



Syncope Trust And Reflex anoxic Seizures®

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Identifying the Undiagnosed Person

How mobile devices can make a difference



Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures

www.stars.org.uk

Registered Charity No. 1084898

TAKE THE PULSE CHECK CHALLENGE

KNOW THE RHYTHM OF YOUR HEART – MANUAL OR MOBILE

It only takes 30 seconds – yet could save your life!

KNOW YOUR PULSE

Is your heart rhythm too fast, too slow, or jumping around (irregular)?

It could be an arrhythmia (a heart rhythm disorder)

Learn to take your pulse to monitor your heart rhythm



KNOW YOUR ECG

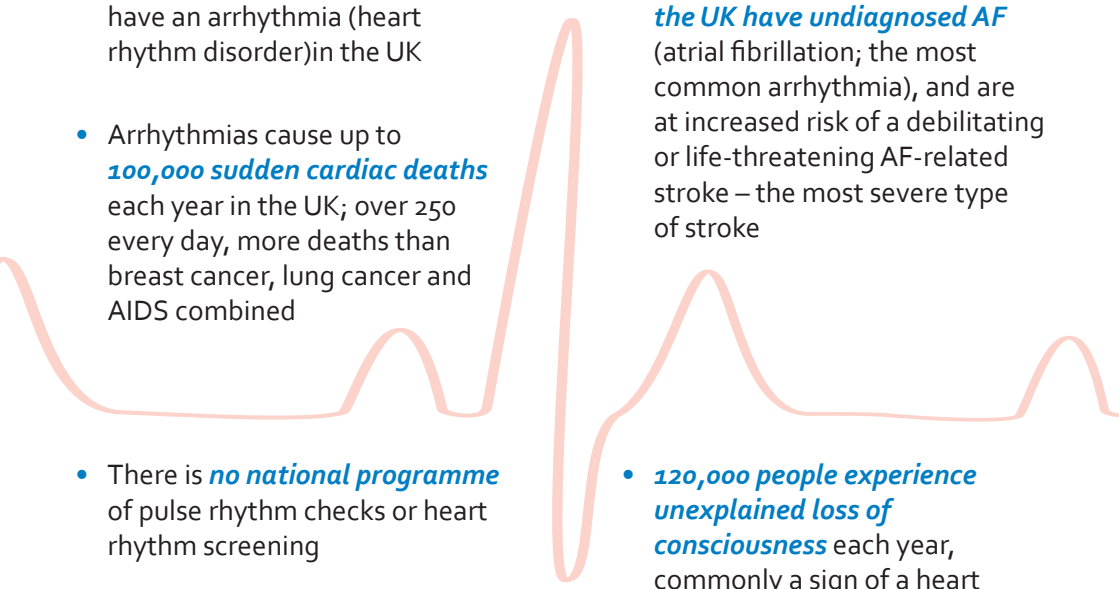
Monitor your heart rhythm with a mobile ECG device

It records your heart rhythm and confirms if normal, AF suspected or if you should discuss the results with your doctor

For more information contact:
info@stars.org.uk



EVERYONE NEEDS TO KNOW THEIR PULSE RHYTHM – IT COULD SAVE YOUR LIFE!

- 
- More than **two million people** have an arrhythmia (heart rhythm disorder) in the UK
 - Arrhythmias cause up to **100,000 sudden cardiac deaths** each year in the UK; over 250 every day, more deaths than breast cancer, lung cancer and AIDS combined
 - There is **no national programme** of pulse rhythm checks or heart rhythm screening
 - Nearly **500,000 people in the UK have undiagnosed AF** (atrial fibrillation; the most common arrhythmia), and are at increased risk of a debilitating or life-threatening AF-related stroke – the most severe type of stroke
 - **120,000 people experience unexplained loss of consciousness** each year, commonly a sign of a heart rhythm disorder

Glossary

Anticoagulant A group of drugs which help to thin the blood and prevent AF-related stroke

