AF Association calls for change to achieve better AF management

In July 2014, the UK National Screening Committee issued guidance on AF screening and found that systematic population screening should not be recommended as it is not clear that those identified as at risk through screening would benefit from early diagnosis. In light of this, Professor John Camm writes that the current state of affairs on screening for AF within the UK is: “a sorry story which we must solve”.

An AF-related stroke is more disabling, debilitating and more likely to be fatal than any other type of stroke. If AF is detected and managed earlier, at least 1 in 3 AF-related strokes could be prevented. That’s 12,500 strokes in England each year. The sudden nature of AF-related stroke leaves victims and their families devastated and faced with a very different life and outlook.

Professor John Camm says: “Early detection of the disease would have many benefits, as we would then be able to manage the condition and potentially prevent life changing complications, such as AF-related stroke.” AF Association believes that there is sufficient evidence, access to effective therapies and clinical management guidance all in place and that it is now time to offer all people with AF the opportunity to be screened to reduce premature death, suffering and avoidable costs to families and the NHS. Furthermore and without doubt, AF screening will alert individuals to AF and their AF-stroke risk, therefore it is vital that a national policy should be implemented to support this.

Detect, Protect and Correct AF:
Sign our petition online today: www.afa.org.uk

James was looking forward to an active retirement when one day, with no warning, he suffered a devastating AF-related stroke. His wife, Jenny, recalls:

“Some time before we had laughed when I noticed that his heartbeat was all over the place; then just a few weeks later, James had an AF-related stroke. If we had known earlier that the irregular heart rhythm was AF, this could have been prevented. James could have been saved and our lives relieved of this unimaginable strain and the incredible burden it has placed on the whole family…”

James suffered an ischaemic stroke, later attributed to undetected AF.

Evidence strongly indicates that early diagnosis and appropriate management of risk result in an improved outcome for patients, as well as a decrease in the number of AF-related strokes suffered. Therefore, AF Association has launched an online petition and is calling for an early review of the National Screening Committee’s policy on screening for AF in the over 65s. Read about our pilot work on pages 2-3.
Awareness activities
Pulse check: Glasgow

In collaboration with Boots Pharmacies, and with the help of senior pharmacist Clair Smith, AF Association ran lifesaving pulse check events across Glasgow and Lanarkshire during AF Aware Week 2014.

Atrial fibrillation (AF) is the most common arrhythmia or heart rhythm disorder. AF can affect adults of any age, but it is more common as people get older. Among those aged over 65, it affects about 10% of people.

It is important that AF is detected early and then managed by your doctor. If it is left undiagnosed or poorly managed, your risk of an AF-related stroke is increased.

The simplest way to detect AF is by quickly checking your pulse. If you notice that your pulse seems to be irregular then this could indicate AF. In this case, it is important that you speak with your doctor so that it can be investigated and a diagnosis can be confirmed.

AF can lead to stroke, as blood clots form in the heart and then travel in the bloodstream to the brain; hence it is essential that it is diagnosed and managed as soon as possible.

In order to raise awareness of the risks of undiagnosed AF, AF Association teamed up with Clair Smith, a senior pharmacist for Boots UK Ltd, and provided free pulse checks in various Boots pharmacies across Glasgow and Lanarkshire.

These events aimed to:
- Raise awareness of arrhythmias
- Share information on why, and how, to take your pulse
- Offer pulse checks, particularly to those over 65 years of age
- Provide and share information on atrial fibrillation
- Share ECG readings and interpretations with individuals and their GPs

In order to provide information and education to as many people as possible, AF Association hosted the pulse checks events in more densely populated areas.

The events were advertised in local newspapers, as well as in all GP and primary care centres nearby. AF Association also engaged with local GPs in order to provide their practices with additional resources and patient information on pulse checks, arrhythmias and AF.

Is your heart ticking like a clock?

1. Sit and rest
2. Feel your pulse
3. Count the beats from your pulse for 1 minute

If your heart is not ticking like a clock, make an appointment to visit the doc!

Does your GP have plans in place to support pulse checks? Please ask them to get in touch on info@afa.org.uk or 01789 867 502 for information and resources.
To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.

Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent. With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.

Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rate is too high, you should count the time, and do not multiply.

Maureen Carroll, Coronary Heart Disease & Respiratory Network Manager for NHS Lanarkshire, said:

"Detecting AF in the community is vitally important.

"One in four people will develop AF in their lifetime, with up to a third of people with AF displaying no symptoms. Having AF increases your risk of suffering a stroke five-fold; for this reason, early AF detection is imperative. NHS Lanarkshire is thrilled to be part of this effort to reduce the risk of disabling AF-related strokes locally."

Over the course of four days, 288 people had their pulse checked in Boots pharmacies across Glasgow and Lanarkshire. The age of those tested ranged from 16 years old to late 80s, showing that there is a wide variety of people interested and concerned about the health of their hearts. A single-channel electrocardiogram (ECG) was used to record the electrical activity of the heart for 216 individuals.

The heart rates recorded varied from 50 beats per minute to 162 beats per minute, and several anomalies were detected. The results are in the table below, demonstrating how important it is to check your pulse:

<table>
<thead>
<tr>
<th>ECG interpretation</th>
<th>Number identified</th>
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<tbody>
<tr>
<td>AF</td>
<td>1</td>
</tr>
<tr>
<td>Bradycardia</td>
<td>8</td>
</tr>
<tr>
<td>Ectopic beats</td>
<td>1</td>
</tr>
<tr>
<td>Multiple activities</td>
<td>1</td>
</tr>
<tr>
<td>Sinus arrhythmia</td>
<td>12</td>
</tr>
<tr>
<td>Tachycardia</td>
<td>15</td>
</tr>
<tr>
<td>Highlighted for urgent review</td>
<td>9</td>
</tr>
</tbody>
</table>

This shows that 47 individuals were identified with a heart rhythm disorder that had not previously been diagnosed. This means approximately 26% of individuals tested were found to have an arrhythmia, and 5% were recommended for urgent review.

All ECG readings and their interpretation were sent to the identified medical centres for each individual or to the individuals themselves - with a cover letter and information.

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Trudie Lobban MBE FRCP (Edin), Arrhythmia Alliance Founder & Trustee, said:

"AF affects at least 1.8% of the UK population, and 95% of those affected are aged 65 or above. Prevalence of AF rises in the elderly, as 23% of people aged 80-89 have AF."

"For this reason, it is important that pulse checks are made available to those over 65 when they see their GP for their annual flu jab – a pulse check is simple to perform and might just save a life.

"As part of this work, Arrhythmia Alliance hopes to build on recent success supporting screening for AF in Lanarkshire - during three days of pulse checks across several local Boots pharmacies, a number of people were detected with AF after living with the condition unknowingly, at possible risk of suffering from an AF-related stroke."

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Diagnosed with AF aged 19

I’m 19 and from a small town called Stonehouse in Glasgow. I was diagnosed this year with paroxysmal atrial fibrillation after I noticed my heart racing when I went to bed every night.

One afternoon just before Christmas I was admitted to my local hospital and was attached to ECG monitors. My heart rate was initially around 200 bpm, but it dropped to 40 bpm and then stayed around 180 bpm for a while. I hated the noise of the monitor as it would go crazy and wouldn’t stop. When my family came in and saw me they would stare at the monitor and it would make me feel on edge to see how fast or slow my heart rate was. I was petrified and asked the nurse if I would die. She said she didn’t know - which made me more on edge.

At 4am I was taken to the Emergency Care Unit. The cardiologist said they thought it was supra-ventricular-tachycardia and talked me through it. I was then given 200 mg of a beta blocker called labetalol. I was also experiencing pain alongside my other symptoms. The doctors said it was unexplainable because everything looked fine. After being monitored for 24 hours, I was sent home.

That night I still didn’t feel right so I phoned my GP the following day and they prescribed me with diazepam 5 mg because they thought I was having panic attacks.

That night I felt nauseous and then became violently sick. I became so unwell an ambulance was called and my blood pressure was low but picked up in the ambulance which also remained unexplained. I arrived to the hospital and had to follow the same process as before. I had a treadmill test but my heart rate stayed at 170 bpm for the duration of the test. I also had an echocardiogram and that was perfect as well. They checked my thyroid a few times to make sure that there were no abnormalities. I was discharged with a few follow up appointments to do different tests, such as a 24 hour urine test and a 24 hour heart monitor.

