



atrialfibrillationassociation

November 2011 Issue 7

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

A new era in anticoagulation

After almost fifty years of limited choice in anti-coagulation therapy, 2011 marks the eve of a new era. Extensive trials, involving several hundred medical centres across the globe and tens of thousands of patients have now brought new options to market to reduce stroke in people with Atrial Fibrillation (AF).

Warfarin, the best known of the oral anticoagulants (OAC), has a great deal of evidence in reducing the risk of stroke in people with AF. It is clearly very superior to Aspirin and the experience of use is extensive. However despite being effective, as safe as aspirin in clinical practice and cost effective its use in those at risk of stroke in AF remains limited to about 50% of those who could benefit.

The challenge with all anticoagulants is to find something predictable or easily managed; Warfarin needs a great deal of careful management to remain effective and safe. It is possible to self-test with approved and reliable home International Normalised Ratio (INR) testing kits. This can ease the burden of frequent clinic visits but unfortunately the availability of such systems remains limited and variable across the country.

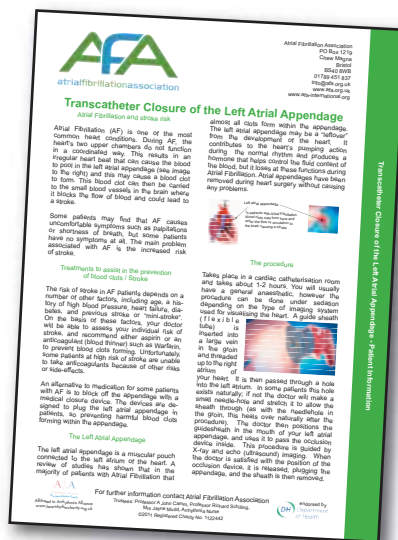
There is no one certain reason as to why Warfarin is under used. Education? Fear? Certainly managing a therapy which impacts on many aspects of a person's daily life, from food and drink to work, travel and drug interaction, is a considerable issue for many patients. Falling outside of the therapeutic levels, frequent appointments and risks are undoubtedly of concern to clinicians.

So, in the 21st century, we find ourselves with a very effective therapy, but one which is significantly under used. Even by National Institute for Health and Clinical Excellence (NICE) standards, more than 166,000 known AF patients who should be on anticoagulation are not.

Of course, some are unsuitable to use OAC, and for these there are device options. There is now available a tiny 'plug' or 'filter' which can be placed across the opening of the Left Atrial Appendage where clots can form. The device prevents many of the clots forming or breaking free, so reduces the risk of stroke. Often not even known about, this is an effective alternative when anti-coagulation therapy is not an option but stroke risk is high.

Hitting the headlines are the new oral anticoagulation therapies - Apixaban, Dabigatran and Rivaroxaban. NICE are reviewing the first to come to market, Dabigatran (Pradaxa).

Based on the RE-LY study involving over 18,000 AF patients, Dabigatran is a two dose per day therapy at 150mg per dose or 110mg. The lower dose, more suited to those at raised risk of bleeding or suffering kidney problems, has shown the drug to be as effective at reducing the risk of stroke as Warfarin, but better at preventing bleeds. The 150mg dose shows a 35% increase in reducing the risk of stroke. Currently, Dabigatran has a European Safety License (ESL) and has been launched in the UK. NICE met in July to appraise the medication for use in the NHS, and the Final Appraisal document is due in late November.



Rivaroxaban is the next expected OAC, with the ESL due within a few months. Evidence for this therapy is largely based on the ROCKET-AF trials, and has been shown to be as effective as Warfarin and safer with fewer bleeds. It is a one dose per day drug, and NICE expect to appraise it during 2012.

Finally for now, in the drug options, is Apixaban. Its first trial; AVERROES looked at people with high risk of stroke but only able to take Aspirin. Reported in 2010, the study finished early as the benefit in stroke risk reduction was so evident. It proved Apixaban was better than Aspirin at reducing stroke and had similar bleeding risks.

Reported in August 2011, ARISTOTLE, a trial comparing Warfarin and Apixaban, concluded that Apixaban was superior to Warfarin in both safety and effectiveness. With such recent trial

results, NICE has yet to appraise Apixaban, this is expected later in 2012.

All three therapies have shown themselves to be at least as good or better at preventing strokes in AF patients, than Warfarin. All three need very little monitoring and are very stable, having few interactions, so for patients and doctors, these new options may be appealing. Of course they are new, and as such less is known about their long term use; but for many they may offer safety along with a lifestyle which needs little pre-planning or abstaining.

However, new licensed therapies are costly. Trials which have developed them and brought them to us have taken years and billions of pounds to run. It is reported that clinicians have to treat at least a further 300 people to prevent one possible stroke or

bleed that could have been caused by Warfarin to make them cost effective.

Others would argue, can Warfarin be considered as cost effective with widespread underuse and evidence revealing lack of time a patient is within therapeutic levels? Integrating new therapies will be challenging where cost, safety and patient outcome has to be balanced. What we do know is that diagnosing AF promptly and assessing an individual's risks, then using an appropriate anticoagulation therapy DOES reduce avoidable deaths and disability.

Please ask your GP, 'am I safe? Do I need an annual review for my stroke risk?' Then welcome the discussion of what is now available.

