January 2011 Issue 6

Providing information, support and access to established, new or innovative treatments for Atrial Fibrillation

Has your MP pledged to ACT on AF?

Nigel Mills MP, Amber Valley | Eric Illsley MP, Barnsley Central | John Baron M..., Basildon and Bille... | ...ett M..., Crayford | ...Smit..., ...au C... | ...nnis Skinner MP, Bolsover | Julie Hilling MP, Bolton West | David Tredinnick MP, Bosworth

Madeleine Moon MP, Bridgend | Simon Kirby MP, Brighton, Kemptown | Jonathan Evans MP, Cardiff North | Alun Michael MP, Cardiff South and Penarth | Tom Brake MP, Carshalton and Wallington | Mark Hunter MP, Cheadle | Toby Perkins MP, Chesterfield | Martin Vickers MP, Cleethorpes

Henry Smith MP, Crawley | Edwa... MP, Crewe ...vich | ...hame M... MP, Easin... | ...tephe... ...rd M..., Eas... ...ne | Jo Swinson MP, East Dunbartonsh... | ...hir... ...P, ...amp... | ...ndy Love MP, Edmonton | Andrew Miller MP, Ellesmere Port and Neston

Nick de Bois MP, Enfield North | David Burrowes MP, Enfield Southgate | Mark Durkan MP, Foyle | Willie Bain MP, Glasgow North East | Richard Graham MP, Gloucester | Andrew Jones MP, Harrogate and Knaresborough | Bob Blackman MP, Harro... ...st | Jim Dobbin MP, Heywood and Middleton

Andrew Bingham MP, High Peak | Angela..., Hornchu... ...d U... ...ster | A... Turn..., Isle of Wight | ...remy..., Kenilworth and S...ham | Joan..., Lewisham Deptfo... | ...P, Ludlow | ...e MP, Wakefield | John Whittingdale MP, Maldon

Annette Brooke MP, Mid Dorset and North Poole | Glyn Davies M..., Montgomery... | Andrew Bridgen MP, North West Leicestershire | Chloe Smith..., Norwich N... | Gordon Ba..., ...chil and Sou... ...ishire | Car..., O... ...and Shetl... | ...ouglas Alexander MP, Paisley and Renfrewshire South | Jim Fitzpatrick MP, Poplar and Limehouse

Penny Mordaunt MP, Portsmouth North | Mike Hancock MP, Portsmouth South | Robert Wilson MP, Reading East | Caroline Nokes MP, Romsey and Southampton North | Nic Dakin MP, Scunthorpe | Nigel Adams MP, Selby and Ainsty | Fiona Mactaggart MP, Slough | Heather Wheeler MP, South Derbyshire

Andrew Selous MP, South West Bedfordshire | Andrew Murris..., South West ...e | ...vid A..., ...ther... ...st | John Pugh MP, Southport | K... ...radley M..., ...affo... ...e Moorl... | Alex Cunningham MP, ...on North | N... ...Zahawi MP, ...ord upon Avon | Neil Carmichael MP, Stroud

Laurence Robertson MP, Tewkesbury | David Simpson MP, Upper Bann | Peter Aldous MP, Waveney | Graham Evans MP, Weaver Vale | Paul Uppal MP, Wolverhampton South West | Barbara Keeley MP, Worsley and Eccles South | Julian Sturdy MP, York Outer

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AF Patient Charter – By patients, for patients

Trudie Lobban MBE

The Atrial Fibrillation Association (AFA) is the UK's leading charity which focuses on raising awareness of Atrial Fibrillation (AF) by providing information and support materials for patients and medical professionals involved in detecting, diagnosing and managing AF.

AF is an abnormal rhythm of the heart involving the upper chambers of the heart – the atria. It is the most common sustained electrical disturbance of the heart, occurring in about 1-2% of the total population. The prevalence of this condition increases with age and over the age of 80, about 15-17% of the population is affected. Although there is a higher incidence of AF in men, women are at more risk of forming clots in the heart, and these clots can result in a stroke. AF is associated with five-fold increased risk of thrombo-embolic strokes, and these are often severe leading to long term disability or death. The annual cost of AF to the total NHS budget is a staggering £1.8 billion.

Unfortunately, awareness and understanding of heart rhythm disorders amongst many health professionals is low, so many patients are not currently receiving an appropriate and joined up journey of care across levels of service provision. This results in poor detection rates and sub optimal treatment for AF patients. AF is not currently prioritised despite its rising prevalence and significant contribution to stroke risk amongst patients. Furthermore, it is estimated that by 2050, 2% of the population will have AF. This is why we are working to ensure improved prevention, diagnosis and management of the condition.

It is our belief that patients should have a greater say in their care and we are therefore calling on the Government to prioritise AF, and for the NHS to ensure that there is better diagnosis and treatment options available to patients with AF. This will also ensure that patients are offered the restoration of quality of life and the ability to participate in society again; whether that is caring for one's family, earning a living or contributing in another way.

The Government has embarked on an ambitious programme of reform for the NHS, and is committed to shared patient decision making – 'no decision about me without me'. AFA believes that patients are best placed to inform the care they should receive, and their patient journey. AFA held a patient workshop to agree a series of practical and pragmatic recommendations that support 'no decision about me without me', and to agree minimum standards of care that patients must receive. This Atrial Fibrillation Patient Charter sets out ten recommendations to be adopted and implemented in the course of the NHS reform programme.

We are making representations via MPs and directly to service providers – PCTs and GP Commissioners – urging them to consider the ten recommendations. We hope you will write to your MP and enclose a copy of the Patient Charter (page three-four); AFA has drafted a sample letter to assist you with this (shown on page five). The AFA stand ready to work in partnership with all health service providers to deliver these goals, and to improve the quality of care received by patients with AF.

