University Hospitals of Leicester
NHS Trust

Inherited long QT syndrome (LQTS) affecting the heart

Cardiology and Clinical Genetics

Information for Patients

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What is long QT syndrome?

Long QT syndrome (LQTS) causes problems with the electrical activity of your heart. This happens often because you inherit a faulty gene from your mother or your father. This makes the chemicals like sodium and potassium become out of balance. This makes your heart take longer to reset itself electrically after every beat.

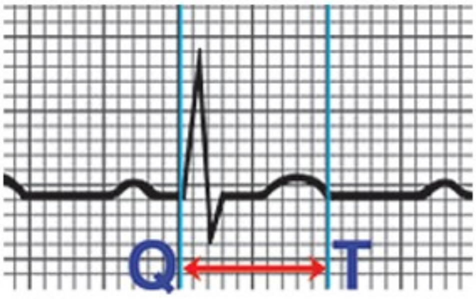
This can show up on a test called an electrocardiogram (ECG). We measure it using the **QT** interval. If this interval is longer than normal we call it 'long' QT interval (see picture below). If this happens you can be at higher risk of having abnormal and sometimes life threatening heart rhythms. This happens in the bottom chambers of your heart (ventricles).

How is LQTS diagnosed?

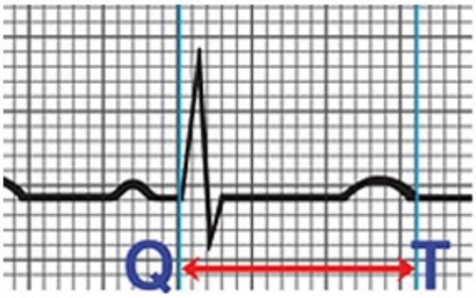
Your doctor may have found out that you have LQTS when looking for symptoms like blackouts, fainting, dizziness, heart palpitations, or from a routine ECG.

Sometimes, we can make a diagnosis after screening someone who has a family history of LQTS. Or a family history of unexplained sudden cardiac death.

Some people may have no symptoms but are found to have LQTS from genetic testing. This is when a specific genetic change is linked with LQTS in their family.



Normal Q-T interval



Long Q-T interval

What tests will I need?

Tests may include:

- an ECG
- 24 to 48 hour (1 to 2 days) home ECG monitoring
- an exercise ECG test

All of which are painless and involve attaching sticky labels (sensors) to your chest.

We often need to do genetic testing. We can do this on a small amount of your blood or sometimes a small amount of your spit. You may have inherited a gene that causes LQTS, but your QT interval in a normal range. This does not mean that you do not have the condition. It means that we cannot see it on the test.

We will offer you regular reviews in the cardiology clinic. We will look at your symptoms, ECG, and to look at your response to treatment.

What do my genetic test results mean?

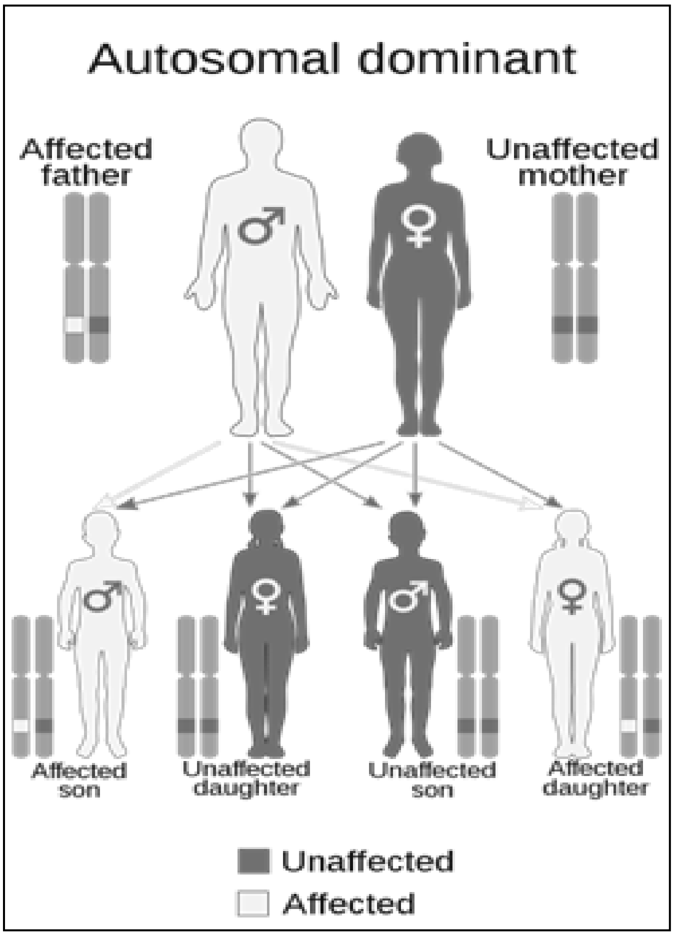
Our genes are like instructions. They control how we grow and all the functions within our body. Most genes come in pairs. 1 copy of the pair is from our mother and the other is from our father. A change (alteration) in a certain gene causes a specific medical problem. This may be inherited within a family.