Information Fact Sheets from AFA will shortly be available on all of the new therapies and options.

AFA Affiliation

We're here to help and support

AFA is delighted to highlight four new AF Patient Support groups in the UK. Led by AF clinicians and patients, 2011 heralds the first AF specific local groups. To welcome and support this new and exciting advancement, Caroline Holmes has been appointed as AFA's 'Affiliate Officer'.



'Hello! I would like to take this opportunity to introduce myself as the new UK Affiliate Officer. 2011 saw the birth of the first local AF Patient Support groups, with Sheffield, Southampton, Torbay and Brighton and Hove leading the way! However, we hope this is just the start of a wealth of local networks.'

Are there times when you feel like the only person in the world with AF?

Do your family and friends struggle to understand the condition?

Would you like to get together with other people in similar positions as yourself, in a friendly, safe and well informed group on a regular basis?

If you have answered 'YES' to any of these, then AFA would like to help. Please contact me for details – whether you are a carer, have been diagnosed with AF or are a healthcare professional, we have guidance and can help you establish an affiliated group which reaches out to many others. We can also help with practical aids such as advertising, poster design, a dedicated website page, AFA publications and speakers. Below are just a few comments from members of the already established AF support groups:

- ♥ "It's great to be able to talk to someone who understands what I am saying."
- ♥ "I feel more in control of my condition now I have been able to talk with others."
- ♥ "I look forward to our meetings, I've met some great new friends and feel safe in the knowledge this is with fellow sufferers and caring, informed medical staff."

I would be happy to share information about established support groups along with guidance on forming a new group. Please do not hesitate to contact me either by email: caroline@afa.org.uk or phone 01789 450787.

Caroline Holmes

Duncan recalls the TIA which uncovered AF

It was June 10th 2009, two days before my birthday, I was a fit and healthy 57 year old, or so I thought. I was physically active, ran, attended the gym and had a reasonable amount of energy. I had attended a cardio unit for a check-up about a year earlier because of a high heart rate during training but I was given the all clear at that time.

“I was given the all clear”

On the evening of the 10th June I ran upstairs, as I came back down noticed that my vision was beginning to blur and I felt light-headed, I then felt a tingling sensation down the left side of my face. This sensation only lasted about 30 to 40 seconds, but I felt exhausted after this occurred. Stupidly, I did not call the emergency services, and only attended the doctors the next day.

I was lucky and managed to see my own doctor who immediately gave me an Electrocardiogram (ECG). After the examination, she explained that I had experienced a TIA (mini stroke), and that my heart-beat was uneven. She diagnosed AF, but first of all I was booked immediately into the stroke clinic at my local hospital. I was not to know that this was going to be the start of a long journey of hospital visits and consultations.

The stroke clinic addressed two aspects; the TIA and treatment to reduce the possibility of another TIA or a full blown stroke. Firstly I was examined by a consultant, who explained what a TIA was and stated that they would put me on Warfarin. This reduces the stickiness of your blood and helps prevent the blood

from forming clots. To stabilise me to a level that they needed to took over a week and required daily attendance at the clinic.

After this I visited the consultant again and he confirmed that my Warfarin level was stable and that he was referring me to the Cardio Unit.

“Stupidly, I did not call for the emergency services”

The Cardio Unit checked my heart with the usual ECG and then an ultrasound of the heart and the carotid arteries. I would say at this point of the check up I was having difficulty in walking any distance without puffing and panting and generally feeling totally shattered. The cardiology consultant confirmed the initial diagnosis of AF and my heartbeat was not in sinus rhythm. He explained the way forward with this condition, and medication was prescribed. This was a tablet called Securon; initially I was prescribed half a tablet (half Securon). I must say the effect after a day or two of taking this tablet made a difference, my energy levels came back, though it was not completely normal.

I was scheduled to see the consultant within a month of starting the medication again and during this time I was asked to attend a clinic to have a 24 hour monitor attached.

The monitor hangs around your neck and is the size of a small iPod. The leads are attached to your chest and back area. It constantly records your heart rate over the period of time specified by the clinic.



At the next meeting with the consultant this information was available to him, it was noted from the results that even with medication I was still suffering from an irregular heartbeat (symptomatic AF). The consultant prescribed an increase in the medication to one full tablet per day. All of this had taken just over a month.

During my consultation with the stroke consultant he had prescribed Statins, and had put me on Symvostatin to reduce my cholesterol level, even though it was not high in the first place. My own doctor called me in when this happened and told me that they had queried this medication as it clashed with the Securon the cardio consultant had prescribed. She said that she would monitor this closely, by having frequent blood tests. Within six weeks I was off the Statins and due to me having an adverse reaction to the tablets, I ended up with a High CK figure. I was immediately put on another form of tablet called Ezetab. This appears to be working without adverse effects.

“I had adverse reactions to the tablets”

My episodes of AF reduced for a period of three months or so and my energy levels improved during this period. As my time came to see the consultant again I felt okay and on my visit they stated that my heart rate was back in sinus rhythm, I should carry on taking the medication, and that they would see me again in six months. About a month or so after this visit I started to experience sessions of AF again. This began with very brief sessions, but by the time of the next consultation I was back to my bad times again with days of exhaustion and fatigue. I suppose I was lucky at the time as I was also unemployed, so it did not affect my job! The consultant stated that it would be beneficial to have another monitor test.