Arrhythmia Heart rhythm disorder

Asystol Lack of any electrical activity in the sinus node

Atria The two lower chambers of the heart

Atrial Fibrillation (AF) The most common heart rhythm disorder, caused by chaotic rhythm in the atria (top chambers of the heart)

Bradycardia A slow heart rate, normally less than 60 beats per minute

Cardiologist A doctor who has specialised in the diagnosis and treatment of patients with a heart condition

Ectopic Extra beats arising from the atria or ventricles

Electrocardiogram (ECG) A simple test that records the heart's rhythm and rate

Sino-atrial node (SA node) The natural pacemaker of the heart

Sinus rhythm Normal regular heart rhythm

Stroke A medical condition which is now referred to as a 'brain attack' where the brain is deprived of oxygen

Sudden cardiac arrest (SCA) When the heart stops beating suddenly and unexpectedly without warning

Supraventricular tachycardia (SVT) Rapid abnormal heart rhythm that begins in the upper chambers of the heart

Syncope A medical term for a faint caused by a sudden lack of blood supply to the brain (often due to bradycardia or asystole)

Tachycardia Fast heart rate

Ventricles The two lower chambers of the heart, providing most of the pumping force

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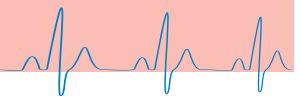
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COULD MOBILE ECG TECHNOLOGY WORK FOR YOU?

A number of new mobile devices are now available that can measure your heart rhythm and detect if you may have an arrhythmia (irregular heart rhythm).

NHS England has recently announced funding for those devices it has endorsed through the Health Innovation Network and the National Institute for Health and Care Excellence (NICE), for example, Kardia Mobile ECG.

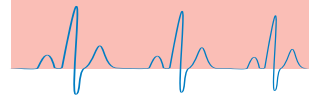
Often, when someone visits their GP following symptoms, such as palpitations, the irregular heart rhythm may not be detectable, and people can be sent to a specialist for a 12-lead ECG recording to determine if there is an arrhythmia (irregular heart rhythm).

A recent study from the University of Leeds¹, using Kardia Mobile, found that 85% of people who experienced palpitations had normal sinus rhythm and that their symptoms were caused by benign ventricular ectopic beats.

Many people purchase these devices themselves to record when they are experiencing symptoms, such as palpitations, breathlessness or an irregular heart rhythm, so that they can share the information recorded with their healthcare professional. Many use the mobile device to monitor an existing arrhythmia for reassurance or when to go their doctor for advice.

*"I find the monitor invaluable and take it with me whenever I am away from home for monitoring and reassurance."
LB, Cumbria*

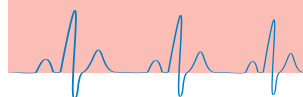
*"You could take the view that my possession of the Kardia unit has saved the NHS some money already, reducing unnecessary visits to GP and A&E when I get palpitations."
IS, West Midlands*



Even more people are now using a mobile device for reassurance and to save unnecessary visits to a healthcare professional. Knowing that your palpitations or irregular heart rhythm may be caused by other benign reasons is in itself a great reassurance.

Arrhythmia Alliance asked members of its message board forum if they used any existing mobile ECG device, what they used, and to share their thoughts on how they used their device. Here are just a few of the overwhelming positive comments focusing on how the devices made the individual feel in control of their symptoms and management.

*"I have used the Kardia Mobile on two GPs at my surgery as they have shown an interest in it after hearing a talk by cardiologists at our local hospital. Luckily both doctors have normal heart rates!! They were impressed with it and pleased that I have one to record whenever I experience an irregular heart rhythm."
AL, Herts*



WHAT DEVICES ARE AVAILABLE?

Automated BP monitors for detecting AF

Some automated BP monitors have a built-in AF algorithm to analyse any irregularity of the pulse rate and apply a threshold for detecting AF. These are referred to as 'AF detectors' and are specific for detecting AF, for example, WatchBP Home A.

