

# The Heart Rhythm Charity

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

Register now for the A-A Patient Day, on 18th October 2009 - See page 8 for further details

September 2009 Issue 1

## Welcome to the FIRST Patients' Newsletter!

This publication will help you to learn more about the support and advice we offer, including free, medically endorsed information publications and news of forthcoming events.

Along with our 24/7 Helpline, The Heart Rhythm Charity provides FREE, patient information booklets covering symptoms, diagnosis and treatment for cardiac arrhythmias; all titles have been approved by international medical experts and endorsed by the Department of Health. Our booklets are designed to help patients before, during and after diagnosis and help share information between the patient, carer and doctor. Contact Heather at The Heart Rhythm Charity for further information or to order a publication. Email your story to [heather@heartrhythmcharity.org.uk](mailto:heather@heartrhythmcharity.org.uk) or to seek further information.

As this is the first issue, we will be sharing a patient's story and learning more about our affiliated groups. For the future we would welcome YOUR feedback. What would you like featured in future editions? Could you share your experiences by sending in your story? Or would you be willing and available to get involved helping to promote the charity and raise much needed awareness?

The 2009 campaign 'Know Your Pulse' has witnessed Pulse Check Clinics being held across the UK during Arrhythmia Awareness week;

and a current call to action to sign the 'Pulse Check Petition' (<http://petitions.number10.gov.uk/KnowYourPulse/>) which seeks to ensure pulse checks are taken during every routine visit to a GP surgery. If you have yet to sign please take a few minutes to do so now.



NEW for October, you can attend the **Arrhythmia Alliance Patient Day** - an opportunity to meet fellow arrhythmia patients and carers in a friendly, informal setting, to listen to presentations from patients and leading arrhythmia specialists, to learn more about issues relating to arrhythmias and to pose questions to a panel of medical experts. Mark **SUNDAY 18th OCTOBER** in your diary now, and complete and return the registration form (on page 8). Booking directly through Arrhythmia Alliance will entitle members to a **50% discount!**

I look forward to meeting many of you there and hearing from you over the next few months.

Trudie Lobban, MBE  
Founder and Trustee, Arrhythmia Alliance

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# Living with SVT-

## Catheter Ablation for Supra-Ventricular Tachycardia and Complications requiring a permanent pacemaker

I have had supra-ventricular tachycardia (SVT) for 25 years, since I was 10 years old. I had classic symptoms – sudden onset racing heartbeat pounding throughout my body, upset stomach, looking grey, breathlessness, feeling sick and sweating.

Investigations as a teenager never caught an attack on the 24 hour monitor, I was told that SVT was harmless and I'd probably grow out of it. In the early years, the attacks stopped easily, normally as soon as I lay down. However, as I got older though, the attacks continued.

I never smoked, but general triggers for me were caffeine or alcohol, bending over to pick things up, dehydration, tiredness and laughing too much. After one particularly bad attack, I gave up caffeine for a year and didn't have any attacks. Gradually though, even though I stayed off caffeine, the attacks came back. I never let it stop me though – when an attack happened, I just dealt with it, taking myself away somewhere to lie down and try various tricks to stop it. In the meantime, I travelled all over the world, learnt to scuba dive and worked overseas. I was so used to the SVT that the attacks didn't scare me, and they always stopped eventually.

Over the years however, I was getting SVT more frequently, often for hours (particularly if it started at night) and it was getting harder to stop, so my GP referred me back to a cardiologist. I knew how difficult it would be to catch the SVT on tape so the next morning when it started, I went to our local hospital and had an ECG done during SVT for the first time in 25 years. It turned out that what I'd got used to during attacks was a pulse of 250 beats per minute

(bpm), and my blood pressure was sky high. After the ECG and tests were done, I was treated with *Adenosine* and my pulse returned to 80 bpm immediately.

Within days, I was referred to an electrophysiologist for an ablation. Until then, I had no idea that my heart arrhythmia could be dangerous, I had always just thought it was annoying.

Before the ablation, I talked to an arrhythmia nurse about SVT, treatment with ablation and its benefits and possible complications. I was keen to go ahead and get rid of my SVT, especially as I now realised that it was a risk to my health. I was aware of the potential risks from catheter ablation (including a 1 in 200 chance of needing a pacemaker) but, at 35 years old, I didn't think for a second that any of those risks would affect me.