This time it would be on for about a week, and once this had been analysed he would see me again. On my next visit he increased my dose of Securon from one a day to two a day; one in the evening and one in the morning. He stated that this was the maximum they could go to with this type of medication, and explained that it was not uncommon to have to increase the dosage as the body gets use to the drugs.

The increased dosage started to improve how I felt and reduced the AF, although it did not go away completely. Shortly after this period I started a new job and I felt that things had started to look up. Over the next few months I settled into my new position, and the AF stayed about the same even with the

increased workload. I visited the consultant in November 2010 and he suggested that I see another consultant in Glasgow with regards an ablation procedure. As my profile fitted the requirements for this procedure (my age and fitness condition), it appeared that the medication route could be one of a temporary nature in my case.

In February 2011 I received notification that I had a date with the consultant in Glasgow. The consultation duly took place; it was explained to me the pros and cons of the procedure. I will say that in all the consultations I had, this was the first time I felt that the consultant understood what I was going through. The decision was mine to take, even though there was a risk I felt it was worth going for, I just wanted to get back to the levels of fitness I had in 2009.

Things moved quite quickly from here on. By April I would be having the procedure. The date drew closer and I must admit I had reservations but all I could focus on was to regain my health and fitness back.

The day of the procedure arrived and I found myself in the Golden Jubilee Hospital in Clydebank. This hospital specialises in heart procedures for the west of Scotland. The staff excelled in their care and attention, from explanation, procedure and after care. I was out the next morning, feeling bruised and missing some body hair. The consultant informed me that it might take up to a month to feel any benefits from the procedure. Over the following week I had a couple of AF bouts, but they did not last for any length of time.

“I was back to my bad times again with exhaustion and fatigue”

At the time of writing this article it is nearly two months since the ablation procedure and I feel completely different-no more fatigue, and no AF that I can detect at least! I am still on all the medication, and I am due to meet with the consultant shortly. I can only guess as to whether he will reduce my medication, but to be honest, if I have to stay on it and I have my life back, who cares!

This whole period has lasted close to two years, but as I reach sixty I do feel that I can and am looking forward to the future.

For anybody interested in a more factual blow-by-blow account see my blog at <http://duncsramble.blogspot.com>

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Margaret's Story

Left to search for information after a diagnosis:



The day arrived and, although I felt a little tired when I got out of bed, I managed to get to the venue where I taught yoga early. I was fairly flexible and healthy from teaching yoga since the mid 70s. However, as the morning went on, I began to feel uncomfortable.

Soon after that I noticed my ankles were swelling, I was putting on weight and I felt exhausted. I saw my GP and it was suggested

that I needed counselling. I did not think that would help but attended a few sessions. After these visits, I saw another GP who referred me for tests.

had an underactive thyroid I had to stop eating broccoli, sprouts and spinach. I ignored this, presuming that I would have been told before.

In January 2006 I had the heart surgery. I decided that I needed to do more research and I was encouraged to use a computer. I always checked and double checked and preferred to get information from people who were experts in their field.

In the spring of 2006 I went back to work. I decided I would concentrate on working with people with medical conditions. During all of that time I still did not know enough about arrhythmia, Warfarin and Vitamin K. I was anaemic and my GP suggested I take vitamin and mineral supplements. From further research, I came to understand why I had two nose bleeds and burst blood vessels in my eyes. I still have to remember not to rest my elbows on the table: my left elbow is bruised most of the time.

'I still did not know enough about arrhythmias'

A blood test showed I had hypothyroidism and I was placed on Thyroxine. My weight soon shot up to 11 stone. At the hospital, I had ECGs and echoes carried out. It was amazing to watch the movements of my heart on a TV screen.

I continued with my classes as I was happy to help others but by the summer of 2004 I had to give up four of my classes and had three months away from teaching as, in 2003, I found out I was born with a hole in the heart. I knew I had to have open heart surgery, as the hole was too close to the valves.

'I had to give up four of my classes'

In November 2004 I started taking Warfarin. My first thought was, "crumbs, rat poison!" and then "here goes, let's see what happens". I was not provided with any information regarding Warfarin by my doctor, instead being told by a fellow teacher that, because I

'I am more able to deal with my condition now'

Over the past years I have learned more about thyroid conditions and the link between the heart conditions. I am also taking Digoxin for bradycardia and also must not forget Verapamil, for something or other to do with the heart.

In January 2011 I finally got to the anticoagulation clinic. There I was provided with a lot more information. Armed with that, I was able to contact the AFA group who sent me papers on Warfarin. I am more able to deal with my condition now. There are foods that I no longer have. I miss the cranberry sauce at Christmas, and I miss not having grapefruit for breakfast, but I eat almost all the foods that I enjoy. I am in control.

To all of you at AFA, my deepest gratitude for the information you provided. I believe that more and more people should know about the condition.

Margaret

Fundraise for AFA



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We could not provide our vital services without your help. If you would like to get involved, there are many ways you can help us to continue to provide information, support and access to established, new or innovative treatments for Atrial Fibrillation.

