



**IRISH HEART
FOUNDATION**
Fighting Heart Disease & Stroke

LONG QT SYNDROME SUPPORT GROUP IRELAND



Long QT Syndrome Support Group

This is a voluntary group of people, all of whom have families with Long QT syndrome (LQTS). It was set up in association with the Irish Heart Foundation to help people with LQTS and their families, by providing information and support. The support group aims to create better awareness of the condition in Ireland so that more people get the help they need.

Understanding your condition is important and members receive information bulletins and invites to information meetings. If you would like to get in touch with other members or sign up to our mailing list you can contact us through the Irish Heart Foundation's National Heart and Stroke Helpline on Locall 1890 432 787 or email info@irishheart.ie

Long QT Syndrome and Sudden Cardiac Death

LQTS is usually an inherited condition which means it runs in families. If you have LQTS it is critically important to look after other family members. Many families have lost young people to sudden cardiac death through a lack of awareness of the hereditary nature of LQTS and a lack of understanding of the need to continuously monitor the children of people with LQTS even when there are no obvious symptoms.



What is Long QT Syndrome (LQTS)

LQTS is a disturbance of the heart's electrical system which causes heart rhythm problems.

There are two main types of LQTS:

- The more common Romano-Ward syndrome, which is inherited from one parent.
- The Jervell, Lange-Nielsen form of LQTS is rare, as both parents must have the abnormal gene to pass on the condition. This type of LQTS has a link with deafness.

A person with LQTS is prone to fainting spells, dizziness, palpitations and even sudden cardiac death. These symptoms are caused by a very fast heart rhythm called Torsade de Pointes. Symptoms happen suddenly and often without warning.

If you have LQTS it is important to take your medication and follow your cardiologist's instructions. It is also very important to have family members regularly checked for LQTS by a doctor, even if they don't have any symptoms.

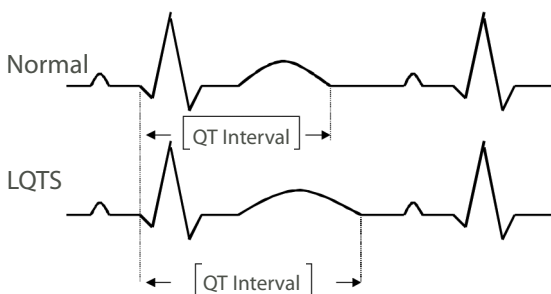
Sometimes the gene carrying LQTS can be identified in a family, in which case identifying members with LQTS becomes much easier.

What does the name Long QT Syndrome mean?

The name comes from a measurement on an electrocardiogram (ECG) called the QT-Interval. When a person with Long QT syndrome has an ECG test, the QT-Interval recorded on the ECG is longer than normal. However, a small percentage of people with LQTS will have a normal ECG.

The condition is usually inherited. Each child of a person with inherited LQTS has a 50% chance of having the condition. If you have Long QT syndrome, your mother or father is likely to also have the condition. There is a rare, acquired form of Long QT syndrome. It is brought on by some prescribed medicines and illegal drugs. However, it is not known whether or not people affected by acquired LQTS already have a genetic pre-disposition towards the condition.

ECG - QT-Interval measurement



Symptoms


What are the symptoms of Long QT Syndrome?

A faint (syncopal episode) is the most common symptom of LQTS. But there are many other reasons for a fainting spell.

A common faint usually gives warning signs such as, blurred vision or sweating just before the faint occurs. However, a syncopal episode or faint due to LQTS is usually sudden and without warning. It often happens during or shortly after some form of physical and emotional strain. This could be during exercise or, on hearing very good or very bad news. Sudden noises such as alarm clocks and doorbells can also act as triggers.

It is very important to look at family history. LQTS symptoms generally appear in young people (under 40 years) and thus a family history of sudden, unexplained death of young people or family members with a history of unexplained fainting spells is a very important consideration.

Other symptoms of LQTS include dizziness and palpitations. Unfortunately, sometimes the first symptom of LQTS is cardiac arrest (when the heart stops pumping) and sudden cardiac death.



Up to 50% of people with Long QT syndrome never have any symptoms. Therefore it is very important if you have LQTS that your close family members are regularly checked for the condition, even if they have no symptoms.

Who should be tested?

- All first-degree relatives of the person with LQTS should be tested for the condition. If you have LQTS, your first-degree relatives are your mother, father, brothers, sisters and children. It is very important that your parents and grandparents are tested so that other relatives at risk can be identified.
- Relatives should be tested regularly on the advice of their doctors.
- Children, who are thought to have epilepsy, should be checked for Long QT syndrome to make sure the epilepsy diagnosis is correct.

