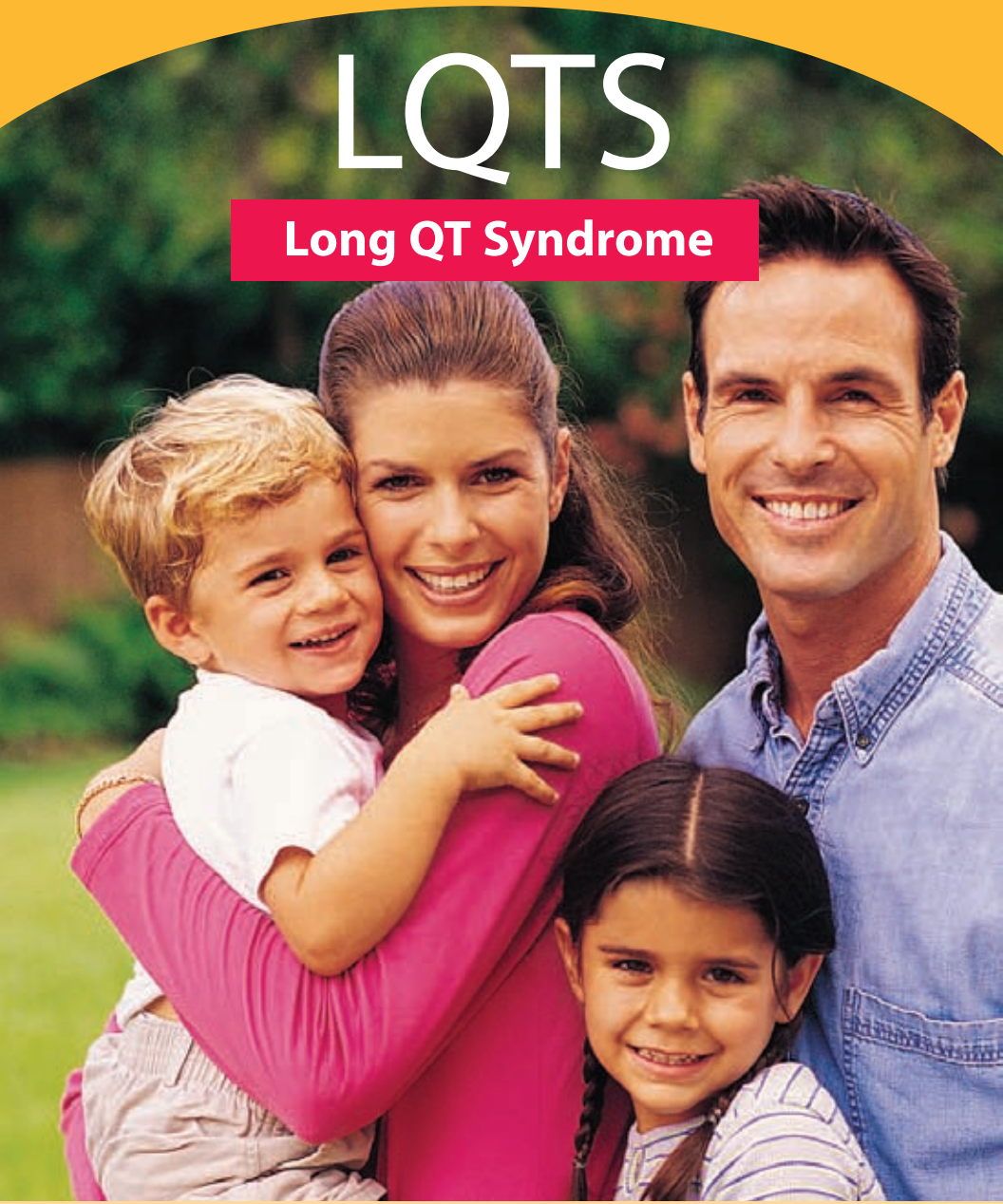
The Canadian SADS Foundation

Supporting Families.
Saving Lives.