The ablation itself was fascinating. I opted for minimum sedation so I could watch what was happening on the screens next to me. I could feel the catheters inside me, but it wasn't painful. My biggest worry was that they wouldn't be able to trigger the mechanism of the SVT in order to treat it, but my heart dutifully went into SVT and the second pathway in my AV node was ablated.

A week later, complications began to become obvious...



### Fancy a chat?

"This board has helped me feel less alone and more in control of my arrhythmia"

"Being able to talk with other arrhythmia patients has lessened the fear I first experienced"

The A-A Forum is a moderated chat board enabling arrhythmia patients and carers to talk with fellow A-A members. The forum is confidential with no full names or contact details disclosed, and it is free to join via the A-A website: [www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk)

Fancy a chat with someone who understands? Then join the A-A Forum.

I soon started to have dizzy spells when I was eating. At first, I ignored them as they only lasted for a few seconds but the problem was more frequent and much worse, with my vision blacking out, loss of balance and waves of nausea.

I reported the new symptoms to the electrophysiology team who were not initially concerned, as the ablation had apparently gone well. About two weeks later, they arranged for me to have a 24 hour heart monitor. By then, I was feeling pretty bad – with pre-syncope episodes repeatedly during most meals and at other times, and constant nausea. The hospital called me back in the same afternoon. The tape had shown that I had been having episodes of second degree heart block and ventricular standstill. The longest gap recorded that day had been over 7 seconds. It doesn't sound like long, but it is amazing how bad a gap of 7.3 seconds makes you feel.

My pacemaker was implanted the next morning. The consent form was sobering – “to avoid syncope and death”.

### Adjusting to life with a pacemaker

Nine months on, my SVT has not recurred, so it's fairly safe to say it has gone – and with it, the unpredictable episodes of tachycardia at 250 beats a minute and high blood pressure. The need for a pacemaker was something I never imagined though. That said, it's become my own internal insurance policy, and is working brilliantly. I haven't had any blackouts or dizziness since it was implanted. I've been able to get back to my job overseas, have been travelling and scuba diving again and my scar is small and neat.

But having a pacemaker has taken me a lot of getting used to, and I'm not sure that I'm fully reconciled with it yet. It has shaken my confidence enormously that my heart doesn't work properly on its own anymore. Despite the best efforts of reassuring doctors and nurses, I worried that I would do something to pull out the leads or damage the pacemaker. Occasionally, I even worry that my next pacemaker (which I won't need for 6 years) won't work as well as my current one does, or I'll have problems with lead removal and replacement.

I find it harder to sleep now - sleeping on your side, as I did, is uncomfortable with a pacemaker. Perhaps as a kind of stress reaction, I also began to feel like I was choking. The hospital was great, quickly checking out the pacemaker and my throat. Both were fine, and there was no obvious reason for the choking feeling, but it felt real to me.

I'll probably always wish that I didn't need a pacemaker. But I do need it, and I know I'm fortunate to be able to live life pretty much to the full again (with occasional trepidation, a bit of extra thought, and care to keep my snazzy new wifi phone away from the snazzy circuitry in my chest). I was extremely grateful to attend the A-A Patients' Day soon after my pacemaker was implanted – meeting other patients and handling dummy pacemakers and leads made a huge difference to me. I also appreciate more than ever how fortunate I am to have the NHS to look after me, and to be on the receiving end of medical technology that is benefitting from so much research. When the time comes for a replacement, my next pacemaker might even be rechargeable or wireless!

Nicola Jenns,  
Buckinghamshire

## Affiliated Patient Information Groups

As this is the first newsletter we have produced, many of you may not be aware that Arrhythmia Alliance offers a free Affiliation scheme to provide support and guidance, of a national standard, to all cardiac patients. We recognise that patient groups and organisations provide a valued and much needed service to cardiac patients, carers and family members. Through the Affiliation scheme, we hope to network all cardiac patient groups and organisations.

So far we have been able to network over 40 groups, ranging from ICD and Heart patient groups to charitable organisations, and we hope to build on this to enhance the services and support available to all cardiac patients.

We would welcome the recommendation of any groups you belong to or know of, that could benefit from the affiliation scheme and the information we have available.

For more information, please contact Ben at [development@stars.org.uk](mailto:development@stars.org.uk) or on +44 (0) 1789 450787

Milton Keynes ICD  
Support Group



## What is your pulse?

♥ Your heart beat ♥ Your heart rate ♥ Your heart rhythm

One of the easiest places to feel your pulse is on your wrist, just below your thumb. You can feel your pulse in other areas of your body, including the crease of your elbow, in your groin or behind your knee.