**First-degree
relatives
should be
tested for
LQTS.**

Diagnosis & Treatment

How is Long QT Syndrome diagnosed?

LQTS is generally diagnosed by electrocardiogram (ECG). The machine records your heart's electrical activity, which can show a prolonged Q-T interval.

- An exercise stress test may be used. This measures your heart's electrical activity while you are exercising.
- A holter monitor records your heart's rate and rhythm over 24 hours to pick up intermittent heart rhythm disturbances that may be missed by an ECG.

How is Long QT Syndrome treated?

All patients should be treated whether they have symptoms or not. This is because sudden death may be the first symptom a person with LQTS experiences. It is not possible to identify the patients who will and will not develop serious symptoms of LQTS. Therefore all patients should receive preventative treatment.

The most common medicines for LQTS are beta blockers. These medicines stop hormones, such as adrenaline, that make the heart beat faster. For most people with LQTS, medicine is the only treatment needed. Some people may need devices such as pacemakers or ICDs fitted to help control dangerous heart rhythms.

How will LQTS affect my life?

Counselling

Accepting the diagnosis of a medical problem is never easy. Some people find it more difficult than others. As many people diagnosed with LQTS are children or young people, coming to terms with LQTS is even more difficult on top of all the other psychological challenges of growing up. Counselling services are available through both of the national screening centres at the Adelaide and Meath Hospital and the Mater Hospital. Make sure to ask your doctor about the availability of counselling in your area and don't delay if you think that you or someone else in your family would benefit. The Irish Association for Counselling and Psychotherapy can also provide you with details of counselling services in your area.

Sport

People with LQTS should avoid competitive sports and activities that place high physical demands on the body. Physical activities such as walking, moderate hiking and cycling, and golf are suitable. However you should check with your doctor about your individual case. If you have LQTS, it is also important to get advice on exercise in relation to your children, even if they have no symptoms. After treatment, it may be possible to resume certain sports, in consultation with your doctor.

Foods

There are some foods that can affect how well your LQTS medicine works. Please check with your doctor and read the information sheet provided with your tablets for information on foods that might interfere with your medicine. There are also foods that can increase your heart rate, such as caffeine, and act as a trigger for symptoms of LQTS. Caffeine is found in tea, coffee, fizzy drinks, high-energy drinks and in many over-the-counter cold & flu remedies and pain medicines. Make sure to read the list of ingredients on foods, drinks and medicines.

Medicines and medical treatment

Some medicines can prolong the QT-Interval and should not be taken by people with LQTS. You can get a full list of these drugs from web sites such as www.qtdrugs.org. As new drugs are always becoming available, you need to check the list regularly. Make sure that your doctors and dentist are fully aware of your condition and that they know there are many medicines that are dangerous for you to take. Always ask your doctor and pharmacist before taking any new prescription or non-prescription medicine.

Travel

When you are travelling always carry enough of your medicines for the journey and for your holiday in your hand luggage. If you have an ICD or a pacemaker, bring your ID card and show it to airport security officials so that you don't have to walk through the metal detector. Make sure to have your European Health Insurance Card (EHIC) with you and that it is in-date. There are a number of companies offering travel insurance to people with heart conditions. See the fact sheet on the Irish Heart Foundation's web site at www.irishheart.ie or email info@irishheart.ie and we will send you a copy.

Important websites:

www.qtsyndrome.ch
www.qtdrugs.org

Medical Terms

Arrhythmia

Abnormal heart beat. The heart may beat too quickly, too slowly or in an irregular way. Arrhythmias that come from your heart's lower chambers (ventricles) can be life-threatening.

Blackout

A sudden loss of consciousness, also commonly called fainting, passing out or a syncopal episode.

Cardiac arrest

When your heart stops pumping.

Electrocardiogram (ECG)

This test measures the rhythm and electrical activity of your heart.

Exercise stress test

An ECG carried out while you run or walk on a treadmill.

Holter monitor

A machine that continuously records your heart's rhythm over 24 hours.

ICD

A small device that's placed in your chest. It uses electrical pulses (shocks) to help control life-threatening abnormal heart rhythms.

Inherited conditions

Medical problems that are passed through families and are caused by abnormalities in our genes.

Long QT Syndrome

An inherited disorder of the heart's electrical system. It can cause dangerous heart rhythms to develop suddenly.

Pacemaker

A small device that's placed in your chest to monitor and help control abnormal heart rhythms.

Pacing

Electrical impulses that are sent into your heart muscle to help it beat at a normal rate.