There are many ways in which you can assist AFA:

- Make a regular or one off donation
- Participate in an organised event such as a marathon, swimathon, bike ride, sponsored walk, raffle, table top sale
- Organise your own exciting challenge, or something a little less energetic such as a coffee morning or cake sale
- Leave a gift in your will

For further ideas on how you can support AFA, get in touch with the Fundraising Team and we can provide you with as little or as much help as you require; call **01789 451837** or email: info@afa.org.uk



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Frequently Asked Questions

Dr Andrew Grace, Consultant Cardiologist and Electrophysiologist, answers your questions



Q. I have been diagnosed with Atrial Fibrillation. Is it likely that my children will also develop AF?

Atrial Fibrillation (AF) is a common condition and is widely regarded as being multi-factorial. That is, many factors are involved in

determining the expression of the condition in a particular individual.

All diseases are determined by both intrinsic (and often, therefore, genetic) and extrinsic (usually environmental) influences. The importance of intrinsic and extrinsic factors change, as we get older. Young people presenting with AF means that genetic factors may be more powerful in terms of their influence on the disease than in older people. Of course, Atrial Fibrillation is an age-related condition and the very fact of aging itself may be the determinant of Atrial Fibrillation. Other factors that influence AF may have developed during a person's lifetime, such as the appearance, for example, of very high blood pressure or obesity.

Accordingly, the impact of the expression of Atrial Fibrillation in an individual, and the likelihood of this appearing in their children, will be determined by things like the age of appearance in the parent and other co-factors such as for example, the amount of alcohol consumed or possibly the amount of extreme exertion participated in.

My general view in discussion with patients is that, because of this multiplicity of influences, patients with AF should not be particularly concerned about the risk for family members. In very few individuals is there a single major genetic determinant. It is rather the influences of chance that will determine the expression in those in succession in that family. The chance of your children having AF may be marginally higher than those who do not have an affected parent. However this is not something that should particularly concern you or them as we can do little to influence events. Should AF appear, then appropriate referral and management should be embarked upon as it would if there was no family history. This general position may change with the advent of personalised medicine and predictive testing but it is what we have for the time being and works well within the bounds of what can be achieved.

Q. I have recently developed AF. Is it safe for me to carry on attending my keep fit classes and jogging twice a week?

In an individual developing Atrial Fibrillation the first step in terms of getting a management plan is proper medical assessment. Once that has been achieved and appropriate

medications have been prescribed and/or interventions have been embarked upon, then physicians would generally encourage patients to return to full and normal activities. The general attitude of heart specialists is for individuals to return to normal lifestyles and maintain general cardiovascular fitness. Such a programme will provide the maximum long-term advantage to patients.

Accordingly, we would want individuals to attend keep fit classes, pursue fitness to the best of their capabilities and if they were able to go out jogging, this would also be encouraged. The maintenance of normal weight, joint flexibility and muscular strength is important to global fitness.

In the vast majority of patients exercise is unlikely to have an adverse influence. It is certainly safe in the majority of patients for exercise to continue and most doctors would encourage this for most of their patients affected by Atrial Fibrillation.

Q. Will I have to change to one of the new anticoagulants?

Warfarin is the one tried and tested agent for the protection against the risk of stroke in patients with AF. For the time being it remains the gold standard in the management of the risk of thrombosis and embolism in those with Atrial Fibrillation and it will retain that position, at least in the immediate future.

Emerging data on at least two new anticoagulant agents indicates that they may have potential advantages when compared to warfarin in those with AF and therefore they may displace warfarin as the standard of care and become the new gold standard treatment. However, more clinical trials and then a period of further assessment and information gathering will be required before that new situation emerges.

If and when the new drugs become the standard of care will be determined by questions that concern efficacy, safety and tolerability. If the drugs are shown to be safer, have higher efficacy and be better tolerated than Warfarin, then this is likely to lead to their acceptance by the healthcare community and patients. In addition, if they were to provide a more cost-effective approach, that may also switch the opinion of the medical community (and payers) to the use of these newer agents over Warfarin. However, again, this may be some time in coming.

I would anticipate that, if one was already taking warfarin, then it's unlikely for several years if you were happy taking that agent that anyone would try and get you to change to a new agent. Accordingly, the answer to your question is that unless there is an enormous body of evidence and opinion then there would be no mandated change to new anti-coagulants any time soon.

Q. Can I make AF better without medication or without having an operation?

The question relates to the capacity of lifestyle modifications to improve both symptoms and objective measures of Atrial Fibrillation. With paroxysmal Atrial Fibrillation, it may well be that interventions, such as decreasing alcohol intake, losing weight and generally increasing fitness and controlling blood pressure are capable of controlling Atrial Fibrillation.

However, other permissive influences, such as the influence of age, may also be pushing the fibrillation forward and in those who manifest with Atrial Fibrillation in my experience it is unusual that single dominant lifestyle interventions will make the fibrillation better to the extent that no other actions are necessary.

Even if a lifestyle modification approach is considered as the first line strategy for symptoms then this should not change a pro-active medical approach in measures to reduce the risk of stroke.

Having said this, we would encourage lifestyle modification in all our patients with Atrial Fibrillation, as these are likely to lead to a better overall outcome in terms of quality of life and prognosis whether or not other interventions are applied.