The genes KCNQ1, KCNH2 and SCN5A are important for electrical function of your heart. An alteration in 1 copy of these genes may lead to someone getting an inherited type of LQTS (LQTS type 1, 2 or 3).

Why is my genetic diagnosis important for my family?

Having LQTS in the family means there is a 1 in 2 (50%) chance that a child may inherit it. This called autosomal dominant inheritance. The picture shows how this happens.

Both men and women can inherit LQTS. Each person is affected differently by LQTS. This is even within the same family. The effects are different depending on how bad the LQTS is and the age when you get any symptoms.



https://commons.wikimedia.org/w/index.php?curid=18567014

If you have:

- a family history of LQTS
- a known link with the genetic alteration in your family
- an unexplained sudden death particularly at a young age (under 40 years)

Please talk about this as a family. Ask your GP for a referral to Cardiology and/or Clinical Genetics for an assessment.

Can LQTS be treated?

There is no cure for LQTS at the moment. Your heart doctor (cardiologist) will talk to you about the best way of looking after yourself.

Most people with LQTS will need treatment with medicines called beta blockers. This reduces the risk of blackouts or your heart stopping (cardiac arrest). Sometimes we may use other drugs.

If you have had a cardiac arrest or at high risk you may need to have an implantable cardioverter defibrillator (ICD) fitted.

In some cases of LQTS, surgery may be needed on the left side of your neck. This is to treat the nerves and control the flow of chemicals into the heart. This is called sympathectomy.

Living with LQTS

With the right treatment, you should be able to lead a fairly normal quality of life and normal life expectancy. You may need to make some lifestyle changes to lower your chance of having more problems.

We advise everyone with LQTS to:

- Try not to do energetic exercise or play competitive sports. Do not swim if you have LQTS type 1.
- Avoid startling noises, such as alarm clocks if diagnosed with LQTS type 2.
- Avoid stressful or very upsetting situations if diagnosed with LQTS type 3.
- Make sure you keep well hydrated. Make sure to do this if you have an illness which causes diarrhoea.
- Try adding more potassium-rich foods to your diet or take prescribed potassium supplements. Good food sources of potassium are bananas, certain meat and vegetables, nuts and seeds. You can find more advice at: www.nhs.uk/conditions/vitamins-and-minerals/others/.
- Always tell medical staff that you have LQTS. Do this when you are given any medicine (prescribed or bought over-the-counter). This is because some medicines can increase the QT interval and increase your risk of getting abnormal heart rhythms. The CredibleMeds® website www.crediblemeds.org/ (free, but registration required) has a complete and updated list of medicines to avoid.

- Try seeing a genetic counsellor. Get counselling before planning a pregnancy as LQTS can be passed onto your child.
- Let your family members know that they would benefit from heart (cardiac) screening for LQTS.

More information and support

- Sudden Arrhythmia Death Syndromes Foundation: www.sads.org/
- British Heart Foundation: www.bhf.org.uk/
- Cardiac Risk in the Young (CRY): www.c-r-y.org.uk

Contact details

Cardiology:	**0116 258 3297**
Genetics:	**0116 258 5697**

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

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