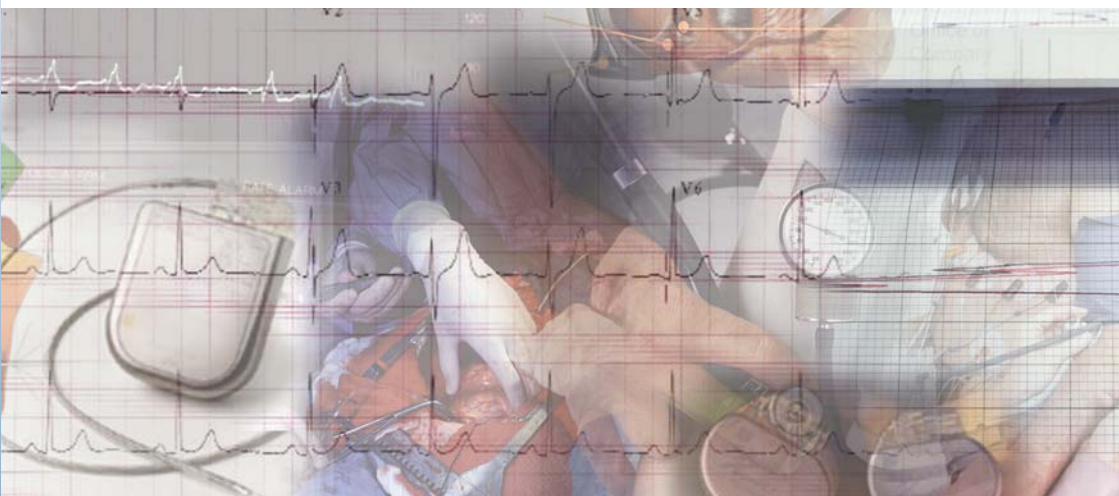


Arrhythmia Alliance

Promoting better understanding, diagnosis,
treatment and quality of life for individuals
with cardiac arrhythmias

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The Heart Rhythm Charity



I saw equipment everywhere
I even saw some in the air.
My blood pressure was very high
I just kept asking myself why oh why?

The wires were everywhere around my heart
And then the test was about to start.
I lay so frightened on the big bed
I then felt dizziness around my head.

Time passed by and I became bored
But I knew my heartbeat had to be stored.
I then felt funny and fell asleep
I woke up and felt the nurse kissing my cheek.

I wanted my mum oh so much
Just to feel her gentle touch.
It was all over and I was glad
Even though I was feeling sad.

Nicola, aged 11 years

A Sort of Quest...

Beating Hearts - message of support from Bill Beaumont



As a sufferer of atrial fibrillation, I am well aware of the effect that arrhythmia can have on people's lives. Even if they are not immediately or directly threatened by an arrhythmia, it can still be very disruptive. I have a business to run, duties in the sporting world and in the media. These commitments can suffer greatly if an arrhythmia takes hold. Also, you never know when it's

going to strike, so planning meetings and events can be disrupted.

Nevertheless, I am lucky that my atrial fibrillation is more of a nuisance than a threat. Many families are struck by sudden unexpected death, which can affect people in the prime of life, in childhood or as young adults, causing terrible bereavement. My heart goes out to families who have lost loved ones. I have been lucky to get help from a cardiologist with a special interest in cardiac arrhythmias, but in the UK, there are only about 70 such cardiologists.

Arrhythmias have been regarded as less important than heart attacks until now. Thankfully, the Government is now focusing its efforts and resources on increasing the awareness of the potential effects of arrhythmias, the need for better services to detect and correct them, and the need to grow the workforce to ensure that every patient has had the expert care that I have received.

I am pleased to be associated with the Arrhythmia Alliance as a patron. The Alliance has done a tremendous job in a very short time getting the arrhythmia community ready to meet the challenges of the new National Service Framework for Arrhythmias. I extend my best wishes to Trudie Lobban and the Trustees of the Alliance, and to Professor Camm and the Executive Committee, and wish them well for the hard work to come.

*Bill
Beaumont*

What are Arrhythmias?..

A Cardiologist explains - "An arrhythmia occurs when the normal electrical cycle of the heart is disturbed. Normally, tiny currents activate the top part of the heart (atrium), just before the bottom part of the heart (ventricles), which are the muscular chambers that pump blood around the body. Fast arrhythmias are referred to as 'tachyarrhythmias'. When the heart goes too slowly due to a failure of electrical activation, it is referred to as a 'bradyarrhythmia'.

