

If you have LQTS:

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

- **Do not** do strenuous (hard) exercise. This can cause you to black out.
- **Do not** take part in competitive sports.
- **Do not** swim alone. Swimming can cause you to black out and may lead to drowning.
- Surprises or sudden noises (like the sound of an alarm clock or a phone ringing) may cause a dangerous heart rhythm. **This dangerous rhythm could cause death.**
 - › **Do not** use alarm clocks or cell phone alarms.
 - › Turn the volume of your phone ringer **off or down.**
- **Do not** use recreational drugs (substances that affect your body's nervous system), especially stimulants. This includes energy drinks.
- Some prescription and over-the-counter medications can make LQTS worse. See the list of **drugs to avoid** at:
 - › www.crediblemeds.org
- If you have an illness that causes diarrhea (loose, watery poop) and vomiting (throwing up), **avoid dehydration (not having enough fluids) and salt loss (not having enough salt).**
 - › If you get dehydrated or lose too much salt, take an oral (by mouth) rehydration solution (salt).

- **Tell your family members that you have LQTS.** It can be hereditary and they may need to be tested for it.
- **Tell your loved one(s) and support person(s) that you have LQTS.** Tell them to help you if you have symptoms.

More information about LQTS:

The Canadian Sudden Arrhythmia Death Syndromes (SADS) Foundation

- › www.sads.ca
- › Includes information about inherited heart diseases and a booklet about LQTS that you can download.

The CredibleMeds® (drugs that can make LQTS worse)

- › www.crediblemeds.org/everyone/info-congenital-lqt-and-drugs-avoid

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

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Long QT Syndrome (LQTS)

The Jordan Boyd Inherited Heart Disease Clinic

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 the body into the top chambers. The blood is pumped to the bottom chambers, and is then pumped back out to the body.

Electric signals that pass through the heart muscle control the pumping of the chambers. This electrical activity is called the **heart rhythm**.

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.

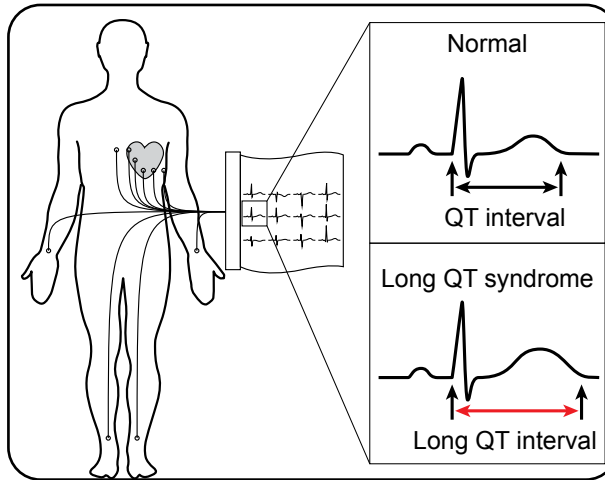
What is Long QT Syndrome?

LQTS is a rare disease that can change your heart's electrical activity. With LQTS, the channels in your heart cells do not open and close the way they should. This can cause abnormal heart rhythms. **These abnormal heart rhythms are dangerous.** Your heart may beat so fast that it cannot pump blood out to your body. These abnormal heart rhythms can make you collapse (faint). **If the rhythm does not stop, they can cause sudden death.**

What causes LQTS?

LQTS can be caused by:

- › changes in your genes. LQTS can be hereditary (passed from parents to their children).
- › some medications (certain antibiotics, some antidepressants and antipsychotics).



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

What are the symptoms of LQTS?

Symptoms may include:

- › Fainting
- › Seizures (brief, abnormal, excessive [too much] discharge of electrical energy in the brain)
- › Palpitations (feeling like your heart is jumping, racing, or fluttering)
- › Blackouts (passing out or not being able to remember a certain amount of time)

How is LQTS diagnosed?

The most common tests used to diagnose LQTS are:

Electrocardiogram (ECG/EKG): A recording of your heart rhythm for 10 to 20 seconds. LQTS causes a long QT interval on your ECG/EKG (see image).

Exercise stress test: A recording of your heart rhythm and blood pressure while you run on a treadmill.

Genetic testing: A blood test can check if changes in your genes caused LQTS.

Your cardiologist (heart doctor) may want you to have other tests when they are diagnosing you. They will talk with you about this, if needed.

Genetic testing and family screening

If your cardiologist thinks changes in your genes 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 ask other members of your family to test for LQTS. They may ask you to help by giving letters to your family members.

How is LQTS treated?

There is no cure for LQTS, but there are treatments that can control fast heart rhythms and help with your symptoms.

Treatments may include:

- › medications called beta-blockers.
- › a pacemaker (for slow heart rates).
- › a pacemaker called an **internal cardioverter defibrillator** (ICD). The ICD identifies fast heart rhythms and slows your heart rhythm down to a safer speed.