
Long QT syndrome

Summary

- Long QT syndrome is a heart rhythm condition.
 - Fainting can be a symptom of long QT syndrome.
 - See your doctor about long QT syndrome if you faint for no apparent reason, or during or after exercise or emotional excitement.
 - Long QT syndrome is usually inherited, although it can be acquired after taking certain medication.
 - If you have long QT syndrome, always tell your doctor before they give you a prescription.
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Long QT syndrome is an electrical condition of the heart that affects the heart's rhythm. A person with long QT syndrome may experience fast, erratic heartbeats when exercising, or at times of emotional excitement. This may cause fainting, seizures or, in some cases, sudden death. Long QT syndrome is a relatively common cause of sudden death in children and young adults. Long QT syndrome is diagnosed by electrocardiograph (ECG). About one third of people who have long QT syndrome do not have any symptoms.

Long QT syndrome warning signs

You should be investigated for long QT syndrome if:

- you faint for no apparent reason
- you faint during or shortly after exercise or emotional excitement
- there is a history of unexplained fainting or sudden death in your family
- there is a family history of long QT syndrome.

Types of long QT syndrome

There are two main types of long QT syndrome: inherited long QT syndrome and acquired long QT syndrome.

Inherited long QT syndrome

There are two types of inherited long QT syndrome:

- Romano-Ward syndrome – is being recognised with increasing frequency. Researchers have found more than 15 genes that cause long QT syndrome, and more are expected to be discovered in the future. Genetic testing for long QT syndrome is now available.
- Jervell and Lange-Nielson syndrome – this form is rare and also causes deafness.

Acquired long QT syndrome

Long QT syndrome can also be acquired by taking certain over-the-counter medications and some prescribed medications, including some:

- antiarrhythmic medications (used to maintain a normal heart rhythm)
- antibiotics
- antidepressants
- antipsychotics
- anti-nausea medications
- diuretics.

In some cases, stopping taking the medicine may prevent further symptoms. In other cases, further treatment may also be required.

If you have long QT syndrome, always tell your doctor before they give you a prescription. There is an updated list of medications to avoid at [**Center for Education and Research on Therapeutics**](#).

Causes of long QT syndrome

Long QT is caused by a change in one of at least fifteen different genes. It has an autosomal dominant inheritance pattern. 'Dominant' means that only one copy of the changed gene is required to cause the condition. 'Autosomal' means that the gene change occurs on one of the non-sex chromosomes.

If you have long QT syndrome, the chance of passing the changed gene on to your child is 50 per cent for each pregnancy, regardless of the sex of the child.

Sometimes the long QT gene change occurs at the time of the formation of the egg or the sperm for that child only (this is called a *de novo* gene change).

Genetic testing for long QT syndrome

Genetic testing for long QT syndrome involves testing for six common genes that are known to be associated with the condition. If you are found to have long QT syndrome, your biological family members are encouraged to visit a cardiologist to have their heart checked.

Event triggers of long QT syndrome

An event can be triggered by:

- exercise
- being startled by a loud noise, such as a horn, ringing telephone or alarm clock
- exams, tests or other stressful situations
- anger or crying.

Treatment for long QT syndrome

Treatments include:

- medications – beta blockers are effective for 90 per cent of people with long QT syndrome.
- implantable cardioverter-defibrillators (ICDs) – ICDs are devices placed inside the body to detect and correct abnormal heart rhythms. ICDs may be necessary for patients that do not respond to beta blocker therapy.

Genetic counselling for long QT syndrome

If your child or another family member has been diagnosed with long QT syndrome, or if it runs in your family, it may be helpful to speak to a genetic counsellor.

Genetic counsellors are health professionals qualified in both counselling and genetics. As well as providing emotional support, they can help you to understand long QT syndrome and what causes it, how it is inherited, and what a diagnosis means for your or your child's health and development, and for your family. Genetic counsellors are trained to provide information and support that is sensitive to your family circumstances, culture and beliefs.

If long QT syndrome runs in your family, a genetic counsellor can explain what genetic testing options are available to you and other family members. You may choose to visit a genetic counsellor if you are planning a family – to find out your risk of passing the condition on to your child, or to arrange for prenatal tests.

The **Genetic Support Network of Victoria (GSNV)** is connected with a wide range of support groups throughout Victoria and Australia and can connect you with other individuals and families affected by long QT syndrome.

Where to get help

- Your **GP (doctor)**
- **Cardiologist**
- **Genetic Support Network of Victoria (GSNV)** Tel.(03)8341 6315
- **Victorian Clinical Genetics Services (VCGS)** Tel.1300 118 247
- **Australian Genetic Heart Disease Registry** Tel.(03) 3945 5702

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