

Long QT Syndrome (LQTS)

The Jordan Boyd Inherited Heart Disease Clinic

Notes:

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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Connect with a registered nurse in Nova Scotia any time:
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To be reviewed September 2029 or sooner, if needed.
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Long QT Syndrome (LQTS)

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 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 normally. This can cause an abnormal heart rhythm.

- If you have an illness that causes diarrhea (loose, watery poop) and vomiting (throwing up):
 - › Avoid dehydration (not having enough fluids). This can cause your body to lose too much salt.
 - › If you get dehydrated, drink a rehydration solution (like Pedialyte®).
- **Tell your family members that you have LQTS.** It can be hereditary and they may need to be tested for it.
- **Tell your loved ones, and any support persons, that you have LQTS.** Tell them what to do to help you if you have symptoms.

For more information about LQTS:

- **The Canadian Sudden Arrhythmia Death Syndromes (SADS) Foundation**
 - › www.sads.ca
- **CredibleMeds®** (medications that can make LQTS worse)
 - › www.crediblemeds.org/everyone/info-congenital-lqt-and-drugs-avoid

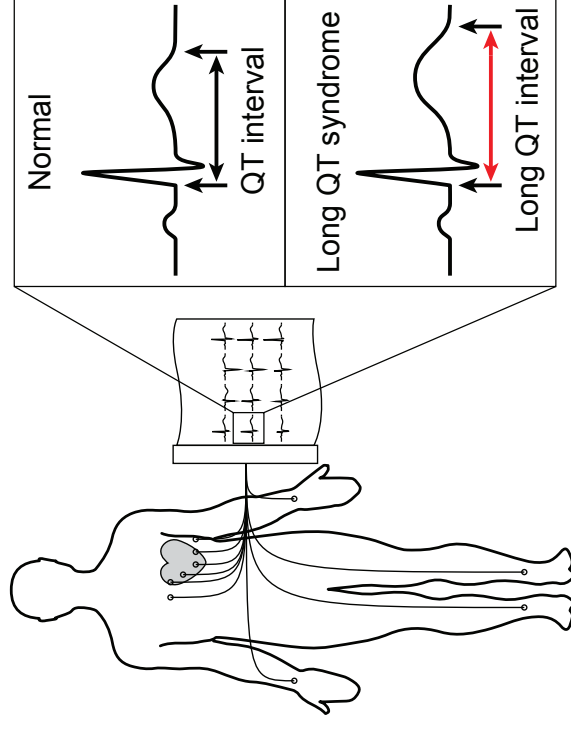
If you have LQTS:

- 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 intense 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 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 (like cocaine), especially stimulants. This includes energy drinks.
- Some prescription and over-the-counter medications can make LQTS worse. Talk to your pharmacist before starting any new medication.
 - › www.crediblemeds.org

- **An abnormal heart rhythm is dangerous.** Your heart may beat so fast that it cannot pump blood out to your body. The abnormal heart rhythm can make you faint. **If the rhythm does not stop, it can cause sudden death.**

What causes LQTS?

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



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, 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 on page 2).
 - › **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 give letters with information about LQTS to your family members.

How is LQTS treated?

- There is no cure for LQTS, but there are treatments that can control a fast heart rhythm 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 a fast heart rhythm and slows your heart rhythm down to a safer speed