## Why and when should you check your pulse?

**Being aware of your pulse is important because it may indicate an abnormal heart rate or rhythm.**

It is a good idea to try taking your pulse at various points throughout the day (before and after various activities). Your pulse rate will change during the day depending on what activity you are doing. This is normal. To get your baseline pulse and normal rhythm, try taking your resting pulse when you wake in the morning and before going to bed.

## What is a normal heart rate?

**Between 60 and 100 beats per minute.**

However, there are normal reasons why your pulse may be slower or faster. This may be due to your age, medications, level of fitness, any other illness including heart conditions, stress or anxiety.

## When should you seek further advice?

- ♥ If your pulse seems to be racing some or most of the time and you are feeling unwell.
- ♥ If your pulse seems to be slow some or most of the time and you are feeling unwell.
- ♥ If your pulse feels irregular (“jumping around”), even if you do not feel unwell.

Everyone is different and it is difficult to give precise guidelines. Certainly many people may have pulse rates over 100 beats/min (bpm) and less than 60 bpm. Irregularity is quite difficult to assess since the normal pulse is a bit irregular, varying with the phase of respiration. You should see your doctor if you have a persistent heart rate above 120 bpm or below 40 bpm.

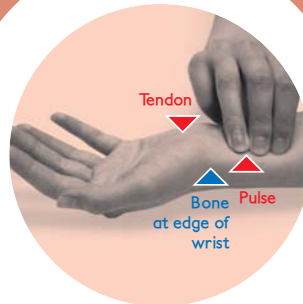
1

To assess your **resting** pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.



2

Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.



3

With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.

4

Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.



## Record your pulse here

Day	Result		Activity (e.g. after a run)
	am	pm	
1			
2			
3			
4			
5			
6			
7			

# RESTART THE HEART CAMPAIGN



- 100,000 lives are lost each year...
- 250 people die each day – the equivalent of a jumbo jet crash...
- More lives are lost each year than lung cancer, breast cancer and AIDS combined...

...through a condition known as 'Sudden Cardiac Arrest' (SCA):  
an abrupt loss of the heart rhythm.

SCA can strike anyone, anytime, anywhere and often without warning. It knows no boundaries, claiming hundreds of thousands of lives around the world every year. People of all ages, fitness levels and walks of life can succumb to it and most do not survive.

An Automated External Defibrillator (AED) is a small, portable device that analyses the heart's rhythm and prompts the user to deliver a shock only if required. Once activated, the AED guides the user through each step of the defibrillation process by providing voice and/or visual prompts. Together with cardiopulmonary resuscitation (CPR), using an AED is the only way to re-establish the heart's natural rhythm when in cardiac arrest and for every minute defibrillation is delayed, a patients' chance of survival decreases by 10%.

CPR alone = 5%

CPR and Early Defibrillation = 50%

The Heart Rhythm Charity is running a national campaign to place AEDs in communities; achieved by facilitating and supporting groups across the country who wish to place AEDs in their locality.

## AED Toolkit and Mini-Anne AED+CPR Kit

In support of the campaign, The Heart Rhythm Charity has developed an AED toolkit to assist individuals and groups wishing to support the project in their area. The toolkit provides a step-by-step guide through the entire process of placing a community AED; from project proposals to fundraising, to launch the unit. The toolkit also includes information about a number of AED placement schemes available across the UK together with template awareness-materials and press-releases which can be tailored to suit individual projects.

In addition to this, the charity has also developed a 'Mini-Anne Self Directed CPR & AED Skills Learning Programme', the first of its kind! With a fully interactive DVD, the self-directed Mini-Anne CPR &



Joanna Goldberg and  
Ben Fry with  
Melanie Grimsdale  
from Ibstone

Photo by The Henley Standard

AED kit allows individuals to learn the core skills of CPR and the use of an AED in less than an hour.

The interactive DVD is a revolutionary method of teaching these life-saving skills. It employs a unique "watch and do" technique where the user can practice CPR (30 compressions: 2 breaths) on a personal manikin (Mini-Anne) and learn how to use an AED.