Q. I have high blood pressure and Atrial Fibrillation. I have found that I am unable to tolerate Warfarin and I wonder if there is anything else available to reduce my risk of stroke.

In general terms Warfarin is an extremely well tolerated drug and we find that the vast majority of patients do respond well to Warfarin. However, there is a subset of patients who, for a variety of reasons, some of them rather non-specific (tiredness, tummy upset etc.), find they are unable to tolerate Warfarin.

For the time being the only widely available drug that has been shown to significantly reduce the risk of stroke in the context of AF is Warfarin. The newer agents currently undergoing review should provide similar protection against the risk of stroke. However for the time being, Warfarin is the drug of choice. In general terms, use of aspirin is now being looked upon with increasing ambivalence in those with AF. Clopidogrel might provide some benefits but this would not compare to those available with Warfarin.

One option that is possibly useful in those with a risk of stroke and intolerance of Warfarin is the use of a left atrial occlusion device. This is usually a catheter-based procedure not dissimilar to ablation from patients' perspectives. The procedure is now available at several regional cardiac centres in the United Kingdom and in selected patients may become the approach of choice.

On warfarin?



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References:

1. Gadisseur APA et al. J Thromb Haemost 2004;2:584-91.
2. Garcia-Alamino JM et al. Cochrane Database of Systematic Reviews, Issue 4, 2010.



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coming to terms with AF
after a surprise diagnosis:

David's Story

I have suffered from palpitations for pretty much as long as I can remember - definitely from my mid-teens on - but never really thought anything of it. The attacks tended to be brief and few and far between, so I guess I just thought it was normal.

In my twenties I also began to notice an "ache" in my chest whenever I was tired, and this ache often occurred before palpitations. I don't know if I had always had this ache and had slowly become aware of it over time, or whether it developed with time, but again it never really concerned me as I found that if I got a good long sleep then the symptoms would go away.

Also, ache is a strong word - this is more of a "sensation" (much like hunger) as opposed to chest pain, and if I happened to remember it when I was seeing a doctor I would mention it - but they never seemed concerned ("It's tiredness", "It's digestion", "It's nothing"), and so nor was I.

"Palpitations for as long as I can remember"

When I was 35 I became a father for the first time, and like most parents endured extended periods of broken sleep. The aches and palpitations got worse because of this, so I decided I should see a cardiologist to put my mind at rest. I underwent a battery of tests, including a treadmill Echocardiogram (ECG), Echocardiogram and Magnetic Resonance Imaging (MRI) but nothing showed up. This reassured me but did not explain the palpitations which the cardiologist was "99% certain" to be ectopic beats.

We decided to do a five day ECG just to be absolutely certain and it was at this point that we got a recording of my AF. This surprised the cardiologist, and shook me quite a bit. I guess that it goes without saying that being told I had a heart condition at the age of 35

was not great news, and a subsequent meeting with an electrophysiologist just served to make me worry more. It was ironic really, as you would think that getting a positive diagnosis and treatment plan would be a relief after all of those years. I guess the news that it was something I would have for the rest of my life, that could potentially cause a fatal stroke and that surgical treatment involved sticking a hot wire "into your heart so that we can burn bits of it away" (!!)

made me worry more. The next few months were pretty horrible, and it took me some time to come to terms with the condition - but the AFA website proved to be a godsend. It was reassuring to know I was not alone, to hear other people's stories, to hear about ablation success and to find others of my age with the same condition.



At 35 David's diagnosis of AF did not bring expected relief, just more worry.

I'm not certain why I ended up with AF at such a young age. My cardiologist, witty chap that he is, reckons it was down to a poor choice of parents, but I suspect it was down to being quite athletic when I was still growing (as a teenager I would regularly do upwards of 100 miles a week on my bike, as well as playing rugby), coupled with problems with my digestion. I, along with many other AF sufferers, can suffer badly from stomach acid - if I have an acidic stomach during the day then I regularly have an AF attack in the evening) and probably some genetic predisposition. My maternal grandfather suffered a series of strokes in his sixties, the last one fatal, this was back in the 1980s and AF did not really seem to be on the health service radar so I do not know if he had AF or not.

"I deduced my primary triggers"

But, it is not all bleak. I am now 38, and since first being diagnosed with AF I have deduced that my primary triggers, in order, are: lack of sleep, stress, hunger, over-eating and excess alcohol. Knowing this, I currently manage my AF through lifestyle and I

am fairly successful at it. I take aspirin for anti-coagulation, and although I still have bouts of AF I can go for months at a time without an attack (although I can also have periods where I have daily “mini” AF episodes that last for a few minutes at a time). My worst attack lasted forty-five minutes (however I can have multiple attacks lasting for minutes in any one day), so compared to many I am fortunate. I am very symptomatic, so I immediately know when I am in normal sinus rhythm (NSR) and when I am in AF, and this helps me to keep track of my attacks. I also have a home ECG machine which means I can capture any attacks I do have and share them with my cardiologist.

