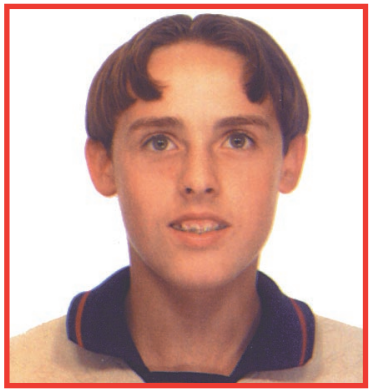
My Son Ashley



My beautiful fit and healthy son Ashley died 28th May 1998, he was 16 years old. He went to bed on the 27th and didn't wake up the next morning. The official cause of death was an asthma attack. He had never had asthma, or even a hint of it.

Ashley didn't suffer from many bugs that went around, his immune system seemed impenetrable! He even won awards for having no time away from school. Ashley was always looking towards another goal in his life. He tried so many activities; trampolining, badminton, roller skating, skateboarding, fishing, just to name a few! His main passion was football, which he played since the age of 6 years old. At 13 he bought a go-kart and loved go-karting with his dad.

Ashley had an enthusiasm for life that inspired those he met; a quiet, gentle boy, someone people could depend upon. He was my best friend and soul mate. Ashley's life would not have been done justice if I did not discover why he died and try to stop this happening to other people.

After months of research I discovered a condition that could occur with the 'electrics' of the heart (Long QT Syndrome) which could cause a fit and healthy person to suffer a fatal cardiac arrhythmia and die suddenly. It could be inherited or induced by medication. I believed Ashley's was induced by medication taken as prescribed for hayfever.

The inherited condition can affect other members of the family and it is for this reason that we believe that after a sudden death all family members should have thorough heart checks carried out.

The Ashley Jolly Sudden Adult Death Trust (SADS UK) was formed in honour of Ashley. The Trust fundraises and seeks donations and grants to provide heart-monitoring equipment and Automated External Defibrillators (AEDs). It supports education and research into cardiac arrhythmias.

SADS UK,
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Tel: 01277 230642

Affiliates:

The SADS Foundation USA
www.sads.org

The Canadian SADS Foundation
www.sads.ca

Australian SADS Foundation
www.sads.org.au

SADS – An umbrella term

Sudden Arrhythmic Death Syndrome (SADS) is an umbrella term which covers cardiac conditions that may cause sudden and unexpected death if not treated. SADS is sometimes reported as Sudden *Adult* Death Syndrome, but this term is misleading, as these types of death also occur in children and young people.

It is estimated that, each year in the UK, 3,500 apparently fit and healthy people under the age of 65 die suddenly and unexpectedly. Some of these are children and teenagers. These people have no previously documented heart disease.

The following conditions can predispose people to suffer a cardiac arrest:-

- Hypertrophic Cardiomyopathy (HCM)
- Arrhythmogenic Right Ventricular Dysplasia (ARVD)
- Long QT Syndrome (LQTS)
- Wolff-Parkinson-White Syndrome (WPW)
- Brugada Syndrome, and
- Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT).

Once diagnosed these conditions can be treated and lives saved.

Many cardiac conditions have a hereditary (genetic) origin. If a cardiac condition is detected or suspected, or if there has been a premature sudden death of a healthy person, other family members should be referred to a cardiologist and genetic counsellor to find out whether they may have inherited the same condition.

Epilepsy is sometimes wrongly diagnosed instead of a cardiac condition. This is because a blackout caused by an arrhythmia can look just like a blackout caused by generalised epilepsy, with abrupt loss of consciousness, twitching arms and legs and incontinence. A significant number of patients who have suffered a syncope episode have been diagnosed first with epilepsy, and given epilepsy treatment. Long QT Syndrome and other genetic cardiac conditions have later been diagnosed.

Heart attack is not the same as Cardiac arrest.
A heart attack; (myocardial infarction) occurs when blood flow to the heart muscle is blocked.

A cardiac arrest is when a sudden and severe disturbance of the heart rhythym stops the heart beating or causes it to beat so slowly or so fast that it cannot pump enough blood to sustain life.

Ashley Jolly
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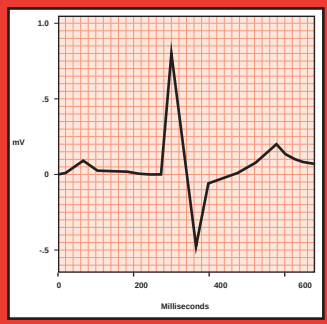
Sudden Adult Death Trust

SADS UK

Supporting Families affected by cardiac arrhythmias



Heart conditions can exist in apparently healthy people, sometimes even children. These conditions may cause a disturbance of the heart rhythym (an arrhythmia). In some instances, if the condition is not treated it could cause cardiac arrest.

Heart disease does not just affect those in the later years of Life.

Ashley Jolly
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Sudden Adult Death Trust
SADS UK

Registered charity no. 1113681

The Ashley Jolly SAD Trust
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BHF Heart health catalogue order number M104A

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What is an Arrhythmia?