LQTS

Long QT Syndrome



An Information Booklet for Patients and Their Families

Dear Patient,

A diagnosis of Long QT Syndrome (LQTS) can trigger feelings of confusion and helplessness. Most people have not heard of this condition, and it can be difficult to access relevant information. The purpose of this booklet is to explain some of the aspects of diagnosis and treatment of LQTS and to prepare you for the practical and emotional issues that can arise when you are learning to live with this condition. Each patient with LQTS is different, and your cardiologist is the best person to decide the course of treatment that will be most helpful for your particular situation.

We hope that this publication will help you to realize that you are not alone in dealing with a diagnosis of LQTS. In addition to factual information, we have included perspectives from other people who are coping with this diagnosis. On page 18, you will find a list of websites that provide constructive information and links to groups that offer emotional support. We sincerely hope that this publication will be useful to you and your family.

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What is Long QT Syndrome?

Long QT Syndrome (LQTS) is an uncommon heart condition that is estimated to affect roughly 1 in 2,500 people. The syndrome gets its unusual name from its characteristic appearance on an electrocardiogram (ECG) where the time interval between the Q-wave and T-wave is longer than usual. LQTS is usually a hereditary condition that is passed down through families in an autosomal dominant way – this means that a parent who carries the gene for LQTS has a 50% chance of passing it on to each of his or her children. Since many people with LQTS do not have any symptoms, a patient may not realize they are a carrier until someone else in their family experiences symptoms. In order to understand what Long QT Syndrome is, it is helpful to understand a little about how the heart works.

The heart is made up of many muscle cells that contract at the same time to pump blood through the body. This contraction is controlled by an electrical current that is created when tiny charged particles (called ions) move in and out of the heart muscle cells. At the beginning of each heartbeat, positively-charged sodium ions rush into the heart cells. This is called "depolarization" and it results in the heart muscle contracting and pumping blood out of the heart. After the heart has pumped out the blood, it has to "repolarize" – to get rid of the positive charge and return to normal so it is ready for the next electrical signal. In order to repolarize, lots of positively-charged potassium ions must rush out of the cell. Ions travel in and out of cells in little tunnels called ion channels. In people with Long QT Syndrome, one of these ion

"When our daughter first started having fainting episodes, our doctor said "kids faint sometimes" and left it at that. I knew in my heart that something else was terribly wrong with her. I'm so glad I listened to my intuition and got a second opinion, or our lovely little girl may not be with us today."

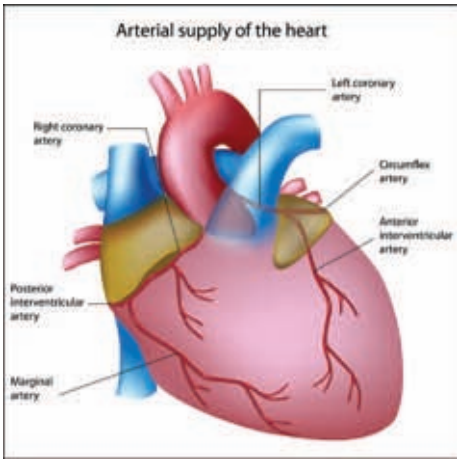
- Alice

channels is an abnormal shape, which means that it takes longer to move ions in and out of the heart cells. Sometimes the heart "repolarizes" too slowly after one heartbeat and it is not ready for the next electrical signal when it comes. If the heart receives a signal when it is not ready, it gets confused and may start to beat extremely quickly. This very rapid heartbeat (an arrhythmia called "torsade des pointes") is too fast to pump blood out of the heart effectively, so not enough blood goes to the patient's brain and they may lose consciousness in seconds. This sudden loss of consciousness is called syncope (SIN-co-pee) and it may look like a simple faint or like a seizure. Often LQTS patients who experience syncope recover on their own, but some require CPR (cardiopulmonary resuscitation) or defibrillation (an electric shock to the heart delivered by electrical paddles) to start their heart beating normally again. Tragically, some patients never wake up because the abnormal beating of the heart cannot deliver enough blood to the brain and vital organs.