Continuous ECG monitors

Continuous ECG monitor (Holters) can continuously record cardiac electrical activity, typically for 24 to 48 hours. This period has now been extended to several weeks with the newer monitoring systems. These devices are used to investigate suspected occasional arrhythmias which have not been detected during shorter, single-time point ECG recordings.

Event ECG monitors

An event ECG device allows intermittent recording of the electrical activity of the heart and is usually given to patients who experience infrequent symptoms and require monitoring over a longer period of time. Patients will initiate an ECG reading when they experience symptoms of arrhythmia (for example: breathlessness, palpitations and/ or light-headedness).

Mobile ECG recorder and Smartphone applications

Several smartphone apps already exist to determine heart rate using the built-in camera. These apps use the smart phone flash or light source and camera to obtain a recording of pulse waves.

Other systems allow electrode attachments to connect with a compatible mobile device (smartphone or tablet computer) and transmit, record, auto-analyse, store and view an ECG recording using a dedicated app. The ECG is captured digitally and can be viewed and transmitted to a secure server. The apps also have built-in AF detection algorithms that provides an instant interpretation to the user.

Kardia mobile ECG and app (AliveCor, Inc.) is currently the main mobile application used in the UK.

Existing mobile ECG users share their thoughts

Diagnosis:

*"Ended months of frustration
knowing something was wrong
but not able to get diagnosis"*

*"It took away a lot of fear and gave me confidence
that nothing more sinister was going on"*

"Useful, as it gave proof that I was still suffering from AF after ablation"

*"If I feel a bit odd it often reassures me that I'm fine and
if I have an arrhythmia I have a record to show a doctor.
Gives me back some control"*

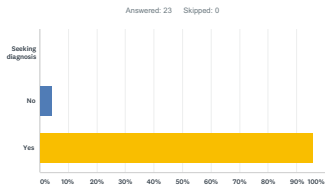
HOW MOBILE DEVICES ARE BEING USED

Arrhythmia Alliance, in partnership with AF Association, have produced a series of monthly surveys asking our patient membership to share their experiences on all aspects of their 'arrhythmia journey' from identification and diagnosis through to treatment and ongoing management.

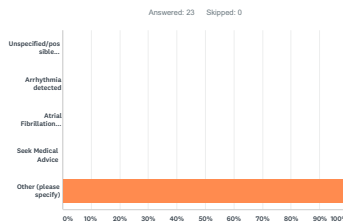
With NHS England about to distribute mobile ECG devices across England we wanted to investigate the uptake and impact of these exciting new diagnostic technologies - the infographic below provides an overview of our findings from 102 survey responses from people who use a mobile ECG device (the survey was undertaken between 2- 6 August 2017).

Mobile Diagnostics Arrhythmia Alliance Survey

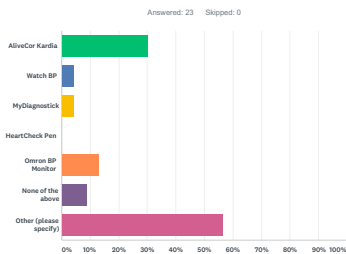
Q1 Have you been diagnosed with an arrhythmia (heart rhythm disorder)?



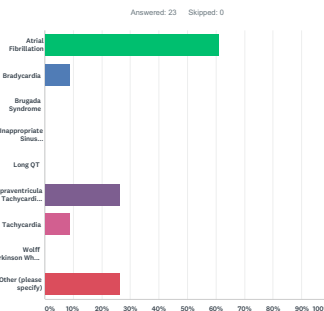
Q5 What did the device tell you?



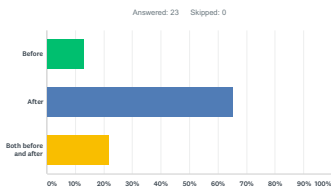
Q2 Have you used any of the following Home Monitoring Systems



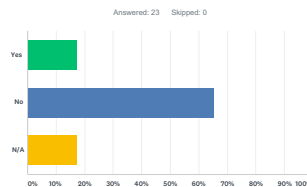
Q6 What is your diagnosis?



