It depends on how high your risk is of getting an abnormal ventricular heart rhythm (from the bottom of your heart). Those at most risk are people who have had a cardiac arrest or blackouts/collapses, a very long QT on the ECG, girls in puberty and young adulthood and boys before puberty.

If you are at high risk, especially if you’ve had a cardiac arrest then an ICD is needed. You may also get beta blocker tablets which can be very protective. Sometimes a pacemaker is a good alternative to an ICD in younger children who are at higher risk. They may also have an operation on the left side of the neck to treat the nerves that go to the heart (a sympathectomy).

If you are not so high risk then only beta blockers may be needed. Sometimes other drugs are used.

Please see our leaflets on ICDs and pacemakers if you are going to have one.

What are the symptoms?

Tests include ECGs, 24-48 hour ECG monitoring and exercise ECG tests, which are all painless and involve having sticky labels on your chest. Often genetic testing is needed which can be done on a small amount of your blood or sometimes a small amount of your spit.

Some genes with faults have been found in Long QT syndrome. So even if you have Long QT syndrome it may be that your family gene isn’t yet known. Or you may have a faulty gene that can cause Long QT syndrome but a long QT interval doesn’t yet show up on your ECG, so you may need to have further testing. It is important to look at your family medical history during this period of time.

Some people get more symptoms than others who may have none at all. The main, and most important symptom, is collapsing and blacking out suddenly. Occasionally you may feel palpitations where your heart seems to have extra beats or missing beats. There are usually no physical signs of LQTS. In some people LQTS can cause a small sudden stop of your heart, where your heart stops pumping blood around the body and you stop breathing. This is called a cardiac arrest. It is very dangerous and needs immediate attention.

1. List of any medicines you should avoid that can worsen the QT interval
   - Loud noises/startle may cause blackouts in some people
   - Physical activity can still continue but may need to be changed
   - Pregnancy and genetic counselling
   - Contraception
   - Illegal drugs and alcohol can often make long QT worse
   - Counselling/support groups

What is Long QT Syndrome (LQTS)?

LQTS is a condition that causes your heart to stop beating normally and you stop breathing. This is when your heart stops pumping blood around the body and you stop breathing normally. It is very dangerous and needs immediate attention.

Please see our leaflets on ICDs and pacemakers if you are going to have one.
Normal electrical pathway

Ventricular arrhythmia

SA node
AV node
right ventricle
left ventricle

QT interval

normal QT interval
prolonged/long QT interval