It is an abnormal heart rhythm (beat) outside of the normally acceptable range of 60 to 100 beats per minute.
Tachycardia – rhythm above 100bpm.
Bradycardia – rhythm below 60bpm.
A disturbance of the heart's electrical signal or an abnormality of the muscular tissue of the heart may cause an arrhythmia. Ventricular (lower pumping chambers) fibrillation is the most dangerous arrhythmia, being fast, irregular and often occurring without warning.

What are the symptoms of arrhythmias?

Palpitations, light headedness, chest pain, sudden fainting (syncope) during exercise or emotional excitement.
In many cases there are no symptoms before sudden death.

Methods of detection

Resting 12 lead ECG, stress ECG (heart rate below 150bpm) or 24hr heart monitor. If you have any of the above symptoms, have a family history of sudden unexplained death, ask your doctor for an examination.

What is the treatment?

Medication called beta blockers may be effective in some sufferers. In others, a pacemaker or implantable cardioverter-defibrillator (ICD) may be required.

Abnormalities of the heart's electrical system

LQTS, Brugada, Wolff-Parkinson-White are the more commonly known syndromes. The changes to the heart's electrical system may be caused by medication (see drugs to avoid list), a genetic disorder or heart muscle condition.

Abnormalities of the heart's structure

Hypertrophic cardiomyopathy (HCM) is an increased thickness of the heart muscle. This thickening is usually seen in the left ventricular septum without change to the size of the ventricular cavities. HCM is a genetic condition, which usually shows a familial pattern.

Symptoms include shortness of breath with activity, sudden shortness of breath at night, difficulty sleeping, fainting, fatigue and palpitations.

Beta-blocker

This is a drug that reduces the symptoms connected with hypertension and cardiac arrhythmias. Beta-blockers are sometimes given to stabilise the heartbeat, it lowers blood pressure and heart rate, stopping arrhythmias.

Drugs (medication) to avoid list

See list on the SADS Foundation web site: www.sads.org, www.torsades.org, www.azcert.org or www.qtdrugs.org

The primary purpose of this leaflet is for guidance;
specialist advice should be sought regarding these conditions.

Long QT Syndrome (LQTS)

LQTS is a disturbance of the heart's electrical signal that can cause an abnormally fast heart rhythm (arrhythmia) which can cause fainting and sometimes causes sudden death. The pores in the heart cells called ion channels are affected, and it is this abnormality that alters the electrical activity that intiates a heartbeat.
The usual symptom is sudden fainting during exercise or emotional excitement such as anger, fear or startle, but it can also occur during sleep or arousal from sleep. A family history of fainting (syncope) or unexplained sudden death may indicate a genetic basis to a disorder.

Wolff-Parkinson-White Syndrome (WPW)

This is a hereditary condition where the electrical signal controlling the heartbeat that should pass over the atria and flow through the atrio-ventricular (AV node) before passing over the ventricles, bypasses the AV node and triggers the ventricles too soon.

The presence of this electrical bypass (short circuit) causes atrioventricular reentry tachycardia (AVRT). The bypass consists of an extra piece of heart tissue, which is present from birth. WPW syndrome may cause tachycardia but this does not normally occur until the teens or early twenties.

Brugada

As with LQT the heart structure is normal but Brugada has a distinctive ECG trace resembling right bundle branch block and ST segment elevation. Symptoms may include fainting episodes due to ventricular fibrillation or ventricular tachycardia. Beta-blockers and other antiarrhythmia drugs have little effect in the treatment of Brugada thus an implantable cardioverter defibrillator is often necessary.

Arrhythmogenic Right Ventricle Dysplasia (ARVD)

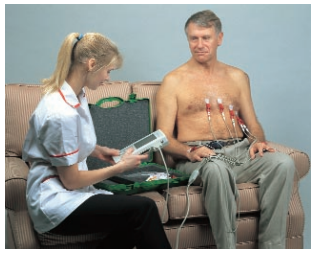
The right ventricle, the lower right pumping chamber of the heart has an abnormal (dysplasia) structure. The ventricle muscle tissue is progressively replaced by a fatty and fibrosis structure. This weakens the muscle and causes the heart to function abnormally, with evidence of the disorder sometimes recognised on a resting ECG.

ARVD is most commonly found in adults between 20 and 40 years of age, but ARVD has also been diagnosed in children and older people. There is strong evidence that ARVD is often a familial (genetic) disorder.

Implantable Cardioverter-Defibrillator (ICD)

This is a device implanted in the body near to the heart that briefly passes an electric current through the heart. The ICD can vary the intensity of the shock administered (dependant on the heart condition) to resynchronise the heartbeat. It protects patients whose heart rhythms may escalate to the lethal condition called fibrillation.

Phone 01277 230642 for leaflets giving details about the above conditions



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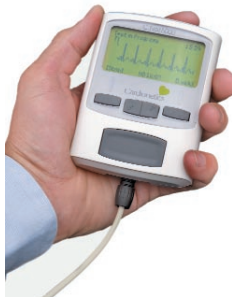

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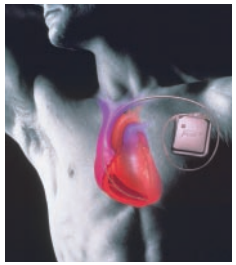

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Cardioverter-defibrillator**

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