Trudie Lobban MBE
Founder & CEO

ACT on AF

AF Patient Charter – By patients, for patients

1. Atrial Fibrillation is the most common heart rhythm disorder, with more than 840,000 diagnosed cases across the UK, and with possibly as many more undetected. Yet, patient friendly information about Atrial Fibrillation (AF) is limited.
   - We call on service providers to ensure patients are provided with, and sign posted to, multi-media, medically approved sources of reliable information and support ideally endorsed by the Department of Health. We support the early development of a Patient Decision Aid on Atrial Fibrillation by NHS Direct.

2. Early diagnosis of AF should actively be encouraged. Identifying and treating AF at an early stage will deliver significant cost benefits.
   - A local AF strategy, in line with best practice models and toolkits from the NHS Heart and Stroke Improvement Programmes, and adapted following involvement by local patient representatives, should be developed by PCTs and GP Commissioning consortia, and adhered to.
   - Patients want their condition to be fully understood and appropriately administered at all stages of the care pathway. We therefore call on health service providers to ensure better joined up working between primary and secondary care to ensure that patients receive appropriate treatment throughout the care pathway.

TEAR OUT THIS PAGE

3. AF led to an estimated 851,095 GP visits, 575,000 hospital admissions and 5.7 million bed days in 2008, and the cost to the NHS is in excess of £1.8 billion. Early detection, diagnosis and appropriate medical management does lead to fewer appointments and admissions, saving the NHS money and individuals long term ill-health.
   - We call for service providers to deliver a public information campaign to raise the general public's awareness of AF and pulse checks through the ACT initiative:

     Ask could AF affect you?
     Check your pulse.
     Talk to a medical professional.

4. Pulse checks are quick, simple and extremely low-cost. The importance of pulse checks should be widely publicised and undertaken both inside and outside of medical practices.
   - Service providers must ensure they make Pulse Checks compulsory within the local delivery of NHS Health Checks.
   - Existing Health Promotion campaigns in schools and community groups must educate people how to measure their pulse.
   - Opportunistic screening programmes (such as pulse checks in flu clinics) have been shown to deliver immediate cost savings by preventing stroke .

5. AF is the single most relevant risk factor for stroke, increasing an individuals' risk by five-fold and being responsible for at least 20% of all ischaemic strokes. Furthermore, AF related strokes have the worst prognosis for severe disabling and mortality rates.
   - Three quarters of AF related strokes could be prevented, thus ensuring considerable savings are made by PCTs. We call upon service providers to ensure patients have access to high quality

information regarding AF-stroke risk and anti-coagulation options, and that patients are routinely assessed by informed practitioners .

6. Incidence of AF is set to rise 2.5 fold by 2050, and needs far more management in primary care, which we anticipate could be a positive outcome from GP commissioning.
   - We call on service providers to deliver AF rapid access clinics, led by community-based AF specialist nurses. These clinics would link with local GP centres to ensure that patients are diagnosed and treated closer to home in a timely and cost effective manner.

7. Improved awareness and use of new and innovative technologies would help to identify and diagnose AF at the earliest opportunity.
   - Local services should engage to ensure emergency electrocardiograms (ECGs) are made available in community health settings. Copies of ECG readings should routinely be given to patients to ensure that they have full benefit of joined up informed care at all stages of their treatment pathway.
   - The development of new anti-arrhythmic medicines that regulate the heart beat are the first new treatments for AF licensed in over 20 years. These novel treatments have far fewer side effects, lead to a reduction in hospitalisation and incidence of stroke, and improve long term cardiac health in AF patients. Service providers must ensure that clinicians are able to prescribe these treatments to appropriate patients.

8. It is imperative that examples of NHS and clinical best practice for the early identification and treatment of AF are widely shared, along with up-to-date clinical information.
   - Examples of best practice from the NHS Heart and Stroke Improvement Programme should be disseminated across the NHS, and adapted and implemented by service providers in line with local priorities.

9. The Government must make AF a national NHS priority.
   - Atrial Fibrillation must be recognised as a priority in the NHS Outcomes Framework; incentives provided in the Quality and Outcomes Framework (QOF); and minimum standards for the commissioning of AF patient care, through a NICE Quality Standard for AF.

10. Awareness and understanding of heart rhythm disorders amongst many health professionals is low, which too often leads to disorders going undetected.
   - We call for service providers to ensure continued medical professional education about the diagnosis, communication and aftercare of patients with AF, as part of medical professionals' CPD. This should be part of all GPs in-service training and the Royal College of GPs should advance it.

http://www.eoe.nhs.uk/downloadFile.php?doc_url=1278861979_xVgv_high_impact_change_1_detecting_atrial_fibrillation.pdf

www.knowyourpulse.org

The support and resources offered by Atrial Fibrillation Association (www.afa.org.uk) would be ideal in supporting PCTs to achieve this.

GPs should be engaged to use the CHADS2 / CHA2DS2VASc and GRASP-AF risk assessment tools already endorsed by the Department of Health and NHSI Heart and Stroke

Sample template letter for members to send to their MP
Website: http://findyourMP.parliament.uk

<NAME> MP
House of Commons
London
SW1A 0AA

2011

<insert name>

ACT on AF

I am writing to you as a member of the Atrial Fibrillation Association (AFA), to draw your attention to an initiative being spearheaded by the charity.

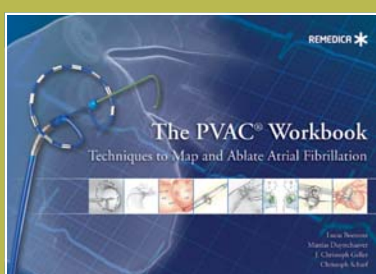
Atrial Fibrillation (AF) is the most common heart rhythm disorder in the UK, with an estimated 851,095 GP visits attributable to AF in 2008. Unfortunately, awareness and understanding of heart rhythm disorders amongst many health professionals is low, which can lead to some disorders going undetected. By diagnosing and treating AF at an early stage, the NHS will be able to save vast amounts of money, and for patients, this will offer them the restoration of quality of life, and the ability to participate in society again, whether that is caring for one's family, earning a living or contributing in another way.