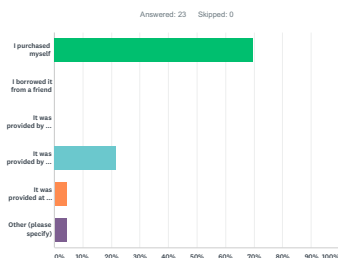
Q3 Did you use the device before or after your diagnosis?



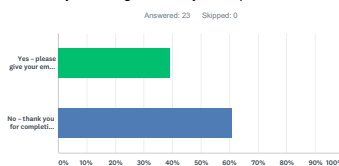
Q7 Did your doctor use the results from the device to make a diagnosis?



Q4 How did you access the device?



Q9 Are you willing to share your experiences with us?



And how did the user feel about their device...

Our survey also captured the thoughts and feelings of over 100 people who currently use one of the mobile devices shown. Over 60% of respondents rated their device very good, excellent, even fantastic! Very few had teething problems in how to use their device (less than 5%), and only a handful of respondents were unsure of the added value.

Stories from the edge

KNOW YOUR PULSE EVENTS IDENTIFY UNDIAGNOSED PEOPLE WITH ARRHYTHMIAS

During World Heart Rhythm Week (WHRW), more than 15 countries held over 600 'Know Your Pulse' events, making over one million people pulse rhythm aware. During these events, we teach people how to check their own pulse to become familiar with their heart rhythm, explain the importance of being pulse rhythm aware, and offer the use of mobile ECG technology, such as Kardia Mobile, to check people's heart rhythm.

We frequently identify AF when using a mobile device and all too often the person is unaware they have an arrhythmia. We offer to e mail the copy of the ECG to their healthcare professional or to their personal e mail so they can share with their GP. With confirmation of a diagnosis this has gone on to save countless lives from the devastation of an AF-related stroke as they receive appropriate anticoagulation therapy and ultimately treatment for AF.

One person attending a WHRW Know Your Pulse event used the mobile device where it detected an abnormal arrhythmia. As the event was at Barts hospital, with permission, the person immediately had a full 12-lead ECG and a diagnosis of left bundle branch block.

Even though this was totally unexpected news the person was so relieved to find out and receive appropriate treatment in due course. Left untreated could have led to far worse consequences.



"I want everybody to become pulse rhythm aware and new mobile ECG technology makes it even easier and quicker to confirm an irregular heart rhythm. Using manual pulse rhythm checks and mobile ECG technology will help us to save thousands of lives from undiagnosed AF-related strokes and sudden cardiac death, reduce the levels of misdiagnosis, and by ruling out benign ectopic heart beats reduce worry and concern of individuals and unnecessary hospital admissions." Trudie Lobban MBE, Founder & Trustee, Arrhythmia Alliance

Trudie Lobban MBE,
Founder & Trustee,
Arrhythmia Alliance



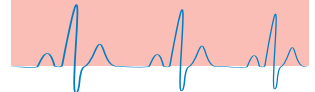
A mobile ECG makes a surprising discovery

John McCann wanted to show his colleagues his low resting heart rate but found out he had atrial fibrillation!

"In April 2016, one of my colleagues purchased an AliveCor Kardia device to attach to her mobile phone and was checking our rates and rhythms with the team. Having a regular sports routine, I wanted to show off my resting heart rate compared to the 70-80 bpm of the others. Sure enough, when my turn came, my resting rate was 52 bpm. However, I could see from the trace that the ECG shape was wrong and the inbuilt diagnostics of the app concluded that I should contact a healthcare professional to assess AF" says John McCann, who was at that time an undiagnosed person with AF!



"I had no palpitations or any other recognisable symptoms"



"I asked my colleague to run the trace again, as I had no palpitations or any other recognisable symptoms. The same result: check with a professional to confirm possible AF.