I was in and out of A&E around four times up until May when I was finally diagnosed with atrial fibrillation. I was told to continue taking 100 mg of labetalol twice a day. I have found the pain, the tiredness and the side effects from the tablets hard but I have been pushing through.

I have since passed my driving test, graduated and even tried to pull my health back together. Since December when all of this came about I have been living in fear; fearing the thought of pain or surgery. I feel like there is always something going on and I initially panic at the slightest ache, but keep calm until it goes away. When I get a cold or a chest infection it is ten times worse than before my diagnosis. I also hate lying in bed at night and feeling my heart beat. It’s like I’m waiting for it to stop but I now sleep on a pillow and it’s a lot better.

“I was petrified and asked the nurse if I would die. She said she didn’t know.”

After having carpel tunnel surgery I was admitted back into hospital and the dosage of my labetalol tablets had to be increased. I have been taking an extra 50mg in the afternoon and I’m back to my old self again for now. I am going to try to meet with my cardiologist to discuss the pain. I have stopped smoking and cut out caffeine since just after my diagnosis. I’m now trying to get fit and healthy again and hopefully move on with my life.

Jennifer Brown, Glasgow (2014)

For more patient stories please visit our website
INR Self-Monitoring

Should you self-monitor your INR?

Patients who take warfarin need to have their international normalised ratio (INR) monitored regularly. This is often very time consuming, as it involves booking a consultation with a medical professional, travelling to the clinic and then attending the appointment. Self-monitoring your INR could be a solution to this problem.

Self-monitoring your INR is an easy and effective step to take as it may allow you to test more frequently, which can potentially improve the quality of your treatment control. The first step towards self-monitoring your INR whilst taking warfarin is to talk to the healthcare professional who manages your anticoagulation: they will be in the best position to help you achieve good health. However, before you speak with them, make sure that you are prepared to discuss the reasons why you would prefer to self-monitor your INR and any concerns you may have about the current frequency of your testing.

Here are some questions you should ask yourself before deciding to self-monitor your INR. If you answer ‘yes’ to most of these questions, you may wish to consider discussing this option further with your GP/healthcare professional:

- Do you want to be in greater control of your INR?
- Have you been taking warfarin for a long period of time?
- Do you have a busy schedule, or live far from the clinic/doctor’s surgery?
- Are you able to follow your doctor’s recommendations and prescription guidance easily?
- Do you have a busy schedule, or live far from the clinic/doctor’s surgery?
- Would you like to spend less time at the doctor’s surgery, clinic or hospital?

Resources and Information

AF Association provides booklets and factsheets for people with AF. These resources are written by medical professionals who specialise in arrhythmias and are available on our website: www.afa.org.uk
Patients with AF who do not have any other concerns with the health of their heart (e.g. congenital heart defects, valve problems or heart muscle problems), can generally expect to experience a normal pregnancy. However, pregnancy does place a greater physical demand on the body compared to usual, hence people with any medical problems will have to be vigilant and remember to consider the risks of this added strain.

When planning a family, patients with AF, or with a history of AF, will need to ensure that they have the support of both their cardiologist and their obstetrician, as they will require more frequent check-ups throughout the pregnancy.

The biggest risk to the unborn child will be the medication which the mother takes throughout her pregnancy; clinicians will work on the principle that the benefit to the mother must outweigh the potential risk to the foetus – the mother must make sure to discuss all potential risks with the clinician, so that both parties have a clear understanding of any potential implications.

If the mother becomes unwell as a result of the pregnancy and requires cardioversion to try and put her back into a normal sinus rhythm then this can normally be carried out safely, with little risk to either the mother or the unborn baby. If cardioversion is not appropriate and the mother has stable blood pressure and an otherwise normal heart, then antiarrhythmic medications could be a good alternative in order to get the heart rate back to a normal rhythm.