It is for this reason that I am writing to you, enclosing a copy of the AF Patient Charter, to ask you to make representations to the Chief Executive of the PCT on my behalf to ensure that AF is made a priority in our area. As you will see, the attached Patient Charter has been developed "by patients for patients", and represents views on what needs to be done in order to improve services for patients with AF, including better preventative measures, wider treatment options, and improved education and awareness initiatives for both medical professionals and the public. The measures in the charter are practical steps that can be introduced and I would urge the local PCT to adopt these in order to improve the management and care of patients.

I hope that you are able to make representations on my behalf and I look forward to receiving a copy of the response in due course. Further information about AF, or ACT on AF can be obtained from Trudie Lobban MBE, Founder and CEO of Atrial Fibrillation Association at trudie@atrialfibrillation.org.uk or by telephone 01789 451837.

Yours sincerely,

The PVAC® Workbook: Techniques to Map and Ablate Atrial Fibrillation



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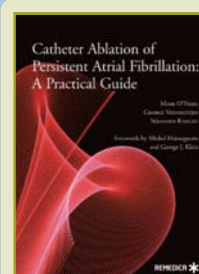
Foreword by
Fred Morady, MD FACC

Catheter Ablation of Persistent Atrial Fibrillation: A Practical Guide



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Supporting a Supporter

Damon, diagnosed with AF, raises funds for AFA

My name is Damon. I'm 39. For the past 4 years I've lived in Amsterdam where I'm an in-house lawyer at the European head office of a Japanese multinational.

About 18 months ago, I woke up one morning and went to the bathroom. No different to most people. Suddenly, I felt my heart beating extremely fast, I became dizzy and the next thing I knew I woke up on the bathroom floor - I had collapsed and was extremely confused by how this had happened, and very thankful that I had not hit my head on the side of the bath. I went to my company doctor later that day and he told me that I'd got out of bed too quickly which had caused the fainting, and told not to worry about it too much. So I tried not to. Although I couldn't shake off the concern that something was not quite right, and frustrated I could not identify what it was.

"I felt my heart beating extremely fast, I became dizzy and the next thing I knew I woke up on the bathroom floor"

Then, almost a year ago, a similar thing happened again. I had been out for a meal with my girlfriend the evening before and had 1 or 2 glasses of wine. Suddenly, almost in a panic I woke up around 7am with my heart racing. I went to the bathroom, although I was feeling extremely weak, light-headed and unstable. I couldn't stand up properly at the toilet so I decided to go into my lounge to sit on the sofa. However I didn't quite make it. I woke up lying on the wooden floor in my lounge in a pool of blood. I looked over and saw blood down the wall. After a few moments I got up and went into the bathroom and looked in the mirror and realised what had happened, I had collapsed into the wall. My girlfriend took me immediately to the Amsterdam Medical Centre. Within the first two minutes of being seen by a doctor, they had determined from my very fast and irregular heart beat that I was suffering from Atrial Fibrillation.

Since that time, I have been on medication which fortunately is working reasonably well. In fact, with the medication I lead a life no different to before. I play tennis once a week, I go to the gym, and I cycle. I have made some changes though. I no longer drink caffeine (only decaf) and whereas before I may have had 2 or 3 glasses of wine when I ate out, I now only have 1, or 2 maximum. I have realised that alcohol and caffeine contribute to bringing on the AF.

Damon, AFA Member

I can also look back now with hindsight and see that I had without knowing been suffering from AF for some time as I can remember episodes prior to the first time I collapsed where I sometimes had no energy to do anything because my heart was beating so fast. Or, where I felt miserable because my heart was beating in an irregular rhythm.

"with the medication I lead a life no different to before"

However, there is a positive side to all this. I am lucky to have discovered I suffer from AF before something more serious could have happened, and I am grateful that there is medication which works reasonably well to more or less control the AF. My Cardiologist has also informed me that I am a good candidate for the Ablation procedure, which I am currently considering. This experience has also introduced me to the AFA and to take part in fund-raising activities which I had not been involved in before. This year, instead of gifts, I asked friends to donate to AFA through an on-line 'JustGiving' page. Over £500 was raised… There's nothing as good as raising money for a good cause! So, there is a silver lining to this!

AFA would like to say a huge **THANK YOU** to everyone who donated to the charity. Donations ensure we can continue to do the work we do, helping patients and raising awareness in the medical profession.

We're always looking for new ways to fundraise. Sandra Harman's firm boosted her fundraising efforts running the York 10k. She wanted to raise money as her husband has AF and this was her first ever race.

While Julia held two evening talks on 'Chinese astrology' which sold out and all profits were donated to AFA!

In May, Dorothy Simpson donated £300 by asking for donations instead of birthday presents, and AFA has also benefitted from those who kindly donated in memory of a loved one.

Everyone at AFA is so grateful, thank you.

If your company supports charities or does matching giving, it can really make a difference. Using the Just Giving online donation service can help too.

There are so many ways to give from one off donations, payroll giving or holding events from coffee mornings to sponsored activities.

All it needs is you, some time and your imagination!

AFA fundraising raffle – You have to be in it to win it!!

Please help to support AFA by selling our raffle tickets.

Ask your family and friends to buy a ticket and be in with a chance of winning £50, £75 or the top prize of £100.

Your AFA newsletter will have included a book of raffle tickets, but if you require any extra tickets, please contact us on **01789 451 837** and we will be happy to send you more.

Best of luck!!

Blazing a trail for AFA – Mark Millinson runs the Mablethorpe Marathon

A personal connection to AF led Mark Millinson to run the Mablethorpe Marathon, 26 miles of open country, fundraising for AFA.

The marathon was held on the same day as Patient's Day at Heart Rhythm Congress (HRC). Mark and his wife Kirsten were disappointed not to have been there, however their presence was felt and a strategically placed 'Mark's marathon' fundraising bucket at Patient's Day resulted in additional funds being collected all adding towards Mark's £1000 target.

If you would like to support the Mark and Kirsten and help them reach their target, you can either send your cheques to AFA or follow the link below to their Just Giving page www.justgiving.com/rhythmnrunAtrialFibrillation; it is a quick, easy and secure way for you to pledge your support.

