

What is the Long QT Syndrome?

Long QT Syndrome is also called LQTS.

Electricity flows throughout your body including your heart. Electricity helps your heart pump your blood through your body.

Chemicals such as Calcium and Sodium are also in your body. As these chemicals move around inside your heart they sometimes cause the electricity in your heart to be too much or not enough.

This makes it hard for your heart to pump your blood the way it should.

When the electricity in your heart is not what it is supposed to be it can also be dangerous.

Some of the things that might happen are:

- Your heart beats too fast
- You get really dizzy
- You may suddenly lose consciousness (faint)

If these problems are not corrected, you can even die. If any of these things happen to you—get someone's help right away.

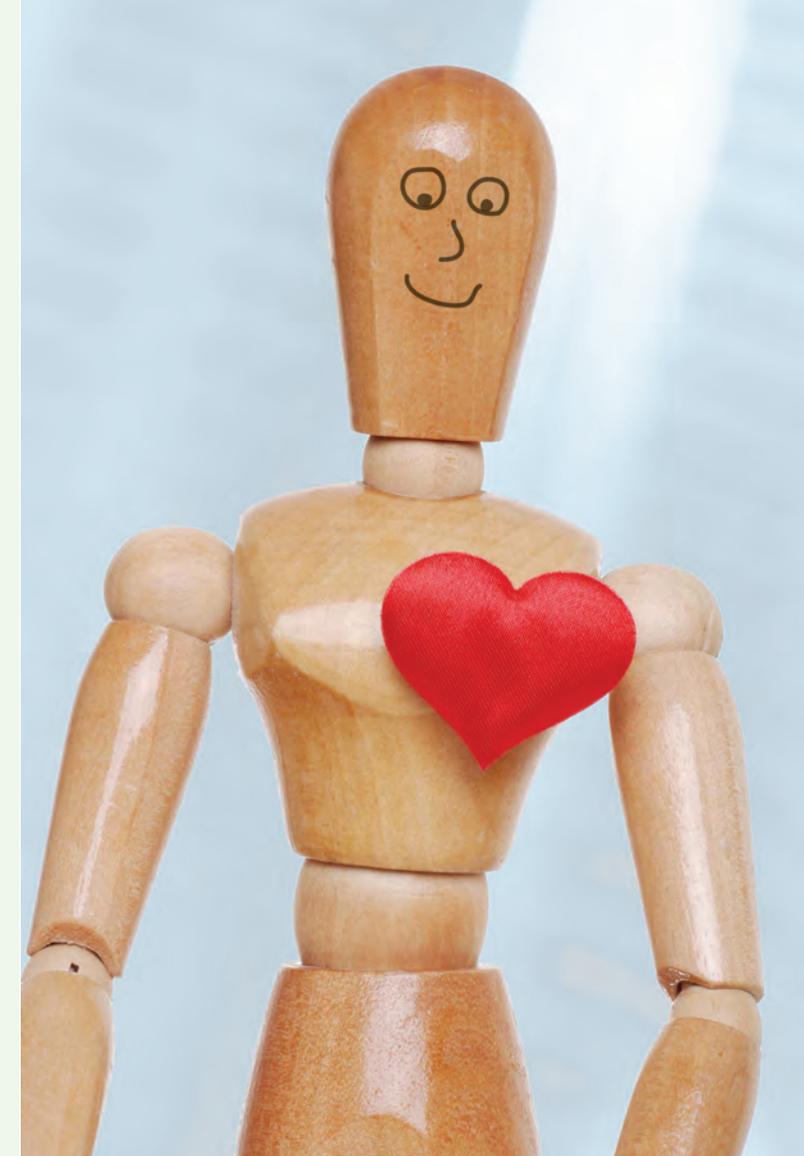
Why Do I Have LQTS?

LQTS is inherited. This means that you get LQTS from your parents and grandparents because you are their child and share their genes.

You have many things that are inherited from your parents and grandparents. For example, you may have the same hair or eye color, the same shaped ears or nose, or even the same sense of humor as one or both of your parents.



Sudden Arrhythmia Death Syndromes
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Now that I have LQTS, what are the things that I need to avoid?

There are some small changes that you need to make in your lifestyle that can make handling LQTS easier. For example, you should not play competitive sports and you should always have a buddy.

This does not mean that you can't have fun. You still can play games like you always do, like playing on the swings or playing basketball, but don't get angry or stressed out while doing these activities. When you do go out and play, you should use the buddy system. The buddy system means that you should take a parent or friend to play with you, just in case you need help. This person should be able to call 911 in an emergency or be able to reach an adult that can help with an emergency.

Be careful about medicines

You should also stay away from certain medicines that can be bad for your LQTS. The medicine you take can cause the electricity in your heart to act up. This can make LQTS even more dangerous. Be sure that your doctor and your parents check the medicine they give you, and don't take any medicine without your doctor and your parents knowing first.

Work with your parents and doctors to recognize these medicines. The SADS Foundation has a whole list of medications to stay away from and they would be happy to give that list to you and your parents. Everyone must take care of his or her body so you can stay healthy. It is important you do everything that you can do to keep your body healthy, because a healthy body is a happy body!



Who can I talk to about LQTS?

Support is something that everyone needs. People around you can help you with whatever you may have worries about. The SADS Foundation is here to help you with any questions that you may have about LQTS and support you in every way. They can even introduce you to other children like you that have LQTS.

You can also ask your parents and doctors any questions, because they are always there to help you. Remember; never be scared to ask a question because there is never a stupid question. Your parents can help you email or call the SADS Foundation with any questions you may have.

What should I tell my friends?

Everyone has something to make them different. This could be that you have brown eyes and your friend has blue. Or it could be that your friend needs to take a certain medicine and you don't. Being different is not bad; it makes us special because there is no one in the world just like us. You should tell your friends about LQTS and tell them the things you can and cannot do. You can even have your friend read this or have them talk to your parents. Real friends are people who support you no matter what and accept you for who you are.

If you don't tell your friends they won't be able to help you and offer you any support.

Remember your friends are one of the best sources for support.



What Do I Do Now?

Here are some of the things you need to do to stay healthy:

- Take the medicine that your doctor prescribes every day. Never skip any doses.
- Never take any medicine without checking with your doctor and your parents.
- Visit your doctor every year.
- Choose activities and exercises that are safe.
- Tell your friends and teachers that you have LQTS.
- Always follow the buddy system.

Doctors use machines that measure the electricity in your heart and to test whether you have LQTS Syndrome. One of these tests is called an Electrocardiogram or EKG. A doctor may use an EKG to test the electricity in your heart.

Youth Support Network

Meet other kids just like you!

- Read letters written just for you by kids with LQTS
- Read stories about other kids who are living and thriving with LQTS
- Meet the SADS youth advisors on www.StopSADS.org. These are young people who know what it feels like to be a kid living with SADS. They are ready to answer your questions and give advice.
- Attend family seminars with fun activities just for kids like you!

Visit the SADS Website to find out more about this program: www.SADS.org