The mother is likely to require some form of anticoagulation to prevent strokes and other clotting problems; these are more common during pregnancy and are made worse by AF. Warfarin or heparin are the preferred anticoagulants to treat AF during pregnancy, but both can increase the risk of miscarriage and at a high dose warfarin can be associated with some congenital defects in early pregnancy. Therefore, heparin is recommended in the first trimester of the pregnancy and warfarin is recommended from the second trimester up until a month before the due date. Warfarin needs to be stopped a month before you are due to give birth to reduce the risk to the baby during delivery and to reduce the risk to the mother of increased blood loss during labour. Babies are also born with an element of vitamin K deficiency and as warfarin is a medication designed to block the uptake of vitamin K, which is used in the clotting process, then this may increase the risk of bleeding once the baby is born. During the last month of the pregnancy you should be switched back onto heparin from warfarin to reduce the risk of coagulation.

If rate control is required during the pregnancy then beta blockers are the preferred medications to use, but there may be harmful side effects on the foetus in the first trimester – once again the risk to the mother compared to the risk to the unborn child needs to be considered. You can also use certain calcium channel blockers such as verapimil or diltiazem but again they are not recommended in the first trimester due to potential adverse effects on the foetus. If you are unable to take beta blockers or calcium channel blockers then digoxin may be used.

This information was adapted from the ESC Guidelines on AF and Pregnancy by Philip Rutherford, Cardiac Arrhythmia Nurse Specialist, at Newcastle Upon Tyne Hospitals NHS Foundation Trust

Please get in touch on info@afa.org.uk or 01789 867 502 for information and resources
Sarah’s story

Sarah first realised that she had AF in her teens, and struggled with the lack of available information when she fell pregnant with her son.

I started to experience arrhythmias in my early teens, however, AF was then seen as a condition for the mature or elderly, and my symptoms were consequently dismissed by doctors. When I fell pregnant, I discovered that there was little information on AF during pregnancy, and I was just told that if there were any difficulties they would be dealt with as and when they occurred. When I asked about heart medication safety, I was given conflicting advice and information.

I decided that I wanted to be medication free during my pregnancy, but my doctor told me that I would have to be open minded as in order to produce a healthy baby, you need a healthy mum! I was told that there was no way to predict how my heart would behave during pregnancy, as it is different for every person.

I absolutely sailed through my pregnancy, and in fact I felt the best I had in a long time. I had a few short lived episodes of palpitations but considering all the changes my body was going through, I had no real problems. My labour was long and difficult and I ended up having an emergency caesarean due to complications which were completely unrelated to my heart. I was told by one of the nurses that my heart was “misbehaving” at some point, but she was unable to give me any further information so I am still unaware of what exactly happened.

Sarah still has to monitor her AF, but she has a healthy son, whom she enjoys spending as much time as possible with.

Sources of information and support for patients and carers

Being diagnosed with AF can come as a big shock, and learning how to cope with the diagnosis and symptoms can be difficult. However, there are many sources of information and support that you can draw on:

- **AF Association website**: please visit [www.afa.org.uk](http://www.afa.org.uk) for a wealth of information regarding AF
- **AF Association helpline**: please call [01789 867502](tel:01789%20867502) to discuss queries or concerns you may have on any aspect of atrial fibrillation
- **AF Association email advice**: please email [info@afa.org.uk](mailto:info@afa.org.uk) with your query
- **HealthUnlocked**: visit our online forum [www.healthunlocked.com/afassociation](http://www.healthunlocked.com/afassociation) to chat with a growing community of people who have AF or care for someone with AF
- **Care AF website**: [www.careaf.org](http://www.careaf.org) is a patient support programme for people who have been diagnosed with AF to ensure that you are informed about your condition and give you all the information you need to be fully prepared for your AF treatment journey
- **Your clinicians**: if you have any concerns regarding your AF or treatment this should always be discussed with your GP or consultant - please do not be afraid to ask

Do you have a story to share?

Get in touch by emailing [charis@heartrhythmalliance.org](mailto:charis@heartrhythmalliance.org) or phoning [01789 867531](tel:01789%20867531).
Ask the Experts

Dr Andrew Grace

Our experts answer your AF-related questions

For this newsletter, your questions are being answered by Dr Andrew Grace, consultant cardiologist at Papworth Hospital. Dr Grace specialises in catheter ablation techniques particularly for atrial fibrillation.

Are there guidelines about when to seek help from clinicians for an AF event?