A big thank you to Mark and Kirsten for their united support and in particular a BIG congratulations to Mark for successfully completing this arduous sporting event.

AFA receives £2000 grant from First Group

The Atrial Fibrillation Association has received a grant of £2000 from the world's leading transport operator, First Group, following an application made possible by AFA member, John Ling. The grant has been secured to help raise awareness of AF in the highest risk group, the over 65s, and also to raise awareness among the medical profession of how taking the pulse can be an effective method of detecting AF.

The money will be used to produce publicity materials and medically and Department of Health approved fact sheets which will be distributed to Primary Care Trusts and Cardiovascular Networks. The factsheets will show people how to take their pulse and will explain why 'Knowing your Pulse' is so important in the fight against Atrial Fibrillation.Trudie Lobban, of AFA said, "*We would like to say a huge thank you to First Group for their generosity in awarding us this grant. I know we will be able to put it to good use carrying out our awareness programme.*"

Be part of the great movement to prevent stroke and heart disease

WatchBP® home S

Hypertension and AFIB are the major risk factors for stroke.

Both high blood pressure (BP) and atrial fibrillation (Afib) condition are listed as the most important modifiable risk factors in Stroke Prevention Guidelines [1,2]. WatchBP Home S from Microlife is the world first home device with innovative and highly accurate Afib detection technology when compared with EKG [3,4].

Innovative AFIB Screening

- Microlife's AFIB detection technology screens for AFIB with high sensitivity and specificity.
- Conveniently screen for AFIB while monitoring blood pressure.

	Subject (n)	Readings used	Readings needed for diagnosis	Sensitivity (%)	Specificity (%)
Stergiou [3]	72	1	1	93	89
		3	2	100	89
Wiesel [4]	405	1	1	95	86
		3	2	97	89

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Be part of the great movement to prevent stroke and heart disease

WatchBP® home S

WatchBP home S screens Afib with high accuracy at 97% - 100% Sensitivity and 89% Specificity while measuring blood pressure at home.

It is that easy and convenient. User at home without symptom could benefit by seeking medical consultation to prevent stroke.

Effectively detect risk factors for stroke and remind patients to seek medical consultation with Microlife AFIB detection technology and animated alert.

WatchBP Home S

- √ Simultaneously screening for Afib and high BP at home
- √ Animated reminder when risk factors been detected
- √ Screening for AFIB is recommended by leading medical societies [1, 2]

Ref.
1. National Stroke Association, www.stroke.org/site/PageServer?pagename=PREVENT
2. European Stroke Initiative (EUSi)
3. Stergiou GS et al. J Hum Hypertens 2009.
4. Wiesel J et al. Am J Hypertens 2009.

For more information, please visit: www.watchbp.com

microlife

BEGINNERS' SQUARE DANCE COURSES

Courses in modern (Western) square dancing are offered for anyone interested in this healthy, low-cost hobby. All courses lead to Mainstream level and consist of weekly lessons costing around £2-£3 including refreshments. All adults (16+) welcome. For details of teaching clubs, visit www.uksquaredancing.com.

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- There's no minimum order and online ordering is through HSBC Secure e-Payments.
- Prices are one uCardit for £5.49, two or more for £4.99 each, five or more for £4.49 each (including VAT and first class postage, non-UK orders have an additional £1.50 airmail charge per order).
- Templates most suitable for AFA members can be found at http://www.ucardit.co.uk/general-medical.aspx
- uCardit limited is registered with the Information Commissioner under the requirements of the Data Protection Act 1998.

Dr Andrew Grace, Consultant Cardiologist & EP at Papworth Hospital, replies to your questions

Q. Why do I have AF if I am healthy in all other ways?

Individuals who are fit and healthy can develop Atrial Fibrillation. In these individuals who have AF two factors may be at play. One is the influence of genetics and the other the influence of exercise. It is increasingly apparent, particularly in young individuals, that a family history can be a common feature. It is also become apparent in those who lead particularly healthy lifestyles, visit the gym on a very regular basis and participate in exercise to a very high level that the risk of AF might in fact be enhanced if they are otherwise predisposed.

Doctors would previously refer to AF occurring under these sorts of conditions where no other heart disease was observed as lone Atrial Fibrillation. However, awareness of the presence of lone AF has increased over time and its incidence may also be increasing.

Q. My Atrial Fibrillation seems worse at night; is this normal?

Classically, two patterns of AF were described. One was the so-called adrenergic pattern in which attacks of AF occurred on exercise, the other pattern was the so-called cholinergic pattern in which AF would often occur at rest in bed at night. Of course, many patients presented both patterns and what is now apparent is that most patients manifest neither pattern uniquely.

Having said this, an account of AF starting at night is not uncommon. When an individual describes this pattern, one of the useful investigations may be an ambulatory ECG monitor (24 hour tape). Some of these patients are seen to have slow heart rates at night which may predispose to the onset of fibrillation and under these conditions the implantation of a pacemaker may allow one to control the symptom very efficiently without much drug therapy or without an AF ablation, although these should also be considered, possibly as adjunctive therapies in conjunction with a pacemaker.

In summary, although this pattern of AF is not seen in everyone, it is not uncommon.

Q. Who can prescribe Dronedarone?

Dronedarone is the recently available anti-arrhythmic drug. One of the points with new drugs is that issues related to efficacy, tolerability and even adverse effects could emerge in the early phases of their clinical use. It is therefore generally advised that new drugs are used just by specialists so that if signals of problems emerge in the population they can be spotted early and action can be taken.

Dronedarone, being a new drug, is in the early phase of its use in the community. Accordingly, specialist prescription by cardiologists is felt to be appropriate at this time. In general terms, doctors, who are not specialists in AF, would not feel particularly comfortable using a drug with which they lack familiarity and are happy that AF specialists prescribe the new drug after proper consideration of all the other treatment options that are available. It might be that general physicians would seek the view of a cardiologist before suggesting the prescription of Dronedarone. General cardiologists might also seek the specialist view of a consultant electrophysiologist/heart rhythm specialist before, again, embarking upon the prescription of this drug.