Most arrhythmias arising from the top of the heart, (supraventricular) are troublesome but not life threatening. Many arrhythmias arising from the bottom of the heart, (ventricles), are life threatening. Many arrhythmias can be completely cured by keyhole techniques, (catheter ablation). Ventricular arrhythmias are often much harder to treat, and often require powerful drugs and implantable defibrillator to prevent premature death. Britain has very low rates of ablation and defibrillator implantations".

Dr Adam Fitzpatrick, Consultant Cardiologist, Manchester Royal Infirmary

So there are two basic types of arrhythmias, with variations of each:

Bradycardia - a heart rate that is too slow, usually less than 60 beats per minute.

Tachycardia - a heart rate that is too fast, usually more than 100 beats per minute.

Cause of Arrhythmias - An arrhythmia can occur for various reasons, such as:



when the heart's natural pacemaker (the SA node) develops an abnormal rhythm;








when the normal conduction pathway is interrupted or blocked;



when electrical impulses originate from another part of the heart

Symptoms of Arrhythmias - Arrhythmias can produce many symptoms. Some are barely perceptible, while others are so dramatic that they can cause cardiovascular collapse and death. Among the more common symptoms are:

-  premature beats, palpitations, or skipped beats
-  dizziness
-  fatigue
-  lightheadedness
-  fainting or near fainting

How are Arrhythmias Diagnosed? - An electrocardiogram (ECG or EKG) is the standard tool used to diagnose arrhythmias. It records the timing of atrial and ventricular contractions. Sometimes arrhythmias are captured by using small, portable recorders called Holter monitors. This device can record 24 hours of ECG signals. An event monitor which lasts about 30 days, is a similar device that records ECG events in a continuous loop. For arrhythmias that occur less frequently, an insertable loop recorder can be implanted under the skin of the chest and records heart activity for more than a year. This is especially helpful for people who suffer infrequent, unexplained fainting spells.

A more proactive way to determine if arrhythmias are present is to provoke them in order to make their diagnosis and treatment easier. A simple exercise test on a treadmill may be used for some people, while a tilt-table test may be used to try and reproduce fainting. Another valuable test is called an electrophysical test (EP test), in which a temporary catheter is inserted into the heart and used to 'map' the electrical signals of the heart. During this test, the heart can be manually stimulated to induce fast heart rhythms, which may be an indication that a patient is prone to dangerous arrhythmias.

Treatments for Arrhythmias - Bradycardia conditions can sometimes be treated with medications that help improve the transmission of impulses through the conduction system. A more common way is with a cardiac pacemaker, a tiny implantable device that is placed just beneath the skin in the upper chest. Small wires (leads) connect the device to the inside of the heart and provide electrical impulses as needed to stimulate the heart when it beats too slowly on its own. Pacemakers can last 10-12 years, depending on use, before needing replacement.

For the more dangerous tachycardias - such as ventricular tachycardia (150-250 bpm) or the usually lethal ventricular fibrillation (250+ bpm) - antiarrhythmic drugs and other medications are used, but recent clinical trials have shown that a small device called an implantable cardioverter-defibrillator (ICD) is the most effective treatment for these arrhythmias. They are slightly larger than a pacemaker, but implanted in much the same way. Rather than speeding up a slow heartbeat, however, they monitor the heart and provide electrical pulses or shocks to slow down a heart that begins to race out of control.

Once the heart goes into ventricular tachycardia, sudden cardiac arrest may follow and a defibrillation shock is needed within minutes or the result will likely be death. Sudden cardiac arrest (SCA) is one of the most common causes of death. It is not the same as a heart attack, which is caused when coronary arteries become clogged, leading to the death of heart muscle. Many people survive heart attacks, but SCA, an electrical problem, is usually 95% fatal without proper intervention by a defibrillator, either using a portable automated external defibrillator (AED), or an implantable defibrillator.

It is important to note that, if someone survives either a heart attack or an episode of sudden cardiac arrest, they are at increased risk for additional potentially deadly arrhythmias. These persons should be evaluated by an electrophysiologist (a heart rhythm specialist) to ensure they receive adequate protection against future episodes.



Sir Roger Moore

"I experienced a syncopal episode, a form of arrhythmia, when on stage in New York. I was fortunate to be fitted with a pacemaker that allows me to continue to live life to the full.

"I certainly support this campaign and feel it is essential for every individual suffering an arrhythmia in the UK to receive as speedy a diagnosis and as effective treatment as I did."

as I did."

Understanding Arrhythmias?..

