

Further information

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Useful Support Groups

CRY (Cardiac Risk in the Young)
Unit 7 Epsom Downs Metro Centre
Waterfield
Tadworth
Surrey
KT20 5LR

Tel: 01737 363 222
Email: cry@c-r-y.org.uk
Website: www.c-r-y.org.uk

**Sudden Arrhythmic Death Syndrome
(SADS UK)**
22 Rowhedge
Brentwood
Essex, CM13 2TS

Tel: 01277 230642
Email: infor@sadsuk.org
Website: <http://www.sadsuk.org>

With thanks to the British Heart
Foundation.

Birmingham Women's 
NHS Foundation Trust

Long QT Syndrome

An information leaflet for
parents and families

If you need more advice about any aspect
of Long QT Syndrome please contact:

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What is long QT syndrome?

Long QT syndrome (LQTS) is a rare condition that is passed on in families. LQTS affects the heart's electrical system. In LQTS the "recharging" of the heart's electrical system takes longer than normal. This can cause a disturbance of the heart's rhythm (an arrhythmia). People with LQTS may have attacks of fast heart rhythm. These attacks can be life threatening. LQTS may explain some rare cases of sudden death in a young person, where no obvious heart problem was found.

How is long QT syndrome passed on in families?

LQTS is caused by a change in a gene. A gene can be thought of as a set of instructions for building and maintaining our bodies. A change in any one of a number of genes can cause LQTS. The gene change that causes LQTS is usually inherited from a parent. So we may recommend ECGs for close relatives as a precaution. Any child, male or female, of a person with LQTS has a 50:50 (1 in 2) chance of inheriting the condition.

What are the symptoms of long QT syndrome?

The symptoms of LQTS vary a lot, even within families. Symptoms vary depending on whether the person is male or female, their age, and the length of their QT interval. Some people may have a genetic alteration for LQTS but never develop symptoms.

Symptoms usually start in pre-teen to teenage years but may start as late as middle age. The most common symptoms of LQTS are fainting or loss of consciousness (syncope) for a minute or two.

How is long QT syndrome diagnosed?

LQTS is diagnosed by looking at the electrical activity in the heart using an electrocardiogram (ECG). A person's QT interval may change, so it may be necessary to repeat the ECG on different days.

Your doctor may need to do more tests (e.g. ECG during exercise or a 24 hour ECG). Genetic testing may be available in some families.

How is long QT syndrome treated?

Your doctor will discuss the most suitable medical care for you. They will also talk about the possible risks and benefits of any treatments.

Treatments may include drugs known as beta blockers. These drugs can help to control the condition in most cases. However, some people may require a pacemaker or an implantable defibrillator. These are medical devices which use electrical impulses to regulate the beating of the heart.