As Dronedarone becomes increasingly used, one can anticipate a situation in which other doctors that might first include general physicians, physicians with an interest in medicine in the elderly as well as rhythm specialists would be more comfortable prescribing this drug. In the longer term its widespread use by primary care physicians might also be possible.

Q. I understand that after a while AF may be harder to treat successfully with ablation and that in general terms drugs have been usually tried first. When is the best time to seek advice from a specialist?

The management of Atrial Fibrillation is evolving. The recent guidance from the European Society of Cardiology (committee chaired by Professor Camm) indicates that the ablation of AF can now be considered as a potential first line therapy for those with AF who have a structurally normal heart. This is a somewhat new position with the general feeling in the community previously being that individuals would have had to fail anti-arrhythmic therapy before being considered for radio frequency ablation. The possibility now that one could proceed to ablation without even trying an anti-arrhythmic drug is thereby raised and therefore early advice from a specialist may well be advisable in many cases with symptomatic AF.

My own view is if one has significantly symptomatic Atrial Fibrillation then one should seek an opinion from a heart rhythm specialist at an early stage. This will allow one to discuss the full range of possibilities in terms of management at the outset of your experience of the condition. This gives the individual patient who suffers AF the knowledge and confidence that allows them to proceed comfortably through the earlier stages of the assessment and management of the condition. Whether early intervention in AF to stop the attacks at an early stage leads to a decreased number of events later on and makes it easier to treat successfully with ablation is not, in a formal sense, fully known at this time. Having said this many of us believe the sooner one proceeds with ablation when appropriate, the better.

Q. I have AF; how often should my doctor review my condition and the drugs that I am taking?

Regarding Atrial Fibrillation and frequency of assessment, I think one could divide the background of the advice into three phases. There is the initial phase of recognition of the condition and its characterisation with the determination of the treatment plan. The second phase would be the initiation and assessment of therapy. Then the third phase would follow entry into a period of stability (after the period of intense treatment modification is at an end) and the individual has returned to a new steady state. It is likely at this point quality of life will have been much improved and AF might have been completely suppressed.

In the first and second phases of the management of the condition, relatively regular reviews by the doctor is normally the order of the day. Once the main treatments have been deployed, then a follow up at say six or twelve months is usual. At the end of that period, if symptoms are controlled and appropriate anti-thrombotic plans are in place, follow up may not be required on a regular basis.

In my practice in those with persistent patterns of AF in whom a rate control strategy, for example, has been embarked upon, then I would propose in correspondence copied to the patient that they would be followed up in, say, three to five years with a further echocardiogram to look at the structure of the heart and assess medication in the light of symptoms and other more objective observations.

Coming soon! AFA Frequently Asked Questions Information booklet. Contact AFA to order your copy!

David's unexpected heart rhythm disorder

Guidance and support from his doctor ensured he found appropriate treatment.

My name is David and I am 65 years old. I wanted to share my experiences to highlight how AF can appear out of the blue, but with the right medical help, there can be a silver lining.

I have been an active sportsman all my life, with football then a football referee, badminton and a regular swimmer. I have been an healthy eater for the last twenty five years and my weight has always been in check. To all intents I was fit, attending the gym twice weekly and swimming regularly.

Then in January 2009 my resting pulse rate two hours after leaving the gym was 140. My wife sent me immediately to our GP who sent me to Kings College Hospital in London for an ECG, which I thought was routine. Had ECG got dressed and was then called back into examination room for a further ECG. I was immediately prescribed a beta blocker bisoprolol, aspirin and arrangements made for blood test to enable commencement of Warfarin. To say it took me by surprise is an understatement (prior to this I was taking an ACE Inhibitor, ramapril only).

Next, I saw a Cardiologist who specialises in Electrical Physiology, he sent me for an echocardiogram following which he said I had an arrhythmia problem (Atrial Fibrillation) and suggested a cardioversion to see if it would re-set my pulse to be regular. This was carried out in March but unfortunately it only lasted for three days before reverting to Atrial Flutter.

A short while later I had a severe chest pain whilst walking up a hill and so underwent another ECG, a twenty four hour and then a seven day event recorder to see what was happening to my pulse rate. My Cardiologist then arranged for me to have another echocardiogram, but it was the exercise Treadmill Test which showed that I possibly had angina.

This meant I then underwent an angiogram which confirmed a blockage and I was told the same day that I would need either a stent or open heart surgery, which again took me by surprise! In fact it shocked me. Within a week I had received a phone call from the hospital informing me that following a review of my case by the hospital Joint Consultative Committee it had been decided that the best option would be for me to have a coronary heart bypass graft operation. I couldn't believe this journey I had found myself on.

During the appointment with the surgeon, he explained the process in detail and so I had a triple bypass on 8th September 2009. It all seemed so surreal that it was happening to me.

I spent twenty four hours in Intensive Care and a further day in High Dependency Ward before arriving on the ward where I spent six days. For the first two days I was not aware of anything due to the drugs that were administered. When I finally came around I found myself feeling like a complete invalid, with tubes a plenty and my movements close to non- existent; the pain was almost unbearable mostly due to my sternum being cut to gain access to my heart.

In addition to the bypass I also had a cardiac ablation, carried out while undergoing open heart surgery. I am told this is the difficult part when carrying this procedure out separately as it needs to then go through the vein in the groin. While the ablation was carried out, the surgeon also found some blood clots which he removed and said to me, 'There for the grace of God Mr C you are OK!' I came to realise this could have been fatal and they had not been detected on previous tests.

My drugs needed to be changed as the surgeon placed me on amiodarone and ezetimibe which did not help my heart rate or rhythm, but did affect my liver, so more blood tests followed. I then had another cardioversion on 28th October because I had gone into AF again - fingers crossed it's been successful.