"I was diagnosed with epilepsy when I was seven years old and I had been taking anticonvulsant medications since then. My mother always thought something else was going on, but it wasn't until I was 32 and my son was found to have LQTS that I was properly diagnosed."

- Zachary

In LQTS patients, "episodes" of syncope often happen in very specific situations. There are currently at least twelve known types of Long QT Syndrome, and triggers of syncope are related to the type of LQTS a patient has. By far the most common types of LQTS are LQT1 and LQT2, which collectively make up almost 80% of all cases of LQTS. Only 4% of LQTS patients have LQT3, and the other forms are very rare.



LQT1 and LQT2 happen when there is a problem with one of the ion channels that move potassium out of the heart cell at the end of a heartbeat. Episodes in LQT1 patients tend to occur in situations of high

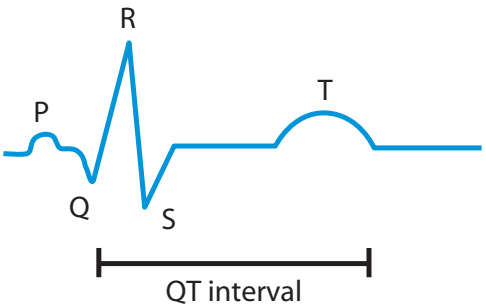
physical or emotional stress, during exercise or periods of anger or anxiety. Swimming is a very specific trigger for syncope in LQT1 patients. In LQT2 patients, episodes often occur following startle or loud noises. LQT2 patients tend to experience syncope after the telephone rings or their alarm clock goes off. LQT3 symptoms happen when there is a problem with the sodium channel that causes it to be overactive. LQT3 patients tend to have episodes at night or while at rest. It is helpful to know which type of LQTS you have so you can change things in your environment to minimize triggers.

What are all these tests I have to do?

Long QT Syndrome is a difficult condition to diagnose; it may be misdiagnosed as epilepsy or not picked up at all. Even after many tests, your doctor may not be able to say for sure whether or not you have Long QT Syndrome. In these cases, doctors use a list of criteria to determine how likely it is that you have the condition, and to decide what the appropriate treatment should be.

Electrocardiogram (ECG), Holter Monitoring, and Stress Testing:

Long QT Syndrome got its name from its characteristic appearance on an electrocardiogram that is seen in most (but not all) people with LQTS. The ECG is one of the most important tests in the diagnosis of LQTS. Since you have been diagnosed with LQTS, you have probably had several ECGs already. An ECG machine measures the electric pattern in the heart through electrodes placed on the skin.



A simplified ECG tracing is shown here. The different waves in an ECG are named P, Q, R, S, and T. Long QT Syndrome gets its name from the fact that most LQTS patients have a longer distance between their Q wave and T wave than do unaffected people. If the QT interval is very prolonged, the cardiologist will be able to tell just by looking at the ECG, but sometimes the prolongation is more subtle.

Holter monitors are portable ECG machines that are worn over the course of at least 24 hours. Holter monitors are useful in diagnosis because they may show QT variability as well as arrhythmias over the course of the day. They may also be prescribed to monitor therapies after a diagnosis has been made.

An exercise stress test may also be part of your testing for LQTS. During a stress test, you will be hooked up to an ECG machine while you run on a treadmill or ride an exercise bicycle. This test is useful because in LQTS the heart may be more likely to beat abnormally while it is beating quickly. This test may also make the long QT easier to see. If your cardiologist sees an abnormality during the stress test, he or she can make the diagnosis more easily.

Echocardiogram:

An echocardiogram is an ultrasound test that determines the size and shape of the heart. Since the heart has a normal structure in LQTS, this test is not used to diagnose Long QT Syndrome, but it may be used to rule out other heart conditions.