"I took a digital copy of the trace and sent it to a local specialist in arrhythmias, who advised me to go to my hospital the next day...and 12-lead ECG confirmed that I was indeed in AF."

Subsequently, John had an echocardiogram to assess the overall heart structure and discussed his management options with his Consultant. All the while he remained effectively symptom-free apart from some breathlessness playing football or squash, but then how many 57-year olds don't get tired in these activities?

John added, "In June 2016, I had a cardioversion to restore sinus rhythm and this was successful. A key part of my medication was to ensure that I was taking anticoagulation to prevent an AF-related stroke."

Tony

In 2015 Tony, a 58 year old Yorkshire man living in Glasgow, experienced his first signs of cardiac problems when he thought he was suffering a heart attack. With a racing heartbeat and discomfort in his chest, he was rushed to hospital showing typical signs of a heart attack. However, thankfully, the doctors in A&E found his ECG to be normal.

Over the next two years he suffered further attacks that were both frightening and painful but clinical investigations were struggling to find a cause. Tony was then introduced to a Consultant Cardiologist at Glasgow Victoria Hospital. The cardiologist pointed out that what he needed was to catch an event as it happened and that is when he recommended Kardia Mobile.

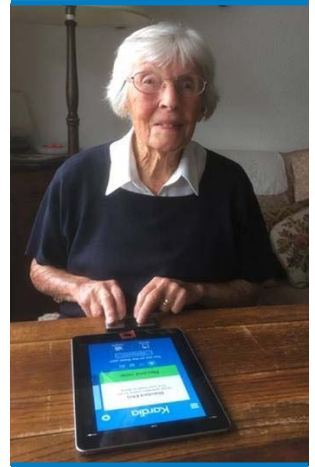
Within two weeks, Tony had captured an event, sent it to his cardiologist and had his diagnosis confirmed as atrial fibrillation (AF). He was then prescribed anticoagulant therapy to reduce his risk of an AF-related stroke and treatment so that his AF is now under control. Needless to say, Tony is very grateful for his Kardia Mobile and he continues to use it to monitor his condition.



Pam

A few months ago, Pam started to experience episodes of palpitations and breathlessness. These are typical symptoms of atrial fibrillation (AF). Often being an intermittent arrhythmia (heart rhythm disorder) however, her doctor was struggling to confirm this possible diagnosis. So he recommended that Pam should get a Kardia Mobile to use with a smartphone and capture events as they happen. She went one better and bought an iPad!

With the help of her daughter Carol, Pam was soon up and running with her Kardia and sending in ECG recordings to her consultant. After a few weeks of recordings and periodic visits to her doctor, the good news is that he was able to confirm that it was not AF after all. He did proudly announce to her though, that same day he had captured another patient with AF with the Kardia device. Pam is 96 and lives happily in Gloucestershire.



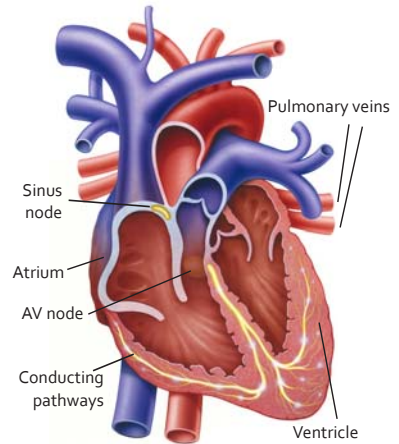
The normal electrical system of the heart

The heart has its own electrical conduction system. The conduction system sends signals throughout the upper (atria) and lower (ventricles) chambers of the heart to make it beat in a regular, coordinated rhythm. The conduction system consists of two areas called nodes that contain conduction cells and special pathways that transmit the impulse. The normal heartbeat begins when an electrical impulse is fired from the sinoatrial node (SA node), in the right atrium. The SA node is responsible for setting the rate and rhythm of the heart and is therefore referred to as the heart's 'pacemaker'.