I had gone from not being able to bath on my own, get out of bed or drive, to joining the hospital Rehabilitation Programme for six weeks, something I would say is a prerequisite for all patients to complete, and I finally returned to my job on 19th January part time initially now full time. I have done everything I have been advised to do, even completing a twelve week course at the local Leisure Centre which is offered jointly by the Local Authority and Kings College Hospital.

I now go to the gym once a week; swim half a mile one day a week and power walk and jog Saturday and Sunday (first time I have jogged since I was a Referee!). My wounds look almost healed although continue to change colour. I think you will agree, I have made a good recovery so far.

Professional advice, help and support in sharing the experiences with other patients has all helped in the discovery, treatment and recovery process and so I would like finish by paying my respects to the Kings College Hospital and in particular my Consultant Cardiologist, Mr Nick Gall. Without his interest and in depth tests in investigating and diagnosing my problems I may not be here to write this résumé.

Education, discussion, debate

Left to right: Dr Todd, Dr Murgatroyd, Mr Jonathan Dimbleby, Professor Lip, Dr Sulke

Dr Wolff | Dr Fay | HRC Patient Exhibition | Dr Fitzpatrick | Dr Grace

This year's meetings brought together patient and carer members, clinicians, local representatives and celebrities! Offering discussion, debate, information, questioning, new friendships and smiles, the 2010 AFA meetings topped the charts, with almost one thousand members attending events up and down the country!

The flagship AFA Patient Days, held in Birmingham at the Heart Rhythm Congress and in London at Europe AF, saw members enjoying presentations and discussions with leading arrhythmia specialists including, Professor Richard Schilling, Dr Andreas Wolff, Dr Adam Fitzpatrick, Dr Matthew Fay, Mrs Jayne Mudd, Dr Steve Murray, Dr Edward Rowland, Dr Mark O'Neill, Dr Mark Earley and members Mrs Jenny Hutton and Miss Maggie Ellis.

Professor Schilling

The AF Symposium held at HRC was a resounding success, topped by an informed and entertaining debate between Professor A John Camm and Dr Derek Todd, and Chaired by Mr Jonathan Dimbleby.

Jenny and James Hutton

AFA would like to thank everyone who supported these invaluable days, freely giving their time and expertise to extend understanding and awareness of this complex arrhythmia. It is AFA's intention to not only continue but expand these meetings during 2011. From accredited on-line training for non-specialist medical practitioners and local Cardiac Update meetings to regional AF Summit meetings and the AF Patient Days.

Register an interest today to receive information on local meetings and preferred registration rates!

Contact AFA: Telephone +44 (0) 1789 451 837 or visit the website www.afa.org.uk

HOLD THE DATE……
Sunday 2nd October 2011

AFA Patient Day at the Heart Rhythm Congress!

Outline agenda:

- How can I access AF services when treatments are not working?
- Up and coming options
- Advances in anticoagulation therapy
- My health in my hands – managing AF
- Where are the services, getting my GP on board?

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

2nd - 5th October 2011

Why not bring this to the attention of your doctor?

Accredited training with CPD points, open to your medical healthcare team!

AFA in collaboration with Arrhythmia Alliance is proud to be continuing its series of cardiac update courses into 2011. Our aim is to increase awareness to healthcare professionals across the UK on the management of cardiac arrhythmias.

Each course will provide a forum for primary and secondary healthcare professionals interested in:

- Improving local delivery of stroke prevention in atrial fibrillation
- Reviewing latest policy and clinical developments
- Assessing local services and how these may be enhanced

These meetings are aimed at medical professionals who are involved in the care of, or providing a service to, patients with cardiac arrhythmias including Atrial Fibrillation and anticoagulation.

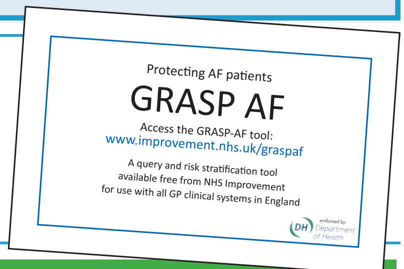
For more information, visit www.afa.org.uk or by contacting AFA: info@atrialfibrillation.org.uk

Venues include: Belfast – Birmingham – Carmarthen – Leicester – Liverpool
Newcastle – Oxford – Reading – Stoke-on-Trent – Southampton

Do you live in England?

NHS Improvements have launched a **FREE** resource available to all GPs practicing in England, which risk assesses patients diagnosed with AF.

Please consider sharing this information with your GP, do you use GRASP-AF?



Arrhythmia Awareness Week (AAAW) 2011: 'Prevention – Putting the Pulse into Practice'

Making pulse checks routine when you visit your GP Practice

Arrhythmia Awareness Week is a national event which gives anyone the chance to raise awareness and promote better understanding of heart rhythm disorders.

AAAW 2010 was a great success, with over 2,500 events across the country and 400+ supporters taking part. During the week-long event, AFA helped medical professionals around the country to perform more than 8,000 pulse checks in supermarkets, shopping halls, schools and medical centres.

AAAW 2011 will mark the eighth Arrhythmia Awareness Week and will focus on the message 'Prevention – Putting the Pulse into Practice'. The easiest way to detect an arrhythmia is to feel the pulse and this is why we want pulse checks to become part of a person's natural health regime.

What will the week involve?

- Collaborations with other organisations
- Parliamentary activity
- Political engagement
- Medical engagement
- Build and publish evidence
- Distribution of literature
- Awareness-raising activities
- Fundraising

How can you get involved?

- Post Posters' and 'Leave Leaflets' in your community
- Write to your MP or local press with our template letters
- Share your story with us - Without your stories we have no voice

Help us to reach other patients

AFA can support you with awareness displays and events, distributing information materials to medical centres, and participating in lobbying and media activities.

There are many ways in which you can get involved and help to make pulse checks routine when you visit your GP surgery. To find our more contact joanna@heartrhythmcharity.org.uk To order your Awareness Pack(s) visit aaaw.org.uk

Spotlight on AF services

New Nurse-led Atrial Fibrillation (AF) Clinic at Musgrove Park Hospital, Taunton, Somerset.