Genetic Testing:

If the ECG shows a very long QT interval, then a cardiologist can be quite sure about the diagnosis, but some people (possibly as many as 25% to 30%) with LQTS have a QT interval in the near-normal range and it is difficult to tell for sure. In this instance, genetic testing may be helpful. Unfortunately, there are many different gene mutations that can cause LQTS, and determining which mutation is responsible for the condition in a particular family is not always possible. However, when it is possible, and once the gene mutation has been found in one member of the family, it is easier to find out which other family members are affected because the laboratory knows which LQTS gene mutation to look for. If you agree to genetic testing, your doctor will

"Genetic testing worked out very well for our family. Three of my children were on beta-blockers for suspected Long QT Syndrome, but the test showed that only one of them actually has the condition. The testing was a huge relief for us."

- Sam

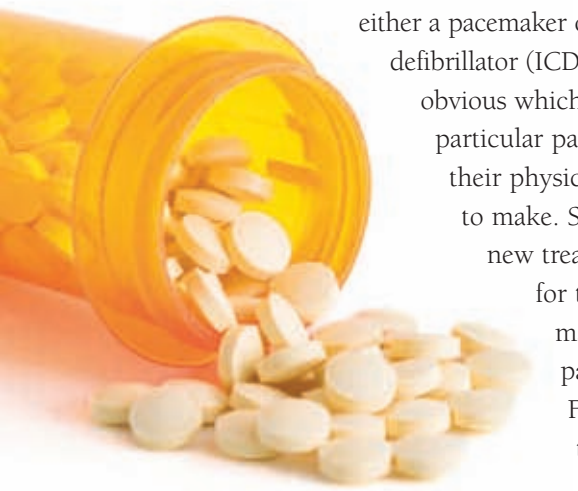
draw a small amount of blood from all the family members to be tested, and this blood will be sent to a laboratory. At the present time, genetic testing for LQTS is not yet available for all people who would benefit from it, but its use is increasing.

Should the rest of my family be tested for LQTS?

LQTS is a hereditary condition. Therefore, if a person with LQTS decides to have children, each child will have a 50% chance of inheriting LQTS as well. Genetic testing is the most accurate way to diagnose LQTS if a disease causing mutation has been found in the family. Unfortunately, in some families who have been tested, the abnormality cannot be identified as one of the known LQTS gene mutations at this time. In these situations, the patient and other family members who may have LQTS need to be identified through ECGs, stress tests, and Holter monitoring. Some other tests, such as epinephrine infusion, may occasionally be considered as well. Blood can also be "banked" or saved so that it can be re-tested if more accurate genetic tests become available in the future.

What are the available treatments for Long QT Syndrome?

The standard first-line treatment for LQTS is a class of medication called beta-blockers. For some people who continue to have episodes even when they are taking the right dose of beta-blockers, the medicine may be changed. In other circumstances LQTS patients may have surgery to install either a pacemaker or an implantable cardioverter defibrillator (ICD) in their chest. It is not always obvious which treatment is the best choice for a particular patient, and sometimes patients and their physicians have a very difficult decision to make. Scientists are currently working on new treatments for LQTS that are specific for the subtype of the condition, and may even be specific for the particular mutation in a given family. For now the following are the main treatments available.



Beta-Blockers:

Beta-blockers are the most effective medication in the treatment of LQTS, particularly the subtypes LQT1 and LQT2. They are prescribed both to patients who have had symptoms and to people who are suspected of having LQTS as a result of their ECG and family history. Beta-blocker medications have names like atenolol, metoprolol, propranolol, and nadolol. Adrenaline is the hormone that our body produces when we are excited, exercising, or frightened. It causes a "flight or fight" response consisting of nervousness, sweating, and increased alertness. More importantly, it causes the heart to speed up suddenly, which can be a trigger for arrhythmias. The "beta" in beta-blocker refers to the molecule in the heart that senses the presence of adrenaline. By blocking this molecule, the drug makes the body less reactive to adrenaline. This reduces the likelihood of arrhythmia by preventing rapid increases in heart rate, but it may also lead to side effects that are opposite to adrenaline's effects, such as a slow heart rate, fatigue, dizziness, drowsiness, cold feet, sleep problems, and weight gain. Sometimes it takes a while for the body to adjust to beta-blockers and sometimes your doctor may have to change the dose or switch medications to deal with side-effects. Also, as a child grows, his or her beta-blocker dose will have to be adjusted for his growing size in order to prevent a recurrence of symptoms. Once you are taking beta-blockers, it is very important that you take the prescribed pills every day, as stopping the medication suddenly puts you at an even higher risk for an arrhythmia. Since LQTS has been treated with beta-blockers, mortality has been reduced dramatically and they are now used in nearly all patients. There are different types of beta-blockers, so other ones can be tried if the first one prescribed doesn't appear to work or if side-effects are excessive.