Dr Grace says: There are two settings in which an individual might seek assistance from a clinician in regard to an AF event: this might be the first episode of AF for which medical assistance has been obtained; or alternatively the person with known AF has noticed a change in their condition.

In the first setting our professional community has strongly highlighted the need for the early detection and evaluation of AF. If AF can be identified and appropriate anti-thrombotic medication instituted, then this in itself can significantly reduce risk of stroke. We would therefore urge any patient who thinks they have AF, through for example, feeling an irregularity of the pulse or through some other awareness for the irregularity of the heartbeat, to seek help at the earliest opportunity from healthcare professionals.

In the second setting, that is, in which a patient has already been assessed and is under treatment for AF then help should be sought if there is a sudden change in the condition. In general terms, in patients with AF there is an overall stability in the pattern of events over time so any deviation may be important. So if there is an unheralded change with significant symptoms that become protracted, then contacting surgery or attendance at the nearest medical facility is likely to be wise.

Should there be regular testing of people with AF who are on medication to check that it is not causing other damage? What, if any, guidelines exist?

Dr Grace says: There are widely publicised guidelines available for patients and clinicians from the manufacturers of drugs, from international regulators and from other organisations, such as NICE, providing guidance as to how patients might best be managed on medication. In addition there may be local synopsis guidance/shared care guidelines regarding the best use of particular drugs.

An established example is anti-arrhythmic drug amiodarone for which periodic checks of thyroid and liver function are mandatory. Warfarin needs blood testing to regulate its anti-thrombotic efficacy and new oral anticoagulants (NOACS) that are excreted through the kidneys require periodic checks of renal function. Again this should follow guidance and systems established locally and nationally.

It is important that patients try to familiarise themselves with the issues that might emerge from the drugs they are on. If they find that the monitoring they need is not being provided, then they should highlight this to their medical advisors. In general terms, of course, no matter how hard people try there will always occasionally be times when a necessary test or observation has not been achieved at a particularly ideal time point. The whole team, including the patient, need to work together and make sure things are done as best as they can be achieved.
How long should I take a particular medication for before trying another, if it is not controlling my symptoms or if it is producing side effects?

Dr Grace says: There are two major objectives in managing patients with atrial fibrillation. The priority is to minimise the risk of stroke with the second objective being improvement of quality of life. The determinants of duration of drug therapy differ dependent on the specific objective.

Regarding drugs for stroke risk these are likely to be advised in perpetuity. The exception would be if blood-thinning agents were started simply to cover a particular episode or intervention e.g. ablation or electrical cardioversion. The individual drug advised might change if a side effect is experienced or medical practice changes. There are recent examples of changing practice most strikingly the move back against aspirin in those with AF.

In general terms anti-thrombotic medication is well tolerated. There will of course be occasional idiosyncratic responses and even warfarin that was always considered a relatively well-tolerated drug may cause issues with non-specific lethargy/tiredness or more specific hair loss that may prompt re-consideration. Usually, however, antithrombotic medication would be commenced after proper discussion on best available advice and continued for life.

With drugs taken for symptoms the considerations are different. The objective is to identify a drug that suppresses symptoms without intrusive side effects and improves net quality of life. The general tactic therefore is to start the drug and assess the individual response, so the question is how long should the period of observation be? With drugs like flecainide, efficacy or tolerability may be obvious immediately. Alternatively, beta-blockers cause untoward usually non-specific effects at the outset that may then in some ameliorate over time. Amiodarone may take a while to work so a longer period of observation is required before deciding on a change. On occasion it’s possible to alter the scheme of drug administration to improve for example, changing the time of day that the drug is taken, or even a particular scheme in terms of, say, twice a day or three times a day to maximise efficacy whilst minimising side effects. Such manoeuvres would again take time.

The key issue is that the impact of AF and the drugs used to treat it is highly individual. The doctors may be unable to define precisely which drug will suit a particular patient at the outset. Accordingly, some form of individual experimentation is to be expected, and this requires patience on both sides. The key thing is to make steps strategically and give sufficient time to assess responses making careful decisive moves at each step. To gain most benefit the doctors must communicate clearly the rationale, the anticipated outcomes and the timelines of any particular intervention they suggest.

