

2020

Long QT Syndrome (LQTS)

Inherited Heart Disease (IHD) Clinic



www.nshealth.ca

How does the heart work?

The heart is a hollow organ made of muscle. It has 4 chambers: 2 at the top (atria) and 2 at the bottom (ventricles). Blood flows from outside the heart into the top chambers, is pumped to the bottom chambers, and is then pumped back out to the body.

In a normal heartbeat, an electrical signal travels through the heart muscle cells, causing them to beat. This makes the heart pump blood from one chamber to another and out to the rest of the body.

Heart cells have special channels that work like doors. They control the movement of electrolytes into and out of the cells. These channels must open and close to let electrical signals flow through the heart cells.

What is Long QT Syndrome (LQTS)?

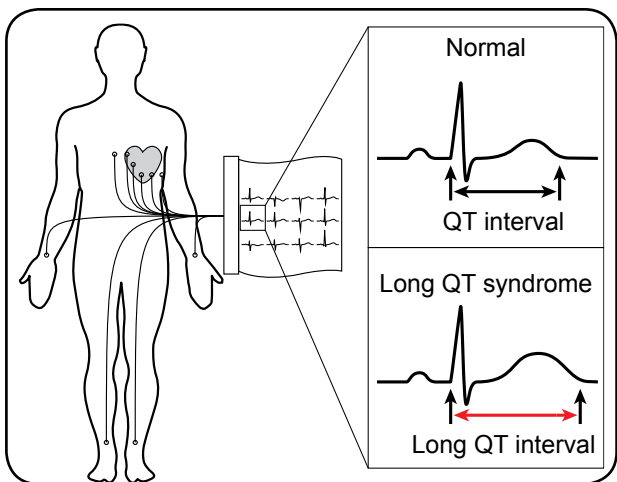
LQTS is a rare disease where there are changes in the electrical signals that make the heart beat.

In LQTS, channels in the heart cells do not work properly. The abnormal opening and closing of the channels can lead to dangerous heart rhythms. The heart may beat so fast that it cannot pump blood out to the body. This can cause collapse and, if the rhythm does not stop, sudden death.

What causes LQTS?

LQTS can be caused by:

- › a change in your DNA (genes). LQTS can be hereditary (passed from parents to their children).
- › certain medications



What are the symptoms of LQTS?

Symptoms may include:

- › fainting
- › seizures
- › palpitations (feeling like your heart is jumping, racing, or fluttering)
- › blackouts

It is important to tell your health care provider if you have a relative who died suddenly at a young age. This could have been caused by LQTS.

How is LQTS diagnosed?

The 3 main tests used to diagnose LQTS are:

1. **Electrocardiogram (ECG):** A recording of your heart rhythm for 10 to 20 seconds. A person with LQTS will have a long QT interval on their ECG (see image).
2. **Exercise stress test:** A recording of your heart rhythm and blood pressure while you exercise on a treadmill.

3. **Genetic testing:** A blood test can be done to check if there is a change in your genes causing LQTS.

Genetic testing and family screening

If your cardiologist suspects that a change in your DNA could have caused your LQTS, they may ask if you would like to talk with a genetic counsellor about genetic testing. Your cardiologist may also want to invite other members of your family to be tested for LQTS. They may ask you to help by passing letters on to your family.

Your cardiologist (heart doctor) may also suggest other tests. They will talk with you about this, if needed.

How is LQTS treated?


There is no cure for LQTS, but there are treatments available to help prevent or treat dangerous heart rhythms.

Treatments include:

- › medications called a beta-blockers
- › A pacemaker (for slow heart rates) or an internal defibrillator (ICD) (to identify and treat dangerous heart rhythms)

If you have LQTS:

Your health care provider will talk with you about what activities are safe for you and what activities and environments you should avoid.

- **AVOID** strenuous (hard) exercise, as this can cause a blackout.
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- **DO NOT** take part in competitive sports.
- **NEVER** swim alone. Swimming can cause a blackout and may lead to drowning.
- **BE AWARE** that sudden, startling events may trigger a possibly deadly rhythm (e.g., a surprise or a startling noise, such as the ringing of an alarm clock or telephone). **AVOID** these items and turn off/down the volume when sleeping.
- **AVOID** recreational drug use, especially stimulants. This includes energy drinks.
- **KNOW** what medications can make the problem worse, including over-the-counter medications. See the list of drugs to avoid at:
 - › www.crediblemeds.org.
- **AVOID and TREAT** dehydration (not having enough fluids in your body) and salt loss if you have an illness that causes diarrhea (loose, watery poop) and vomiting (throwing up).
- **TELL** your family members that you have LQTS. It runs in families, so they may need to be checked for this problem.
- **Make sure your family and friends are aware of your condition**, and that they know what to do if you have any symptoms.

For more info, visit:

The Canadian Sudden Arrhythmia Death Syndromes (SADS) Foundation (includes booklet on LQTS that you can download)

› www.sads.ca

CredibleMeds® (includes a list of drugs that can make LQTS worse)

› www.crediblemeds.org

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Connect with a registered nurse in Nova Scotia any time:

Call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community:

Call 211 or visit <http://ns.211.ca>

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The information in this pamphlet is to be updated every 3 years or as needed.