"When I was first prescribed beta-blockers, the side effects were terrible. I was exhausted all the time, I felt cold, and I was having terrible nightmares. I didn't realize that there are different types of beta-blockers until my pharmacist asked me about side effects. The medication I'm taking now works much better, though I still get tired more easily than before my diagnosis."

- Anna

Pacemaker:

The rate at which the heart beats is usually determined by a special group of cells in the heart's right atrium called the sinoatrial node. Pacemakers are

devices that are designed to take over and set the rhythm of the heart in patients whose own heart rhythm is abnormal. LQTS patients who continue to have episodes while on beta-blocker therapy are usually referred for either a pacemaker or implantable cardioverter defibrillator (ICD). Pacemakers may be especially helpful for patients who have a slow heart rate, and patients with LQT3.

The operation to implant a pacemaker takes about one hour in older children. The device is placed under the skin just under the collarbone and it is connected to wires that are implanted in the heart. In younger children, the pacemaker leads may be sewn directly onto the outside of the heart and the device placed under the skin of the abdomen (belly). The pacemaker contains a battery and a little computer that is programmed to stimulate the heart to beat at particular rates. After receiving a pacemaker, the patient requires regular checkups with the doctor to make sure it is working properly. Sometimes these assessments can be done over the telephone.

Patients with pacemakers require surgeries, on average, every 7-10 years in order to replace the battery. In the cases of children, sometimes, as they grow, they will require surgery to lengthen the wires between the pacemaker and the heart.

Some people may have difficulty adjusting to the idea of having a pacemaker in their body. This feeling is usually temporary, but it is important to seek help if you are having trouble coping.

Implantable Cardioverter Defibrillator:

In some episodes of LQTS, the heart stops beating and begins fluttering in a very fast and dangerous rhythm called ventricular fibrillation. When this rhythm is present, a strong electric shock to the heart is the only way to "reset" it so it can start beating in a normal rhythm again. The process of shocking the heart back into normal rhythm is called defibrillation, and many people are familiar with the electric paddles used for this purpose from medical TV shows like "ER". Implantable cardioverter defibrillators (ICDs) are devices that sit in the chest and work like

"There is a good side to all of this. My siblings and I have a closer relationship to each other because we all share this condition. We learned there is more to life than hockey, and we all learned to appreciate each day we have together."

- Lucy

tiny defibrillators inside the body. If the device detects a heart rate above a programmed threshold, an ICD will deliver a shock to the heart to fix the abnormal rhythm. ICDs are recommended in high-risk LQTS patients who continue to have episodes despite being on the maximum dose of beta-blockers. They are also used as first-line treatment in people who experienced a cardiac arrest and had to be resuscitated. Sometimes patients may ask to have an ICD implanted early on in their treatment, after discussion with their doctors.

Left Cardiac Sympathetic Denervation – LCSD:

LCSD is a operation that cuts some of the nerves that supply the heart. It has been shown that this operation reduces the number of fainting spells and risk of sudden death in many people with the LQTS. Although originally described in 1971, it is now being recommended more often for people in whom beta-blockers are not working or not tolerated and as an alternative to, or together with, an ICD. The operation needs to be done by an expert to make sure it is effective, and it is usually combined with other treatments. This choice could be discussed with your cardiologist.