At least 1,000,000 people in the UK have experienced a cardiac arrhythmia, the medical term for an irregular heartbeat or abnormal heart rhythm. That is a minimum of about 1 of every 85 members of the British population, from infants to the elderly, with a heart rate that occasionally or consistently beats too quickly, too slowly, abnormally or irregularly. Accurate statistics remain elusive because some heart rhythm disorders go undiagnosed or misdiagnosed, and also because of limitations in availability of, or access to, diagnostic tools and screening techniques.

Whatever their true prevalence, cardiac arrhythmias can lead to significant health problems. They can also lead to psychological distress and greatly diminish the quality of life of sufferers and their families. At least 90,000 people die every year from sudden cardiac arrest resulting from a lethally fast heart rhythm. Meanwhile, at least 30 per cent of people being treated for epilepsy actually suffer from a cardiovascular cause of the blackout: often an arrhythmia that leads to syncope. This is a transient loss of consciousness (T-LOC) that sometimes resembles a seizure, but is due to a loss of blood flow to the brain, not epilepsy.

Some cardiac arrhythmias result from congenital heart defects that run in families. Others arise from a variety of diseases that develop in individuals over a period of years. Others still result from sudden events such as heart attacks.

Cardiac arrhythmias vary widely in type and severity, as do methods for their diagnosis and treatment. Once diagnosed, however, they can usually be treated effectively with drugs, devices or surgery - or a combination of these. Cardiologists are the specialists responsible for diagnosing and treating heart rhythm disorders.

If you suspect you might have an arrhythmia or any heart condition at all, insist on seeing a cardiologist as soon as possible. Your health, even your life, may depend on it.

DON'T WAIT UNTIL IT'S TOO LATE

Cardiac Arrhythmias...

Ablations

Atrial Fibrillation

Atrial Flutter

ARVC

Biventricular Pacing

Blackouts / T-LOC

Bradycardia

Brugada

Cardiac Arrhythmias

Cardiac Resync Therapy (CRT)

Catheter Ablation

Cardiomyopathy

Dilated Cardiomyopathy

Fainting

Hypertrophic Cardiomyopathy

Implantable Cardiac Defibrillator (ICD)

Long QT

Pacemakers

Pallid Syncope

Palpitations

Paroxysmal Supraventricular Tachycardia

**Reflex Anoxic Seizures
(Reflex Asystolic Syncope)**

Stoke Adams Seizures

Sudden Arrhythmic Death

Tachycardia

Vasovagal Syncope

Ventricular Fibrillation

Ventricular Tachycardia

Wolff-Parkinson White Syndrome



Shelley Wilson

"I was diagnosed with Vaso-Vagal Syncope when I was 23. At the time, the diagnosis was a tremendous relief as I felt that having RAS was really affecting my quality of life, making me feel disconnected and depressed. As a child and into my late teens I was terribly anxious and experienced severe night terrors which other people found difficult to understand. I now know this is a common symptom.

My RAS attacks really "took off" when I went off to University, occurring often at half term when I was supposed to be catching

up with coursework but of course with feeling sick this was an impossibility.

My mother and I were visiting doctors after nearly every seizure but they could not find a diagnosis. Things came to a head when I had about five in a short period of time - the most memorable being one in the aisle of a plane. The turning point was a particularly horrendous seizure after a travel injection. When I came round I thought I'd had a stroke as I couldn't speak or move properly for about two hours. Luckily my doctor witnessed the attack and referred me to Professor Kenny at Newcastle Royal Infirmary.

I then had the famous tilt table test and was told I needed a pacemaker - which has dramatically changed my life.

Who are the Alliance?..

Arrhythmia Alliance - (A-A) is a coalition of charities, professional medical groups and industry allies. These groups work together under the Arrhythmia Alliance umbrella to promote timely and effective diagnosis and treatment of arrhythmias.

President of Executive Committee - Professor A John Camm
Arrhythmia Alliance Founder Trustees are -



*from the left:
Dr Adam
Fitzpatrick,
Trudie Lobban
and
Derek
Connelly*

- Dr Adam Fitzpatrick - Trustee & Medical Director of A-A
- Trudie Lobban is founder of the STARS charity, (www.stars.org.uk) - President
- Dr Derek Connelly - President - Heart Rhythm UK & Trustee of A-A
- PATRONS - W B Beaumont OBE and Prof. H J J Wellens

Arrhythmia Awareness Weeks...