“Fatherhood meant broken sleep”

I live a normal life to all intents and purposes, except I am now more finely attuned to my heart than I would otherwise have been. Despite having a desk job I am pretty active and go to the gym three or four times a week - AF has not stopped me from exercising. Indeed, I think having a strong heart can only help. I appreciate that exercise will not cure AF (and I am still evaluating if excess exercise actually causes attacks in my case), but I do know that regular exercise helps reduce stroke risk, brings down blood pressure and, coupled with a sensible diet, helps to prevent diabetes - all of which are things that have a direct impact on your CHADS score.

I do not know what the effect of half a lifetime on warfarin would be, and I do not want to find out - so I intend to keep my CHADS score at zero for as long

as possible, and exercise and a sensible diet are the best methods I have available to achieve this.

“I manage my AF through lifestyle”

Going forward I hope to be able to control AF by managing my triggers for as long as possible, but I also accept that it may, and probably will, worsen with time. I currently see my cardiologist once every 12 months and have an annual echocardiogram. I guess I will probably go for an ablation when I find that the attacks are getting more frequent, go on for longer or, if ever, I do not spontaneously revert to NSR.

“I accept it may worsen with time”

Finally, if asked, my advice for someone recently diagnosed with paroxysmal AF would be to get on medication and then try to find their triggers before rushing into an ablation or starting on any drug programme (although with the proviso that their cardiologist supports this and they have a CHADS score of 0). I think AF in the young, particularly AF that appears to be vagal in origin, can be successfully managed at least in the short to medium term through lifestyle choices.

Regards,
Dave

Why might a young, healthy person develop AF?



Individuals who are fit and healthy can develop AF. In these individuals 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 becoming apparent that in those who lead particularly healthy lifestyles and visit the gymnasium on a very regular basis or participate in exercise to a very high level then the risk of AF might in fact be enhanced if they are otherwise predisposed.

Raise awareness of life with Atrial Fibrillation

By sharing your experiences you are helping others to learn more, gain insight into possible treatments and actions which might help them and overcome the lonely despair AF can bring.

Contact Margaret by writing, calling or emailing, for further details.

☎ 01789 451837 ✉ margaret@afa.org.uk
✉ AFA, PO Box 1219, Chew Magna, Bristol, BS40 8SU

What makes the difference for **you**?



“When I first started on the AF route, there was no one, but the practice nurse was a great help and although not a specialist I could always go and talk to her, which at times was all I needed.

As my AF journey progressed the staff on the ward became my life-line. I could always ring them up when I was worried or scared, and at times would go in for an ECG by passing the official channels. This, I suspect was not normal, and I don't know how I achieved this sort of relationship with them, except that I was always on the same ward, but knowing I could do this was absolutely fantastic. I was very lucky.

The main thing I found was having someone I could talk to either for reassurance or who said come in and we will check you out. This gave me the confidence to get on and do things, and when I found the AFA that also gave me the support I needed, and still do.

My support did not come from a regular arrangement, just fantastic ward staff at the time.”

E. Porter, London

“You know I'm always willing to help but to be honest the only help I've had with AF has been the forum and patient days. I have not been offered any other help or support at any time over the last 21 years.”

S. Evans, Northampton



“As far as I am concerned the greatest single asset which changed the way I looked at my AF was my access to a specialist arrhythmia nurse. Having had ablations and other treatment before and after this nurse was available I can vouch for the comfort they can give and also the simple fact that if a patient has a

problem or is worried about changes in their condition, a simple phone call or e mail can re-assure them and often enable the patient to avoid unnecessary and stressful trips to A and E.”

B Dove, Bristol



“I have always used the web as an information source, so that is probably how I found Arrhythmia Alliance (A-A). Through the A-A, I found myself at AFA's Europe-AF, and one of the A-A's patient sessions was a talk by Tara Meredith on the nurse led rapid access clinic at the John Radcliffe (JR). At that point I was under GP care, I was not aware that I could

access tertiary care outside my local area. I managed to chat with Tara over tea between sessions, and she explained about choose-and-book, and that the JR clinic was seeing patients from my area. Within five weeks I attended the clinic at the JR, having had a referral from my GP, this lead to my life-changing ablation. Without Arrhythmia Alliance at that time, I would not have the quality of life that I have today.

The John Radcliffe is open to patients in a way that I had not come across before. I was given a direct line to the arrhythmia specialist nurses, and for out-of-hours I was also given a direct line for the duty cardiologist. That was SO comforting to have. I have an excellent GP who supported me throughout. To me this was a wonderful example of the system working well, both at the tertiary and primary care level and both trusting the patient.”

C. Harmer, Gloucestershire

“MY FIRST AFA PATIENTS DAY was part way through my treatment. There, I met so many other AF patients and I listened to presentations. All this helped me understand my own situation, and moreover realise that I was not alone, as AF was something I still knew so little about. Since then, over time I have been to many more patient meetings, renewed old friendships and we have followed each other's progress, which I found invaluable to my own wellbeing. The AFA team became people I knew as friends, as well as someone I could share my worries with at any time, just a phone call away. Everytime, the clinician's presentations taught me something new I could take home with me, hopefully, a little wiser than before.