BHF Arrhythmia Nurses at Musgrove Park Hospital have recently launched their exciting new Direct Access Atrial Fibrillation Clinic. Janice Bailey and Jacqui Kemp are keen to develop this service for the people of Somerset in line with other Nurse Led Clinics around the country.

Patients with an irregular pulse who have been newly diagnosed with Atrial Fibrillation by their GP can be referred directly to the nurse led clinic. All the GPs need to do is fax a referral form to the Cardiology Department at the hospital and the patient will be contacted directly and offered an appointment at a mutually convenient time.

As well as offering relevant diagnostic tests during the appointment and assessment, treatment planning and prescribing advice (in line with NICE guidance), the clinic aims to improve the information and support given to patients with Atrial Fibrillation.

"We recognise that discovering you have Atrial Fibrillation can be an anxious time and we want to ensure that our patients receive relevant information, advice and support as soon as possible. We find the AFA booklets invaluable as a resource and patients have benefited from the concise and accurate information within them." (Jacqui Kemp, Arrhythmia Nurse Specialist)

The clinic has been piloted since September with GP surgeries who are evaluating the GRASP AF tool, with good initial patient feedback. The clinic is now open to all GP surgeries in West Somerset and the Arrhythmia Nurses are available to arrange an information session with the GP's to provide patient information tools (toolkits) and explain and discuss the clinic.

According to Janice Bailey, Arrhythmia Nurse Specialist, "By spending more time with patients newly diagnosed with Atrial Fibrillation, we hope to focus on their needs and ensure they fully understand AF, the treatments available and the associated risk stroke to enable them to make informed choices about their own healthcare."

Janice Bailey and Jacqui Kemp can be contacted on:
BHF Arrhythmia Nurses
Duchess Building
Musgrove Park Hospital
Taunton
Somerset
TA1 5DA
01823 343595 *BHFarrhythmianurses@tst.nhs.uk*

Accredited counsellor with the British Association for Counselling and Psychotherapy. I have experience working in a large G.P. practice and now have a private practice in the South West. I have personal experience of Atrial Fibrillation and how debilitating it can be. In offering counselling in this specialist area I have undertaken much personal research. Counselling provides space to reflect away from everyday pressures and can help you to explore stress triggers, recognise unhelpful patterns, develop self management techniques, build confidence and manage life better on your terms.
For further details please contact:
hillyc@btopenworld.com

Get PST Aware! – Update!

The campaign, which is supported by leading patient groups AntiCoagulation Europe, the Children's Heart Federation, Atrial Fibrillation Association and the British Cardiac Patients Association, aims to inform people about patient self-monitoring and the resulting impact it may have on patients' lives. The campaign was developed in response to the startling statistic that whilst **up to 50% of patients are eligible** for self-monitoring, many are simply unaware of the potential benefits of being able to do this at home.

Educational information has been provided to people on long term oral anticoagulants, their carers and healthcare professionals including pharmacists, GPs and anticoagulation specialists. Free information sessions for people on anticoagulants and their carers have been held in anticoagulation clinics from Epsom to Warwick and information sessions are continuing to be held.

For further information and details of meetings, sponsored by Roche, visit: **www.coaguchek.co.uk**

DRONEDARONE APPROVED:
Summary of NICE Guidance

NICE DECISION ON THE USE OF DRONEDARONE
The National Institute for Health and Clinical Excellence (NICE) published their final Guidance on Dronedarone (Multaq) on 25th August 2010. The Guidance states that Dronedarone is recommended as an option for the treatment of non-permanent Atrial Fibrillation if:

- You have already tried another type of drug (usually a drug called a beta-blocker) but this has not worked, and
- You have at least one of the following which means you are at a higher risk of developing disease of the heart of blood vessels:
- You are taking at least two different types of drugs for high blood pressure
- You have diabetes
- You have had a type of stroke or a blood clot in the past
- The left chamber of your heart is larger than normal
- Your heart is pumping less blood around your body than normal, or
- You are 70 or over, and
- You do not have a severe form of heart failure; that is, if you have been diagnosed as having heart failure, you are still able to carry out everyday tasks with either no symptoms, or symptoms that are mild (for example, you may experience mild chest pain or shortness of breath when walking or climbing the stairs).

The detailed guidance; quick reference guide; guidance written for patients and carers; audit support; and costing templates were all published and can be accessed from the NICE website (links below).

DRONEDARONE

Dronedarone (Multaq) is an anti-arrhythmic drug belonging to the benzofuran class of anti-arrhythmic compounds. Its main mechanism of action, like that of Amiodarone and Sotalol, is achieved through the inhibition of potassium channels making heart cells less excitable and thereby making AF less likely.

Side effects

Dronedarone is generally well tolerated with no increase in serious adverse effects when compared with placebo. The most common side effects noted are: diarrhoea, abdominal discomfort, nausea and vomiting. There is an increased incidence of skin rash, bradycardia (slow heart rhythm) and prolonged QT intervals on electrocardiograms (ECGs) although the latter is rare. Most side effects resolve within the first two weeks of starting the drug, but it is thought that in a proportion of patients, Dronedarone will need to be discontinued because of intolerance.

Guidelines for access

The NHS Constitution states: "You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you". This means that you have a right to receive an approved drug or treatment if your clinician says it is appropriate for you to receive it and it has been recommended by NICE's technology appraisal. When a NICE technology appraisal recommends use of a drug or treatment, or other technology, the NHS must provide funding and resources for it within 3 months of the guidance being published. The 3 month period expired at the end of November 2010, and therefore PCTs will now be expected to offer Dronedarone to appropriate patients. We are writing to PCTs to ensure they are implementing the Guidance for the benefit of patients with AF.

As a patient you also "have the right to expect local decisions on funding of other drugs and treatments to be made rationally following proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your doctor feel would be right for you, they will explain that decision to you." Decision making on whether to fund a treatment is left to the local PCT in order for them to provide services they feel best fit the needs of their local population. If a PCT decides that a treatment will not be funded, then it needs to be able to consider whether to fund the treatment for an individual patient on an exceptional basis.