*Volunteers take
a well earned break
from duties
at their
first ever
Arrhythmia
Awareness Week*

Consistent with the aims of the inaugural campaign, which took place in May 2004, Arrhythmia Awareness Week seeks to enhance the lives of people with heart rhythm disorders. It aims specifically to raise awareness of arrhythmias among the medical community and the general public with a view to improving the diagnosis and treatment of these common cardiac conditions across England and Wales.

The Arrhythmia Alliance was launched at the start of the first Arrhythmia Awareness Week. The Arrhythmia Alliance was the obvious onward development from the Arrhythmia Awareness Week, to maintain the momentum, and to bring together allied parties, large and small, professional and lay, to funnel their energies toward common arrhythmia goals together.



*Dr Roger Boyle and
Melanie Johnson MP -
Public Health Minister*



*Professor John Camm
President of Executive
Committee
the
Arrhythmia Alliance*



*Congratulations from PM
Tony Blair*







Key Facts about Arrhythmia Alliance and its work...




Aims And Objectives

Overall Aim:

-  To raise awareness of cardiac arrhythmias, to improve the diagnosis and treatment of cardiac arrhythmias, and to enhance the quality of life for people living with cardiac arrhythmias
-  To assist with the implementation of the NSF Chapter on Sudden Cardiac Death and Cardiac Arrhythmias

Objectives:

-  To bring together member charities, healthcare professionals, commissioners and their allies
-  To advance the concerns and needs of all our members
To assist the development of the knowledge and skills base of medical professionals and professions allied to medicine
-  To cultivate multi-centre and multi-disciplinary research
To work with others towards the prevention of sudden cardiac death in vulnerable groups
-  To promote, when appropriate, the value and need for cardiac pacing, implantable defibrillators, catheter ablation, and other treatments for arrhythmias

-  To prevent misdiagnosis in patients suffering from arrhythmia and transient loss of consciousness
-  To assess and quantify unmet need amongst those affected by arrhythmia
-  To secure better care, leading to a better quality of life, for individuals with arrhythmia

Resources for Patients and Carers:

Arrhythmia Alliance Stakeholder Conference: July 1st 2004, Royal College of Physicians, London. 150 doctors, nurses, technicians, industry representatives and, above all, patients, met to discuss the unmet need for arrhythmia care in the UK

Patient Orientated Books: Cardiac arrhythmias explained – “Managing Cardiac Rhythm Disorders in the UK: The Need for Change” (available through www.arrhythmiaalliance.org.uk)

Arrhythmias and Sudden Cardiac Death – NHS National Service Framework – Coronary Heart Disease. The Alliance contributed several members to the Reference Expert Groups, (http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4094275&chk=eTacxC)

Explanation and Understanding of Arrhythmias – The Arrhythmia Alliance 2005, (www.arrhythmiaalliance.org.uk). Arrhythmia Awareness Week 2005 –coincided with the publication of the new Chapter for the Coronary Heart Disease NSF and launch by the Department of Health.

The Need:

Cardiac arrhythmias affect more than 1 million people in England and are consistently in the top ten reasons for hospital admission, using up significant A&E time and bed days. Atrial fibrillation (AF), the most common arrhythmia, affect up to 1.5% of the population (rising to 4% in the over 65s) and absorbs at least 1% of the entire budget of the NHS. The overall incidence of stroke is about 4% per year in people with AF. This and aggravated heart failure explains the significant mortality associated with atrial fibrillation. The substantial majority of the approximately 100,000 sudden cardiac deaths each year in the UK are caused by coronary heart disease. Most sudden deaths in people under 30 years old are caused by inherited cardiomyopathies and arrhythmias. An estimated 400 sudden cardiac deaths each year are unexplained but the majority of these may have a genetic basis.

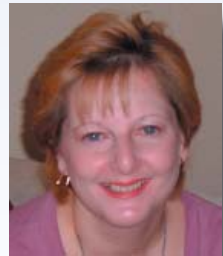
Resources

The UK has only 65 heart rhythm specialists, which is about 1 per million of the UK population – France, Germany and Italy have 5 times as many. The UK has only 650 cardiologists serving a population of 59 million. Countries such as France, Germany and Italy with similar sized populations each have 6,000+ cardiologists. The UK has only 30 heart rhythm nurses. Figures for France and Germany are not available.

Standards

Two examples of incorrect diagnosis:

"After 29 years experiencing blackouts and being misdiagnosed with epilepsy for almost 18 years, I finally received the correct diagnosis and a pacemaker was implanted in September 2004. At 40, my life is only just beginning. It has opened up many new opportunities for my whole family. I now have a husband, not a carer and for the first time ever he has gone to work and not had to worry about what he was going to find on his return. I have applied for new jobs I just wouldn't have previously considered. With my new found confidence, I don't think twice and I am now allowed to drive again."