Would you like to see the answers to more questions? Visit our website: www.afa.org.uk
Paul Elston joined thousands of others around the world this November, or should I say ‘Movember’, and took on the challenge of growing a moustache over the month. Thank you Paul for raising over £120 for AF Association.

“I found the AF Association to be a great source of support information and guidance through the bad days.”

A huge thank you to Mahendra Sibartie who completed The Way of the Roses – a 170mile coast to coast cycle ride from Morecambe to Bridlington. A brilliant effort and fantastic achievement raising £150 for the charity close to her heart.

Mandi Pullen celebrated the end of her six month chocolate abstinence with a Cadbury Creme Egg and a bar of Dairy Milk. With support from friends, family and colleagues Mandi succeeded with her challenge and raised a fantastic £325 for us. Well done Mandi!

“I want to help raise awareness, raise money for research and improve the treatment of AF for all patients.”

AF Association 2015 Raffle

Every raffle ticket sold supports our vital work supporting those affected by AF.

For your chance to win one of our fantastic prizes, please fill in your details on the ticket stub and return to us by 25th May 2015. Tickets are just £1 each.

This year you could win:

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<tr>
<td>1st</td>
<td>One night stay for two at any QHotel with breakfast</td>
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<tr>
<td>2nd</td>
<td>AliveCor Heart Monitor for select Android and iPhone devices</td>
</tr>
<tr>
<td>3rd</td>
<td>WatchBP blood pressure monitor with AF detection function</td>
</tr>
<tr>
<td>4th</td>
<td>Medical alert necklace and pendant</td>
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Fundraise for us

Feeling Inspired? Please consider taking on your own fundraising challenge for us. Whether it’s a cake sale, walk or dance we’d love to hear from you! Email fundraising@afa.org.uk or call us on 01789 867502 and tell us your plans.

• Organise a Swap Shop at home, and invite all your friends and their friends to bring unwanted clothes and/or books. For each swap donate £1 to AF Association.

• Organise a Cake Sale with your friends and family or at your local community group, with all the proceeds going to AF Association.

• The TrekFest challenge will provide you with an extreme physical workout in the beautiful surroundings of the Brecon Beacons or Peak District. Choose to take a 13, 29 or 54 mile trek.

• Take on the British 10k London Run through the heart of London passing many of the Capital’s truly world class historic landmarks. *free places available contact us for more information.

Volunteers

Volunteers make a huge difference to our vital work and help us to reach out to more and more people each year. There are a wide range of opportunities for volunteers across AF Association and we will endeavour to find a role to suit your interest, experience and the time you have available.

Please contact us to find out more by emailing us at fundraising@afa.org.uk or by calling 01789 867 502.

Place an AF Association Collection Tin

Help us to raise money and awareness by placing a collection tin in your area, such as a local shop, pub, hairdresser, GP surgery or your workplace. Order your collection tin fundraising pack by contacting us via email at fundraising@afa.org.uk or by calling 01789 867 502 and we’ll then send you everything you need to place a tin!
Support AF Association

Become a Friend of AF Association

For just £15 per year or £2 per month, you can become a Friend of AF Association and not only help us continue to help others, but also receive:

- Free copies of our patient information resources
- Monthly e-news
- A dedicated telephone help line and email service
- Opportunities to attend local and national meetings
- Help in locating arrhythmia healthcare specialists
- Printed copies of our bi-annual newsletter

For more information please contact us on:
☎️ +44 (0) 1789 867502
✉️ info@afa.org.uk
🌐 www.afa.org.uk

Post to:
AF Association
PO Box 6219
Shipston on Stour
Warwickshire
CV37 1NL

Make a Donation

AF Association relies on donations to enable us to maintain our helpline, resources and support services to patients and carers. Please support us, so that we can continue to support you.

£5 will help to inform a family about a new diagnosis of AF
£10 will help provide personalised support via our helpline
£25 will help to provide education on how to prevent AF-related strokes

✉️ By Post: Please send cheques to us at: AF Association, PO Box 6219, Shipston-on-Stour, Warwickshire, CV37 1NL
☎️ By Phone: To make a donation over the phone, please call us on 01789 867502.
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