The electrical impulse fired from the SA node spreads throughout the atria, causing them to contract and squeeze blood into the ventricles. The electrical impulse then reaches the atrioventricular node (AV node), which acts as a gateway, slowing and regulating the impulses travelling between the atria and the ventricles. As the impulse travels down the pathways into the ventricles the heart contracts and pumps blood around the body. The cycle then begins all over again.

The normal adult heart beats in a regular pattern 60-100 times a minute; this is called sinus rhythm.

The heart and normal conduction



© 2012 Arrhythmia Alliance

What is an arrhythmia?

Arrhythmias are disorders of your heart's electrical system whereby there is a change in the regular rhythm of your heart. Sometimes if the conduction pathway is damaged or becomes blocked, or if an extra pathway exists, the heart's rhythm changes. The heart may beat too quickly (tachycardia), too slowly (bradycardia) or irregularly which may affect the heart's ability to effectively pump blood around the body. These abnormal heart rhythms are known as arrhythmias. Arrhythmias can occur in the atria or the ventricles. Arrhythmias may occur at any age, and are most often a nuisance rather than a serious problem.



What happens in the heart to cause an arrhythmia?

Any interruption in the heart's electrical system can cause an arrhythmia. For example, an irregular heartbeat may begin with an abnormal impulse in a part of the heart other than the normal pacemaker (the sinus node); or the sinus node may develop an abnormal rate or rhythm.

What can trigger an arrhythmia?

Common causes of arrhythmias include electrical variations that people are born with, which may only become a problem in adult life. Certain triggers can include stress, caffeine, tobacco, alcohol, diet pills, and cough or cold medicines, but there is usually an underlying physical reason for it.

If your heart tissue is damaged because of acquired heart disease such as myocardial infarction (heart attack) or congenital heart disease you may also be at risk of developing arrhythmias. In rare cases doctors cannot identify a cause of their arrhythmias.

Types of arrhythmia

Arrhythmias that occur in the atria (the top chambers of the heart) are either atrial or supraventricular (above the ventricles) in origin whereas ventricular arrhythmias start in the ventricles (the lower chambers of the heart). While some arrhythmias are merely a nuisance, others can be life-threatening. A doctor will determine which type of arrhythmia you may have and treat your symptoms accordingly. In general, ventricular arrhythmias caused by heart disease are the most serious kind, and require prompt medical attention.



ATRIAL FIBRILLATION Atrial fibrillation (AF) is the most common heart rhythm disorder encountered by doctors. It occurs in the atria, in the upper chambers of the heart. The electrical impulse normally originates at the sinoatrial (SA) node. However, in AF, many electrical impulses are fired rapidly and at random throughout the atria down to the ventricles. The resulting heartbeat is irregular and usually fast.

Because the atria are beating rapidly and irregularly (fibrillating), they are unable to completely empty all the blood they receive into the ventricles and this can cause blood clots to form. Therefore, if you are at an increased risk of AF-related stroke you may be offered anticoagulant therapy.

ATRIAL FLUTTER Atrial flutter also occurs in the atria. In atrial flutter, the electrical impulses fire rapidly but the resulting rhythm is regular and organised. The rhythm is due to a re-entry circuit within the atria, whereby the electrical impulse travels in circles leaving and arriving back at the same point. There are several types of atrial flutter, the most common being atypical right atrial flutter.

BRADYCARDIA Bradycardia is a term that describes a number of different conditions in which the heart beats at an unusually slow rate. If impulses are sent from the SA node at a slow rate, or if the impulses are delayed as they

travel through the conduction system, the heartbeat will be slow. Sinus bradycardia is an unusually slow heartbeat due to normal causes and commonly occurs in athletes or during a state of deep relaxation. This is perfectly normal and should not usually cause any difficulties. The severity of and treatment required for the bradycardia depends on the area of the heart affected.

Bradycardia may also be caused by age-related degeneration of the heart's electrical conduction system, coronary heart disease or by medications prescribed to treat arrhythmias or high blood pressure. Once these medications have been reduced or discontinued, the bradycardia will usually resolve on its own.