The Mini-Anne CPR & AED kit is suitable for people of all ages and levels of prior knowledge, providing an invaluable source of AED training and demonstration. The information given is clear, concise and easy to follow and is complimentary to additional AED training that may be supplied (either by the Ambulance Service or medical professional).

For more information about the products available, or to order a copy of the AED Toolkit and/or Mini-Anne AED+CPR Kit, please feel free to contact us.

## LIFE-SAVING EQUIPMENT FOR THE VILLAGE OF IBSTONE

On Saturday August 1st, representatives of The Heart Rhythm Charity, Ben Fry and Joanna Goldberg, held a stand at the Ibstone Village Fete together with local villager Melanie Grimsdale, to demonstrate the importance of AED and raise awareness of sudden cardiac arrest. During the event many villagers approached the stand to gain a greater insight in the use of AEDs and to sign in support of a local campaign. Funds are now being raised to provide the village of Ibstone with its own AED and the charity will continue to work with Melanie to make the village of Ibstone a 'Heart Safe' community.





# Patient Information Booklets

Here is a list of our more commonly requested titles:



TITLE	PLEASE TICK
Arrhythmia Checklist	
Blackout Checklist	
Bradycardia	
Catheter Ablation	
Exercising with your Implantable Cardioverter Defibrillator (ICD)	
Patient Info.	
Implantable Loop Recorder	
Implantable Cardioverter Defibrillator (ICD)	
Pacemaker	
Palpitation Checklist	
Remote Monitoring	
Sudden Cardiac Arrest	
Supraventricular Tachycardia (SVT)	
Tachycardia (fast heart rhythm)	

These and further titles can be downloaded from our website:  
[www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk)

We are able to send out one of each booklet free of charge.  
 If you require more than one please contact us by email:  
[info@heartrhythmcharity.org.uk](mailto:info@heartrhythmcharity.org.uk)

Or call: +44 (0) 1789 450787

Help us to improve services for all those affected by arrhythmias and to save lives by making a donation today. Please complete the donation form below and return to P.O Box 3697, Stratford upon Avon, CV37 8YL or visit [www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk) and click the donate icon.

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 a donation to A-A via PAYPAL at [www.hearthythmiaalliance.org.uk](http://www.hearthythmiaalliance.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  Tick here

**GIFT AID**

Name of taxpayer.....

Address:.....

Postcode: .....

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.

Standing Order Authority	Credit Card Payment
My Bank: Account No.: Sort Code:	Card Type: Expiry Date:
Bank Address:	Card Number: Amount of £/€/\$:
Please Pay: A-A, Account: 02685818 Sort Code: 30-98-26, Lloyds TSB Plc, 22 Bridge St, Stratford upon Avon, CV37 6AG	Name on Card: Address:
The Sum of £/€/\$: On (1st Date): / / 20.....	
And after this, every: Month / Year (delete) Signature:	
Date:	Please hand this form in to your Bank

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# Arrhythmia Alliance Patients' Day 2009

**Sunday 18<sup>th</sup> October 2009, Hilton Birmingham Metropole, UK**

**Presentations from leading arrhythmia specialists, opportunity to listen to and meet fellow arrhythmia patients, visit the Patient Day exhibition, lunch and refreshments all included.**

**Book early to avoid disappointment.**

## Registration Form

Arrhythmia Alliance is offering subsidised delegate rates to all patient and carer members who book directly through A-A, bringing ticket prices to £25.00 per person.

### The day will include:

- A Patient's Experience of Living with SVT
- Anti-Arrhythmic Drugs and Beta Blockers
- The Athlete's Heart and Cardiac Arrhythmias
- Psychological Aspects of Cardiac Devices
- Living with an ICD
- Support and the Arrhythmia Nurse
- CBT for Arrhythmia Patients
- Exercise with a Cardiac Condition

A full agenda and travel details will be sent as a receipt of your registration.

Please tick in the box whether you are a:

Patient

Carer / friend

Please record the name of each person attending with you:

Dietary Requirements Please let us know if you have any specific requirements or allergies.

### PERSONAL DETAILS

Full Name:

Address:

Town:

County:

Postcode:

Country:

Contact Details

Telephone:

Mobile:

Email:

Please enter your email address clearly – Patient Day details will be sent to this address.

If you are unable to provide an email address we will post information to you.

Please return your completed registration form to A-A at the address shown below.

**I enclose a cheque for £ / I enclose a postal order for £**  
**Please make payable to 'Arrhythmia Alliance'**

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