Potassium Supplements:

Because LQT1 and LQT2 occur due to problems with the channel that moves potassium in the heart, it is important that there always be enough potassium in the body. The doctor may prescribe potassium supplements if the blood potassium levels are low. During sickness with vomiting or diarrhea, patients are more likely to have low potassium levels. Drinking a sports drink like Gatorade can help correct this.

What lifestyle changes should I make to help prevent arrhythmias?

In addition to medication, pacemaker or ICD, there are some changes you can make to reduce your risk of having an episode.

Not all of these suggestions are useful for every patient. Discuss fully with your doctor which lifestyle modifications he or she recommends.

Avoiding Drugs that Prolong the QT Interval:

This is a very important precaution for all patients who have been diagnosed with LQTS or who have suspected LQTS. There are some medications that make the QT interval of the heart even longer. This does not affect most people, but in people who already have a long QT interval, it can increase the likelihood of a dangerous arrhythmia.

"I think the hardest part of having Long QT Syndrome is avoiding the drugs on the list. I have asthma and I used to suffer from depression, and many of the medications that would have been helpful are contraindicated due to my condition. I give my doctor a lot of credit for finding a way to treat me without all of those medications!"

- Nicola

Because the list of medications is always changing, it is recommended you frequently check the complete list on the website www.qtdrugs.org. Drugs have both a generic name and a brand name so, for example, the generic name of Advil is ibuprofen. Also, brand names are different in different countries, so checking the generic name is always best. In addition to drugs that prolong the QT interval, certain other drugs may adversely interact with your beta-blocker medication.

Before taking any medication, including over-the-counter medications, it is highly recommended that you inform your doctor or pharmacist that you have LQTS and ask them to consult the website at www.qtdrugs.org to become informed about your case.

If you require surgery or any dental procedure where an anaesthetic will be administered, be sure that the surgeon or dentist has consulted the website at www.qtdrugs.org to become informed about the contraindicated anaesthetics/ medications for LQTS.

Participation in sports:

Participation in sports is definitely an issue you should discuss with your doctor. Many physicians caution people with LQTS to avoid participating in highly competitive sports. However, because physical activity is important in order to optimize overall good health, it is recommended that LQTS patients find a level of recreational activity that suits the severity of their condition and their personal preference. If you play on a team or use a community centre for recreation, it would be important that the team or facility have an AED at hand (see page 15 about AEDs). Be sure that you know where these devices are located and that they are available if needed.

"Sports were my son's life. I thought he would be completely depressed when we told him he could no longer play competitive hockey. But he surprised me with his resilience! He still loves sports, but now is a terrific golfer and he gets involved in other ways, like coaching younger kids in hockey and acting as a referee at school basketball games."

- Lily

Swimming is a particular concern in patients with LQT1 because they are at a significantly increased risk of having an episode while in the water. If you do decide to swim, make sure there are people and equipment to assist you if you have an episode in the water.

For parents it is important to discuss your child's physical limitation with his or her school so that accommodation can be made in gym class and recess. Making emergency plans for the school to follow if the child faints or receives a shock from his or her ICD is crucial in making school as safe as possible for your children.

Complementary therapies:

Some patients find complementary therapies, such as reflexology, massage, homeopathy, and chiropractic treatments helpful. Before trying any of these therapies it is important that you consult with your doctor to make sure the therapy is safe for LQTS patients and it does not interfere with your medication. Remember that naturopathic remedies are also drugs, and they can react with beta-blockers and other medicines.

MedicAlert bracelets:

MedicAlert is a company that maintains a database of people with medical problems so emergency personnel can access their medical information quickly.

Members of MedicAlert wear a bracelet, dog tag, or wristband inscribed with a file number. If a person with LQTS is wearing the bracelet and has as an episode of syncope, a paramedic arriving on the scene can contact MedicAlert and reference the file number on the bracelet to find more specific information about the person's medical condition and information about who to contact in an emergency. MedicAlert bracelets are an excellent way to assure that you will get the most appropriate treatment if you have an episode. For more information about MedicAlert, go to their website www.medicalert.ca, or telephone them at 1-800-668-1507. MedicAlert charges for its services, however there is a Member Assistance Program that provides these identifying bracelets to people who may need financial assistance. Although it is possible to purchase medical bracelets from your local drug store, we strongly recommend that you buy the bracelet from MedicAlert because the other bracelet companies do not maintain a database of patient information.