We would like to hear from patients who are unable to secure access to Dronedarone, or where there is resistance from the PCT. Please contact:

Trudie Lobban MBE — E: trudie@atrialfibrillation.org.uk
T: 01789 451837

Jo Jerrome — E: jo@atrialfibrillation.org.uk
T: 01789 451837

For further information visit the NICE website:
http://guidance.nice.org.uk/TA197 to view the Guidance
To view the guidance written for patients and carers:
http://guidance.nice.org.uk/TA197/PublicInfo/pdf/English
(PDF format)
http://guidance.nice.org.uk/TA197/PublicInfo/doc/English
(Word format)
http://guidance.nice.org.uk/TA197/PublicInfo/doc/Welsh
(Word format in Welsh)
http://guidance.nice.org.uk/TA197/Guidance/pdf/English
(Full Guidance PDF format)

For further information on the NHS Constitution:
http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx
http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/COI_NHSConstitutionWEB2010.pdf

For further information on the Atrial Fibrillation Association:
www.afa.org.uk

AFA
atrialfibrillationassociation
www.afa.org.uk
www.afa-international.org

AF QUESTIONNAIRE

By completing the short, confidential and anonymous questionnaire regarding your experiences with Atrial Fibrillation, you will be helping AFA gather evidence about and related to AF. Your assistance will help to better inform AFA of the prevalence and current care experienced by AF patients. If you prefer to complete this on-line, please visit the AFA website: www.afa.org.uk

Please tick the appropriate boxes

1. Are you…

A patient? ☐ A carer? ☐

2. Age category

18-24 ☐ 41-50 ☐ 71-80 ☐
25-30 ☐ 51-60 ☐ 80+ ☐
31-40 ☐ 61-70 ☐

3. Gender of AF patient

Male ☐ Female ☐

4. In which country do you receive most of your treatment?

5. Do you have a definite diagnosis?

6. Please tick any symptoms you experience

Palpitations ☐
Chest pains ☐
Breathlessness ☐
Fatigue ☐
Anxiety ☐
Passing too much urine ☐
Sweating ☐

7. Are you seen by…

A GP? ☐
A Specialist Cardiologist? ☐
A General Cardiologist? ☐
An Arrhythmia Nurse? ☐
Any other (Please state)?

8. Have you had any of the following tests?

12 lead ECG ☐
Loop/event/memo-recorder ☐
24-hour ECG monitor ☐
Treadmill test ☐
Echocardiogram ☐
Blood test ☐
Any other (please give details)

9. Please state any medication you are currently taking

10. Have you experienced a Transient Ischemic Attack or stroke?

Yes ☐ No ☐

11. Do you have a history of high blood pressure?

Yes ☐ No ☐

12. Have you been diagnosed with heart failure?

Yes ☐ No ☐

13. Have you undergone any procedures for AF?

14. Are you satisfied with your treatment?

Yes ☐ No ☐

Please explain…

Please return to: AFA, PO Box 1219, Chew Magna, Bristol, BS40 8WB Tel: +44 (0) 1789 451 837

atrialfibrillationassociation
www.afa.org.uk
www.afa-international.org

Publication List

AFA publications are accredited by the AFA Medical Advisory Committee and endorsed by the Department of Health

PATIENT INFORMATION BOOKLETS — PLEASE TICK

- Atrial Fibrillation: Patient Information ❑
- Atrial Fibrillation: Drug Information ❑
- The Heart, The Pulse and The ECG ❑
- Blood Thinning in AF ❑
- Cardioversion of AF Ablation ❑
- Catheter Ablation for AF ❑
- Complications of AF Ablation ❑
- Atrial Flutter ❑
- Living with AF: Relationships ❑

FACT SHEETS: PATIENT

- Atrial Fibrillation ❑
- Amiodarone ❑
- Aspirin ❑
- Atrial Flutter ❑
- Atrial Tachycardia ❑
- Beta-Blockers ❑
- Blood Thinning ❑
- Cardioversion ❑
- Cognitive Behaviour Therapy ❑
- Dabigatran ❑
- Digoxin ❑
- Dronedarone ❑
- Ectopic Beats ❑
- Flecainide ❑
- Internal Cardioversion ❑
- Medical Cardioversion ❑
- NICE ❑
- Pacemaker and AV Node Ablation for AF ❑
- Pill-in-the-pocket Cardioversion ❑
- Rate Limiting Calcium Channel Blockers ❑
- Rate versus Rhythm Management ❑
- Stroke and AF ❑
- Transcatheter Closure of the Left Atrial Appendage ❑
- Warfarin Therapy ❑
- Warfarin and Diet ❑
- Warfarin and other Medication ❑
- What is a Consent form? ❑
- What does randomisation mean? ❑
- Ongoing clinical trials for AF ❑
- What is a clinical trial? ❑

CHECKLISTS:

- Patient and Primary Care Checklist ❑
- Atrial Fibrillation Checklist ❑

FACT SHEETS: FOR HEALTHCARE PROFESSIONALS

- Ablation of the AV Node and Pacemaker Implantation ❑
- Atrial Flutter ❑
- Care Pathways for AF and Atrial Flutter ❑
- Dabigatran ❑
- Dronedarone ❑
- Focus on AF ❑
- Innovations in Anti-Coagulation ❑
- Primary Care Pathways for AF ❑
- Rate versus Rhythm Management ❑
- Seeking Patients in AF ❑
- Stroke Prevention in AF ❑

All publications are sent free of charge to AFA Patient members. The AFA Tool Kit is available free of charge to Medical Professional. For large orders please contact AFA. A contribution of £2.00 towards the cost of postage is very much appreciated.

Name ....

Address ....

.... Postcode ....

Tel ....

Email ....

If you are a UK tax payer, please tick to allow AFA to claim an extra 28p for every £1.00 you donate, at no extra cost to you. ❑

www.afa.org.uk
www.afa-international.org

Return to:- Atrial Fibrillation Association, PO Box 1219, Chew Magna, BS40 8WB UK

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