Julie Fear

"I was very worried about my child. She and her brother were born after IVF, and we had no idea about their family background, but they were very precious because we had tried so long for a baby. The blackouts were very scary. She would collapse and go blue. Often I didn't think she would ever recover. The doctors told me she had epilepsy, but that didn't seem right to me, and when the drugs

didn't work, we got advice from STARS to seek an opinion from a cardiologist. We saw the cardiologist, and for the first time, the possibility of a heart arrhythmia was mentioned. In the end it turned out that both my daughter and her twin brother had the LongQT Syndrome. We had never heard of this, and we were very scared. We looked it up and found that the blackouts were due to a deadly heart arrhythmia, and that she could die at any time. My daughter was treated with beta-blockers, but her blackouts continued. Eventually, we saw the cardiac electrophysiologist and he recommended an implantable defibrillator. The operation went well, and at 3, she was the youngest person in the UK to get the treatment. We are very relieved that this will save her if she had a life-threatening attack, but we wish that we had had the right diagnosis and seen the right doctor from the very beginning."

3yr old misdiagnosed child

Fast Facts...

Arrhythmia by numbers in the UK ...

- ♥ 1,000,000 people suffer with arrhythmia in the UK
- ♥ 1 in 85 persons has experienced an arrhythmia.
- ♥ there is one electrophysiologist (heart rhythm specialist) for every million people in the UK - France, Germany and Italy have 5 times as many.
- ♥ approximately 90,000 people die from a sudden cardiac arrest. 80% of these deaths could be arrhythmia related.
- ♥ up to one-third of patients diagnosed with epilepsy may be misdiagnosed and many of these may be suffering from cardiac arrhythmias.
- ♥ patients spend approximately 1.5 million days in a hospital bed due to cardiac arrhythmias and heart failure.
- ♥ blackouts are a major drain on healthcare resources and cause 1% of all hospital admissions. Cardiac arrhythmias account for about 40% of individuals who experience blackouts and unexplained falls.
- ♥ hypertrophic cardiomyopathy is a primary cause of sudden death in adults under the age of 35yrs.
- ♥ 750,000 patients suffer from atrial fibrillation.
- ♥ there are about 450 pacemaker implants per million population, compared with 900 million in Western Europe and 1000 per million in the United States.
- ♥ only 45 patients per million receive implantable defibrillators to protect them from sudden cardiac arrest, compared with an average of 85 in Western Europe and 400 in the United States.
- ♥ approximately 75,000 people develop heart failure, a chronic and debilitating condition, each year. 15-20% of these patients could be candidates for cardiac re-synchronisation therapy (CRT).



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MEMBERSHIP APPLICATION FORM



Please use BLOCK LETTERS or type
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 Stratford upon Avon, Warwickshire CV37 8YL
 Email: info@arrhythmiaalliance.org.uk
 Website: www.arrhythmiaalliance.org.uk

Name of organisation or individual member	
Charity No (if applicable)	
Contact name & position in organisation (if applicable)	
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between £100 - £250,000	£100	<input type="checkbox"/>
between £250 - £500,000	£250	<input type="checkbox"/>
between £500 - £1 million	£375	<input type="checkbox"/>
between £1 - 2 million	£500	<input type="checkbox"/>
between £2 - 5 million	£750	<input type="checkbox"/>
over £5 million	£1000	<input type="checkbox"/>

Membership is free to individuals however if you would like to make a DONATION please complete and return.

I would like to make a donation to A-A and enclose:	£
I have made donation to A-A via PAYPAL at www.arrythmiaalliance.org.uk to the sum of:	£
I have arranged a standing order from my Bank/ Building Society Account to A-A. (min amount £10p.a.)	£
Please tick here if you agree to Gift Aid your subscription/donation	<input type="checkbox"/> Tick here

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Please allow Arrhythmia Alliance to claim an extra 28p for every £1 you donate at no cost to you. I want Arrhythmia Alliance to treat all donations I have made since 6 April 2000, and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. I currently pay an amount of income tax and/or capital gains tax at least equal to the tax that Arrhythmia Alliance reclaims on my donations in the tax year. I may cancel this declaration at any time by notifying A-A. I will notify A-A if I change my address. Please note full details of Gift Aid tax relief are available from your local tax office in leaflet IR 65. If you pay tax at a higher rate you can claim further tax relief in your Self-Assessment tax return.

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And after this, every: Month / Year (delete)	Account No.:
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