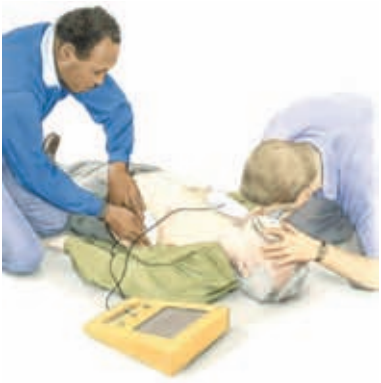
CPR lessons:

Many family members of people with Long QT Syndrome take CPR (cardiopulmonary resuscitation) courses so they are able to respond if their loved one should have an episode at home. In Canada, CPR courses are run in many locations by teaching agencies such as St. John Ambulance, Lifesaving Society, and Red Cross. There are also many private companies that provide CPR certification. Many training companies will arrange for a CPR instructor to come into your home to teach your family or a small group.

For more information or to find a location in your area, use any internet search engine or the yellow pages.

Automatic External Defibrillators:

Automatic external defibrillators (AEDs) are devices that allow a non-medical person to deliver lifesaving electric shocks to a person whose heart has stopped beating. AEDs are similar to the electric paddles used in hospitals and ambulances, but many also have an automated voice telling the user what to do so they can be operated by almost anyone in the case of an emergency.



If you or your child have been diagnosed with LQTS, it is reasonable to discuss having an AED available for your place of employment or for the school your child attends. Please contact The Canadian SADS Foundation for assistance in this matter.

Whether families with Long QT Syndrome should purchase AEDs for the home is somewhat controversial at the moment. While many families feel that owning an AED gives them peace of mind, it also can exaggerate the perception of risk and affect the patient's quality of life. In order to own an AED, you must obtain a prescription and be trained in the use of the device. As with everything, it is best to ask your doctor if he or she thinks this is a good idea for your family.

Other lifestyle modifications:

There are some changes that can be made in your home and activities that can further reduce the risk of having an episode. Not all of these modifications are appropriate for all LQTS patients, but you can ask your doctor which changes he or she recommends.

In patients with LQT2, it is recommended that doorbells be turned to "low", that telephones be turned down and removed from bedrooms, and that loud alarm clocks not be used. If your workplace or school has fire drills, you may ask to be warned when these will be occurring so you can excuse yourself or the child can be taken out of class at that time just before the drill. Some patients also choose not to

"Our family has agreed to be involved in many studies about LQTS; it's great because we've met lots of doctors who can answer all our questions."

- Kia

watch scary movies or take frightening amusement park rides in order to reduce the risk of being startled. As mentioned earlier in this section, people with LQT1 are at a higher risk when they are swimming, so it is important to exercise caution near the water. Some parents put lifejackets on their children when they are close to water.

"This is such a weird thing to have wrong with you – it's something that nobody thinks to worry about in life, and it makes you appreciate life that much more."

- Tessa

It is always good to eat a well-balanced diet with lots of potassium (potassium-rich foods include bananas, orange juice, tomatoes, spinach, squash, potatoes, broccoli, and raisins) and to maintain a healthy weight through non-strenuous exercise. Some patients also choose to avoid caffeine by restricting their intake of products like cola and coffee.

You may wish to explain to family and friends about the significance of being affected by LQTS. This booklet may offer a good source of information for you when informing others.

In cases where your children have been diagnosed, it is important for you to inform the schools they attend, their teachers, and their friends' parents that any fainting on your child's part should be treated as a medical emergency and 911 needs to be called if this occurs.

Warn everyone in your circle that startling you may be dangerous and not funny or appropriate.

What are common parenting challenges when raising a child with Long QT Syndrome?