Palpitations

A feeling that your heart is beating too fast or skipping a beat. Sometimes palpitations are a symptom of an arrhythmia.

Please make a donation today

The Irish Heart Foundation is Ireland's national charity dedicated to the reduction of death and disability from heart disease and stroke. Over 90% of our funding comes from public and business donations. We depend on your goodwill and generosity to continue our work.

If you found this booklet useful, please help our charity to continue to provide heart & stroke information by donating today.

You can make your donation today:

By post: Irish Heart Foundation,
50 Ringsend Road, Dublin 4

Online: www.irishheart.ie

By phone: 01 6685001

Personal Details

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Address: _____

Email: _____

Phone: _____

Mobile: _____

Credit or debit card (one off donation)

Amount:

☐ €250* ☐ €100 ☐ €50 ☐ €25 ☐ Other € _____

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Signature: _____ Date: ____ / ____ / ____

* If you donate €250 in one year (or €21 per month) we can claim tax back at no cost to you.

** Last 3 digits on the signature strip on the reverse of our card.

The Irish Heart Foundation is committed to best practice in fundraising and adheres to the **statement of guiding principles for fundraising** promoting transparency, honesty and accountability. Any personal information you provide will be held in accordance with the Data Protection Acts 1988 and 2003.

SEPA Direct Debit Mandate

Unique Mandate Reference:

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By signing this mandate form, you authorise (A) the Irish Heart Foundation to send instructions to your bank to debit your account and (B) your bank to debit your account in accordance with the instruction from the Irish Heart Foundation.

As part of your rights, you are entitled to a refund from your bank under the terms and conditions of your agreement with your bank. A refund must be claimed within 8 weeks starting from the date on which your account was debited. Your rights are explained in a statement that you can obtain from your bank.

Please complete all the fields below marked*

*Bank Name: _____

*Address: _____

*Account Number (IBAN): _____

*Swift BIC: _____

Creditor Name: IRISH HEART FOUNDATION

Creditor Address: 50 RINGSEND ROAD, DUBLIN 4, IRELAND

*Type of Payment: ☒ Recurrent (Monthly) ☐ One-off Payment

* Signature: _____ *Date Signed: _____

Please return completed form to the Irish Heart Foundation.

My monthly instalment amount is:

☐ €21* ☐ €18 ☐ €15 ☐ €10 ☐ Other € ____ per month

*A regular gift of €21 per month could be worth an additional €9 from the Revenue Commissioners per month at no extra cost to you.

Your first contribution will be taken on either the 2nd or the 20th of the next available month. Please select which date you prefer.

☐ 2nd ☐ 20th

You will be notified in writing ten days in advance of your first direct debit. If you wish to cancel within 7 days of a direct debit payment please contact your own bank.

Preferences

I would like to hear about other IHF events, activities, awareness campaigns and appeals. ☐ Yes

Do you need a postal receipt: ☐ Yes ☐ No

More information

Irish Heart Foundation

50 Ringsend Road, Dublin 4

Telephone: 01 6685001

Email: info@irishheart.ie

Web: www.irishheart.ie

National Heart and Stroke Helpline

Telephone: Locall 1890 432 787

Email: info@irishheart.ie

ICD Support Group

Long QT Syndrome Support Group

c/o Irish Heart Foundation

Telephone: 01 6685001 or Locall 1890 432 787

Email: info@irishheart.ie

SADS Support Group (formerly, SCD in the Young Support Group)

c/o Irish Heart Foundation

Telephone: 01 6685001, Locall 1890 432 787
or 087 3232552

Email: info@irishheart.ie

Heart Rhythm Ireland

www.heartrhythmireland.com

Telephone: 041 6871457

Email: info@heartrhythmireland.com

CRYP Centre

Adelaide and Meath Hospital, Dublin 24,

Telephone: 01 4143058

Family Heart Screening Clinic

Mater Hospital, Dublin 7

Telephone: 01 8034354

Email: familyheartscreening@mater.ie



**IRISH HEART
FOUNDATION**
Fighting Heart Disease & Stroke

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National Heart and Stroke Helpline

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Monday to Friday 10am to 5pm

Web:

www.irishheart.ie

www.stroke.ie



Funding:

The Irish Heart Foundation is the national charity fighting heart disease and stroke and relies on charitable donations for 90 per cent of its funding. We support, educate and train people to save lives, campaign for patients, promote positive health strategies, support research and provide vital public information. We need your support – through donations, as a volunteer or on our training courses.

This publication is sponsored by Boston Scientific.

Published by the Irish Heart Foundation in 2013. The information provided in this publication was correct and accurate at the time of publication to the best of the charity's knowledge.