At one Patient's Day Conference where I heard a presentation from a guest clinical psychologist, I did my homework, and wrote to him asking if he could suggest a specialist in my own area with similar interest in AF. To my surprise, he very kindly responded offering his own help. I was totally indebted for his support. My thanks to him and him alone, I was able to enjoy my summer! “

M Ellis, London

2011: Six months in the life of AFA

In the past six months AFA has been very busy. We have been invited to present at several meetings around the world, including Australia, South America, Asia-Pacific, North America, Canada, Europe and the UK.

These events provided a great opportunity to highlight the current inequalities in accessible services, information, interest, care and review of a person with AF, and hence the resulting fears and frustrations too often experienced.

AFA has also held meetings with UK and European governments and hosted an Awareness Forum for MEPs earlier this year. The Know Your Pulse campaign has resulted in meetings with over three hundred MPs and Peers, events in the Welsh Assembly and Scottish Parliament, the launch of AF Friday and the AF Patient Charter, and most recently, the establishing of an All-Party Parliamentary Group on AF, chaired by Glyn Davies MP.

AFA remains very active in responding to, informing and being part of many National Institute for Health and Clinical Excellence (NICE) review committees on AF related topics, from new therapies and devices for detecting AF, to developing new national standards on service provision, informing QoF (the GP 'Quality and Outcomes Framework') and the NICE AF Guidelines. Obviously with the setting up of the 'new NHS' we are continuing to work with service providers, to ensure that AF is a high priority. AFA is working to ensure that the patient voice, patient outcomes and quality of life are key factors in maintaining, developing and expanding services, and that all areas of patient needs are considered and informed by patients alongside the most up to date clinical data.

This year's Heart Rhythm Week was whole heartedly supported by AFA and as a result events took place across the country, and globally. Supporting members saw coverage on the radio, TV and in the press,

all furthering awareness of AF, its symptoms, risks and varied treatment options, along with the huge importance of early detection and prompt management to restore health and wellbeing.

Working from feedback and requests, we will be offering a few more local meetings around the UK later in 2011 and during 2012. AFA is launching an advanced modular course on AF, in association with Bradford University, to enable non-specialist practice nurses and GPs to enhance their AF knowledge and skills.

To our delight, the summer has seen four new local AF Patient Support Groups establish, all of which are supported by AFA and local arrhythmia clinicians, in partnership with local AF members.

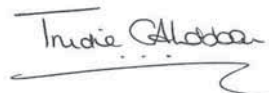
On a daily basis we have increased our support team due to the high volume of enquiries and it is a pleasure to introduce you to Margaret McCarney, our new full time Information and Support Officer.



Margaret McCarney

This year we have published a new booklet entitled 'Frequently Asked Questions' and three new fact sheets, and this summer saw the launch of AFA-US (www.afa-us.org). Welcome to our stars and stripes neighbours!

I sincerely hope that by sharing just a taste of the work AFA is involved with I can reassure you that the fundamental aim to 'provide information, support an access to new or innovative treatments for Atrial Fibrillation' continues. We welcome hearing from all members, without whom we would not be able to achieve our goals, and look forward to your continued support.



Will you ACT on AF?

ACT on AF Friday will be held on **28 October 2011**. As part of this campaign, the AFA is asking MPs, supporters and clinicians in England and Wales to write to key Ministers and commissioners to ensure that AF is an NHS priority.

If you would like a campaign briefing which tells you more about ACT on AF Friday – including tips on how you can write to your MP – please contact Joanna Fearnley on joanna@afa.org.uk or 01789 451 823

ASK if your local commissioners have a strategy on AF

CASE studies – share pioneering best practice on AF across the NHS

TELL the Minister that AF needs to be prioritised and an early Quality Standard is urgently needed (in England).

ON AF



The Pulse in Parliament

In June AFA established the All-Party Parliamentary Group on AF (APGAF). Chaired by Glyn Davies MP, the group aims to raise awareness of AF and ensure diagnosis, care, treatment management and research of AF is a priority for the NHS. With Madeleine Moon, the Labour MP for Bridgend, Conservative Peer Lord Colwyn and Liberal Democrat Peer Lord Jones of Cheltenham, the group opened the first meeting and welcomed presentations from Professor Sir Roger Boyle, who outlined progress to date and challenges now facing the NHS in detecting and caring for patients with AF.

Glyn Davies MP commented that 'as an AF patient myself, I now realise the importance of knowing the signs and symptoms in order to receive a prompt diagnosis and appropriate treatment.'



All-Party Parliamentary Group on AF

Trudie Lobban MBE, speaking after the meeting, said 'we are approaching a critical juncture in the NHS. The APGAF will help to ensure AF is a priority for the NHS.'

Pulse into Politics and Practice!

Mr Amess: To ask the Secretary of State for Health what steps he has (a) taken and (b) plans to take to reduce the number of strokes; and if he will make a statement.

Mr Simon Burns: We are aiming to reduce premature mortality from stroke in a number of ways. The NHS Health Check programme assesses people aged between 40 and 74 for their risk of heart disease, stroke, diabetes and kidney disease and helps them to reduce or manage that risk through individually tailored lifestyle advice and support so they stay well for longer.

