# What is Long QT syndrome?

Long QT is a syndrome which can cause a disturbance in the electrical system of the heart, while the mechanical function of the heart can remain completely normal. It may result in a very fast abnormal heart rhythm (arrhythmia) known as "Torsade de Pointes". When this rhythm occurs, no blood is pumped out from the heart and the brain quickly becomes deprived of oxygen, potentially resulting in a loss of consciousness (syncope) and rarely, sudden death.

Arrhythmia in patients with Long QT syndrome (LQTS) may be triggered by exercise or stressful situations. Not everyone who has Long QT syndrome will have an arrhythmia, but if it does occur it can be fatal.



## What is the QT interval?

Every time the heart beats, it is due to an electrical impulse that spreads across the heart muscle causing it to contract. The QT interval is measured on the 12 lead surface Electrocardiogram (ECG) which is a recording of the electrical activity of the heart. The QT interval is the time taken for the heart to fire off and recover electrically. A long QT interval is an abnormally prolonged interval between two distinct points of the ECG.

## What are the symptoms?

People with Long QT syndrome may start to experience symptoms in childhood, although this is not always the case. Symptoms include:

- Sudden, unexplained fainting, particularly when in response to a stressful situation. This can often be misdiagnosed as having a 'hysterical reaction'.
- Unexplained seizures. A sudden loss of consciousness may be mistaken or misdiagnosed as an epileptic seizure.
- Sudden cardiac arrest or death in the absence of any structural heart disease or other cardiac problems. Approximately 1 in 10 sudden cardiac arrests or death are the first sign of Long QT Syndrome.

## What causes Long QT syndrome?

Long QT syndrome can be inherited or acquired. Acquired Long QT syndrome is usually due to the administration of certain medications. Inherited Long QT syndrome is caused by mutations of certain genes and can be passed onto family members. The frequency of inherited Long QT syndrome is not known. There are several different types of inherited Long QT syndrome and your Cardiologist may be able to tell you which type you have. The 3 most common types of inherited Long QT syndrome are called LQTS 1, 2 and LQTS 3. The type of LQTS may be identified by genetic testing. In Type 1 and 2 the potassium channels within the heart cause the problem. In these types arrhythmia may be triggered by exercise or by emotional stress. In Type 3 it is the sodium channel that is affected. In Type 3 a low heart rate during sleep or rest may be the trigger for arrhythmia.

## What are the risks?

Long QT syndrome is a rare condition, experts would suggest that approximately 1 in 7,000 people are affected but this is not certain as it may never be diagnosed.

You may be at risk if anyone in your family has had an unexplained sudden cardiac death or has had unexplained fainting episodes or seizures.

You are also at risk if you are taking any medications that prolong the QT interval. Your Doctor can inform you whether any of your medications can do this.

# Test and Diagnosis

## ECG

An ECG is a simple tracing of the heart's electrical activity. It involves attaching ten electrodes to the chest and limbs and a recording made. It may reveal a long QT interval which may suggest that it is more likely that you have Long QT syndrome. Not all people with long QT syndrome have a prolonged QT interval on their resting ECG and it may be necessary to undertake several ECGs over a period of time, or have a period of continuous monitoring using a portable heart monitor.

Some people may only have a prolonged QT interval when exercising and it may be necessary to have ECG monitoring done while exercising on a treadmill.

## Medical History and Assessment

Your Cardiologist will ask you a series of questions regarding your symptoms and about your family history. He or she will also want to know what medications you are on. You will be asked if you have any conditions that may cause the potassium levels within your blood to fall, which can trigger arrhythmia. These conditions could include excessive vomiting or diarrhoea, anorexia nervosa or certain thyroid problems. You may have blood taken to check your blood potassium levels.

## Genetic Testing

If your Cardiologist thinks you may have Long QT syndrome he or she may refer you to a Genetic Specialist. The Genetic Specialist can do tests on you and your family to try and identify if you have Long QT syndrome, however these test do not always reveal Long QT syndrome and therefore, a negative test does not necessarily mean that you do not have the condition.

# Treatment

Your doctor may discuss various treatment options with you. The main aim in treatment is to prevent loss of consciousness and life threatening arrhythmia from occurring. There is no cure for Long QT Syndrome. Treatment will be dictated by what type of Long QT you have and what is most suitable for you. Drugs, particularly beta blockers, are often used to prevent arrhythmia. In some types of Long QT syndrome, the arrhythmia can be caused by the heart beating too slowly so you may be offered a pacemaker to prevent your heart rate from falling. You may be offered a device called an ICD (implantable cardioverter defibrillator) which can detect and treat life threatening heart rhythms with electrical therapy.

Depending on the type of Long QT syndrome, you may be advised to avoid using alarm clocks and make sure you turn your mobile phone off at night time when you go to bed. If exercising triggers your fainting, you may wish to avoid strenuous activity. You may also wish to have a diet of foods rich in potassium, and inform your doctor of any illness you have had which could cause your potassium levels to fall (as mentioned earlier).