Raising a child is certainly one of the most difficult tasks there is, but raising a child with Long QT Syndrome presents a whole new set of challenges. Children are often uncomfortable being treated differently than their peers, and this stress may manifest itself as frequent stomachaches and headaches. Diagnosis of a chronic condition in a child places stress on all of the family, and siblings may

feel neglected as a result. The important thing to remember is that everybody has trouble adjusting to a diagnosis of LQTS initially, but most learn how to cope with it. There is always help available as well. Ask your child's cardiologist or genetic counsellor (if you have consulted one) about people who can help your family cope. Many parents find that learning more about the condition helps them to feel more in control. Reading this booklet is a good first step, but using some of the resources listed below can help broaden your understanding. Some people find it helpful to speak with other parents, patients, or siblings, who have had similar experiences; www.sads.ca is a great place to begin finding people to share stories and coping mechanisms. Different parents choose different ways of dealing with LQTS. What remains important is choosing the balance that is right for your family.

Advice from parents of children with Long QT Syndrome

We asked parents of children with Long QT Syndrome which advice they would give to parents who had just discovered their child had LQTS. Here are some of their answers:

"Remember that only a small number of people with LQTS ever have a cardiac arrest – the odds are on your side!"
- Kimberly

"Knowledge is power. Learn all you can and don't be afraid to ask questions."
- Madeline

"Tell everyone you know – there is nothing to be ashamed of, and it is important for people to know that fainting is sometimes not just fainting."
- Jason

"Enjoy your children and don't put them in a bubble!"
- Penny

Where can I find more information about LQTS?

www.sads.ca - The Canadian SADS Foundation website is a great place to start your search for more information. This website provides you with an opportunity to read the latest newsletter, sign up to be on The Canadian SADS Foundation mailing list, or learn about plans for a patient education conference in your geographical area.

www.qtdrugs.org (Maintains an up-to-date list of medications that should be avoided by LQTS patients)

www.sads.org (The American SADS website)

www.chrsonline.ca (A resource to help you find a heart rhythm doctor in your area)

www.cagc-accg.ca (A resource to help you find a genetics counsellor in your area)

www.hrspatients.org (An American site about different cardiac arrhythmias with lots of information about ICDs and procedures)

www.medlineplus.gov (A good general reference for information on any health concerns)

www.qtlong.com/accueil.html (A website with information about LQTS in French)

Preventing Sudden Cardiac Death In Children and Young Adults

The Canadian SADS Foundation , a registered Canadian charity, is the only patient advocacy group in Canada dedicated to supporting families affected by inherited cardiac rhythm disorders and committed to raising awareness about "*The Warning Signs*" for these sometimes devastating disorders.

The Canadian SADS Foundation is committed to promoting awareness to health care professionals, educators, sports groups and the general public and to providing information and support to families affected by inherited cardiac rhythm disorders.

It is estimated that as many as 50% of young people who experience a sudden cardiac death (SCD) had symptoms prior to their event. These symptoms may have been either misdiagnosed or dismissed as insignificant. Recognition of "*The Warning Signs*" and early medical intervention are the keys to preventing an SCD in children and young adults:

- **Fainting (syncope) or seizure** during physical activity.
- **Fainting (syncope) or seizure** resulting from emotional excitement, emotional distress, or startle.
- **Family history of unexpected sudden death** during physical activity or during seizure, or any other unexplained sudden death of an otherwise healthy young person.

A young person who has experienced any one of these "Warning Signs" should be referred to a cardiologist or an electrophysiologist for a complete cardiac assessment. This assessment should include an analysis of the heart rhythm and, where indicated, cardiac imaging and exercise testing.

For further information, please contact **The Canadian SADS Foundation** at www.sads.ca or call 1-877-525-5995.

Supporting Families. Saving Lives.

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www.sads.ca

This booklet was originally written in 2007 for *The Canadian SADS Foundation* by Dr. Kate Houston who, at that time, was a medical student at the University of Toronto.

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Quotes are a summary of patient perspectives.

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