Another cause is conditions that can slow electrical impulses through the heart. Examples include having a low thyroid level (hypothyroidism) or an electrolyte imbalance, such as too much potassium in the blood (hyperkalaemia). There are other numerous causes which can lead to bradycardia such as heart disorders present at birth (congenital heart disease), heart surgery, heart attacks, heart infections, blood salt (electrolyte) abnormalities, hormonal disorders (e.g. thyroid problems) and medication.

LONG QT SYNDROME Long QT Syndrome (LQTS) is a heart rhythm disorder that can cause a disturbance in the electrical system of the heart. It is often the result of inheriting an abnormal gene which causes an imbalance in molecules that control the electrical impulses of the heart. LQTS can also be caused by medications for other conditions.

Electrically-charged molecules (or ions) such as potassium, sodium and calcium, cross heart cell membranes through specialised ion channels. This generates the electrical activity (depolarization and repolarization) that initiates the heart pumping blood to the rest of the body. The abnormal function of one or more ion channels in LQTS prolongs the repolarization process which predisposes patients to cardiac arrhythmias.

LQTS may result in a very fast abnormal heart rhythm (arrhythmia). When these rapid heartbeats occur, no blood is pumped out from the heart and the brain quickly becomes deprived of oxygen, potentially resulting in a loss of consciousness (syncope) and rarely, sudden death.

Arrhythmia in patients with LQTS may be triggered by exercise or stressful situations. Not everyone who has LQTS will have an arrhythmia, but if it does occur it can be fatal. LQTS is an electrical problem so it does not change the shape and function of the heart muscle.

SUDDEN CARDIAC ARREST

Sudden cardiac arrest (SCA) is a condition in which the heart suddenly and unexpectedly stops beating due to a malfunction in the heart's electrical system. The malfunction that causes SCA is a life-threatening abnormal rhythm, or arrhythmia (ventricular tachycardia, ventricular fibrillation). Anyone can suffer a sudden cardiac arrest; it is unpredictable and can strike anytime, anywhere and without warning. During SCA a victim first loses his or her pulse, then consciousness and finally the ability to breathe. All of this can happen in a matter of seconds.

SCA is not the same as a heart attack, although a person suffering a heart attack has an increased risk of SCA. A heart attack can be thought of as a problem with the plumbing of the heart, a SCA is a problem with the electrical system within the heart.

SUPRAVENTRICULAR TACHYCARDIA This type of arrhythmia commonly occurs in young, healthy people. Doctors often refer to supraventricular tachycardia (SVT) as re-entry tachycardias as the electrical impulse does not fade out as with the normal heartbeat but continues to move in a rapid circle within the conduction system. This is due to an extra electrical pathway which can form a short circuit within the heart's conduction system. SVT is usually a rapid, regular rhythm.

SYNCOPE Syncope is a spontaneous loss of consciousness caused by an insufficient blood supply to the brain. There are many causes of syncope, some common and some rare. Reflex Syncope is the most common cause of blackouts. However, many people, including medical professionals, are unaware that some everyday activities can be the cause of many reported fainting attacks.

Reflex Syncope is the most common form of syncope and is also known as Vasovagal Syncope and Neuro-cardiogenic Syncope. A variety of situations (distress, fear, prolonged standing) stimulate the vagus nerve (receptors that respond to being stretched in the heart), which leads to a slowing of the heart rate and dilation of the body's blood vessels. With a slow heart rate and dilated blood vessels, less blood gets to the brain and causing fainting. See Reflex Syncope section for further information.

If you have a story you would like to share, or would like to know more about mobile ECG devices, please e-mail: info@heartrhythmalliance.org or call our helpline on 01789 867501

Thank you

STARS

Syncope Trust And Reflex anoxic Seizures®

www.stars.org.uk

Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures

Please remember that this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional.

STARS would like to thank all those who helped in the development and review of this publication.

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