It is wise to inform other people if you have Long QT syndrome so that they know to call for urgent medical help if you were to faint. Identity bracelets are available from certain charities which carry medical information about you. Your local Arrhythmia Nurse or your Cardiologist may be able to give you more information about this.

There are many medications which might affect the heart rhythm in patients with Long QT syndrome. These include some over-the-counter cough and cold remedies (decongestants) and some antibiotics. Other drugs that might affect the QT interval include some antidepressants, some treatments for fungal infections, and drugs for heart rhythm disorders. If you are prescribed any medicines, always check with your doctor and pharmacist that it is safe for a patient with Long QT syndrome to take these medicines. A list of drugs currently known to affect Long QT are available now on [www.qtdrugs.org](http://www.qtdrugs.org) This list will not be exhaustive as newer drugs are becoming more available. Always inform anyone who is prescribing you medication that you have Long QT syndrome as there may be newer drugs on the market which may have not have been added to the website.



# Life style adjustments, after treatment

Depending on the type of Long QT syndrome, you may be advised not to take part in certain types of sporting activities. It may be that competitive sports are not advisable. However, this will need to be discussed with your Doctor or Specialist Nurse, on an individual basis. Furthermore, your career options will need to be discussed, as there may be certain restrictions within sports, the police force or the armed forces.

## **WARNING**

Recreational drugs such as Ecstasy and Cocaine are particularly dangerous in patients with long QT syndrome, and CAN BE FATAL. Patients with even mild Long QT syndrome should NEVER experiment with these drugs.

## Useful websites

A list of useful sites can be found at:- [www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk) This list is not exhaustive and it is constantly evolving. If we have excluded anyone, please accept our sincerest apologies and be assured that as soon as the matter is brought to the attention of the Arrhythmia Alliance, we will quickly act to ensure maximum inclusiveness in our endeavours.

If you wish to contact us direct please phone on +44 (0) 1789 867 501 or email [info@heartrhythmcharity.org.uk](mailto:info@heartrhythmcharity.org.uk)

## Further reading

The following list of Arrhythmia Alliance Patient booklets are available to download from our website or to order please call +44 (0) 1789 867 501.

- Arrhythmia Checklist - Could your heart rhythm problem be dangerous?
- Atrial Fibrillation (AF)
- AF Checklist
- Blackouts Checklist
- Bradycardia (Slow Heart Rhythm)
- CRT/ICD
- CRT Patient Information
- Catheter Ablation
- Drug Treatment for Heart Rhythm Disorders (Arrhythmias)
- Electrophysiology Studies
- Exercising with an ICD
- FAQs
- Genetic Testing for Inherited Heart Disorders
- Highlighting the Work of Arrhythmia Alliance
- ICD
- Implantable Device Recall
- Implantable Loop Recorder
- Long QT Syndrome
- National Service Framework Chapter 8
- CRT/Pacemaker
- Pacemaker
- Palpitation Checklist
- Remote Monitoring for ICDs
- Sudden Cardiac Arrest
- Supraventricular Tachycardia (SVT)
- Tachycardia (Fast Heart Rhythm)

Please feel free to discuss any concerns with your doctor, physiologist or specialist nurse, at any time.

**Please help us to save lives and improve services for all affected by cardiac arrhythmias by making a donation today.**

**Membership is free to individuals, however, if you would like to make a donation please complete and return to** P.O Box 3697, Stratford upon Avon, CV37 8YL or visit [www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk) and click on donate.

Name of taxpayer: .....

Address: .....

Telephone: ..... Postcode: .....

I would like to make a donation to A-A and enclose (cash/cheque/CAF) to the amount: £..... (Please make cheques payable to *Arrhythmia Alliance*)

To make a donation over the phone, please call 01789 450 787.

**Gift aid**

Please tick here if you agree to gift aid your subscription/donation

Please treat as gift aid donations all qualifying gifts of money made: today  in the past 4 years  in the future

Please tick all boxes you wish to apply.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6<sup>th</sup> April to 5<sup>th</sup> April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5<sup>th</sup> April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6<sup>th</sup> April 2008.

Name: .....

Address: .....

..... Postcode: .....

**Standing order authority**

My bank: .....

Bank address: .....

Please pay: Arrhythmia Alliance, Account: 02685818 sort code: 30-98-26, Lloyds TSB Plc, 22 Bridge St, Stratford upon Avon, CV37 6AG

The sum of £/€/£: ..... On (1<sup>st</sup> date): \_\_ / \_\_ / 20\_\_

And after this, every: ..... Month/Year (delete) Account No.: .....

Sort code: ..... Signature: ..... Date: \_\_ / \_\_ / \_\_\_\_

**Credit card payment**

Card type: ..... Expiry date: .....

Card number: ..... Amount of £/€/£: .....

Name on card: ..... CVS code (3 digit): \_ \_ \_

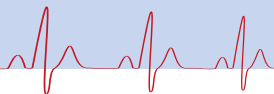
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If you would like further information or would like to provide feedback please contact Arrhythmia Alliance. Please remember that this publication provides general information only. Individuals should always discuss their own condition with a healthcare professional.