Phased implementation began in April 2009 and this Government is committed to the continuation of the programme. At full roll-out, the programme could prevent at least 1,600 heart attacks and strokes a year. Implementation of the National Stroke Strategy and the National Institute for Health and Clinical Excellence Quality Standard for stroke provides the NHS with evidence based characteristics of a good stroke service that have and will continue to improve stroke care resulting in better outcomes for patients in terms of prevention and treatment. The NHS Improvement Programme is leading work on raising awareness of the role of Atrial Fibrillation (AF) in stroke in primary and secondary care. For example, it is promoting opportunistic pulse checks in primary care, such as at flu clinics, to detect AF earlier in older people so that it can be treated and so reduce their risk of stroke.



Sir Roger called for stability in the NHS

AFA wishes a fond farewell to Professor Sir Roger Boyle

Professor Sir Roger Boyle, who was appointed as the National Director for Heart and Stroke Disease just over ten years ago, and known to many as the 'Heart Tsar', recently retired from his post. Sir Roger has had a long and distinguished history as a member of the Council of the British Cardiac Society and was the former Chairperson of the Advisory Committee for training in Cardiology.

In 2007, Sir Roger worked with Arrhythmia Alliance to ensure the successful implementation of an extra chapter, Chapter Eight - Arrhythmias, to the then newly launched, National Service Framework for Coronary Heart Disease, which had previously only mentioned the term 'arrhythmias' once! Through determination and dedication, Sir Roger worked to provide a blueprint which ensured quality and equality in treatment.

Throughout his eleven year term, his inspiring leadership saw death rates due to heart problems fall by half, and stroke survival rise at similarly impressive rates, giving England the fastest rate of improvement in Heart and Stroke in Europe. On top of this, under Sir Roger's management, there were impressive falls in waiting times, improved referrals, and better equipped units with a rise in the number of surgeons, all of which resulted in improved patient care.

Sir Roger's departure is a great loss to the NHS and to patient groups, and he will be sorely missed.

PATIENTS DAY INVITATION



Monday 21st November 2011 London Hilton Metropole Hotel

Europe AF 2011 would like to welcome patients to their own Programme as part of Europe AF. This will take place in Hilton Meeting Rooms 1 - 6 in the East Wing of the London Hilton Metropole Hotel. Registration will take place on the Ground Floor of the West Wing. The organisers and Faculty would like to invite patients to join them for the morning session in the main auditorium on the First Floor of the West Wing. The patients' programme will follow after lunch.

10:20 – 11:20	USING DRUGS TO TREAT AF: HOW TO CHOOSE Chairs: Sam Levy and Antonio Raviele	
	Dronedarone 1 year later. What is the experience?	George Wyse
	Vernakalant: what to expect	A John Camm
	Why move from CHADS2 to CHADS2VASC2?	Gregory Lip
11:20	Coffee and Visit the Exhibition	
12:00	TREATING AF WITHOUT ABLATION Chairs: A John Camm and George Wyse	
	What are the alternatives for rhythm control?	Sam Levy
	LA appendage occlusion: when and how?	Thorsten LeWalter
12:40	Lunch and visit the Exhibition	

14:00 – 14:20	Seamless AF care, a successful model	Suzanne Robson (TBC)
14:20 – 14:40	Catheter ablation – could I be a suitable candidate?	Andrea Natale (TBC)
14:40 – 15:10	Question time	
15:10 – 15:30	Tea/coffee	
Working together for improved outcomes:		
15:30 – 15:40	AFA 2012	Trudie Lobban
15:40 – 15:50	Affiliation	Caroline Holmes
15:50 – 16:00	Volunteering and Fundraising	Wendy Adams
16:00 – 16:20	Discussion / break out groups	

VENUE

Europe AF will take place in the Kings and Monarch Suites in the West Wing of the London Hilton Metropole Hotel.

London Hilton Metropole Hotel
Edgware Road, London W2 1JU

Tel: +44 (0) 207 402 4141
Fax: +44 (0) 207 724 8866

www.hilton.co.uk/londonmet



LOCATION DETAILS AND TRANSPORT

The nearest underground station to the Hilton Metropole is Edgware Road or alternatively, Paddington which is also the nearest main line station and has an express train link to Heathrow Airport.

Gatwick Airport has a direct rail link to Victoria Station.

Waterloo International Station has an underground link to Hyde Park Corner or is fifteen minutes from the hotel by taxi.

London City Airport is approximately 45 minutes away by taxi & Heathrow and Gatwick airports are also served by a regular shuttle bus service to hotels in Central London.

Parking is available at the hotel at NCP rates.



HRC2012
23rd - 26th September 2012
The ICC, Birmingham UK

Save the date
HRC AFA Patient Day
Sunday 23rd September 2012

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PLEASE PRINT:

Patient

Title: Mr / Mrs / Miss / Ms / Dr _____

Full Name: _____

Address: _____

Postcode: _____

Daytime Telephone no: _____

Evening Telephone no: _____

E-mail: _____

Date of Birth: _____

Ethnicity: _____

Carer

Name: _____

Tel: _____

Email: _____

Address: _____

Tick box if happy to receive newsletters and updates from AFA

Patient Diagnosed: Yes No

Diagnostic tests done: _____

Diagnosis: _____

If Diagnosed by whom:

GP Cardiologist

Geriatrician Paediatrician

Name: _____

Hospital/Medical Centre: _____

Medication: _____

Devices used: _____

Registered Charity No: 1122442

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