

### Frequently asked questions







Providing information, support and access to established, new or innovative treatments for atrial fibrillation

#### **Glossary**

Abdominal aortic aneurysm (AAA) An abdominal aortic aneurysm (AAA) is a bulge or swelling in the aorta, the main blood vessel that runs from the heart down through the chest and tummy. An AAA can be dangerous if it is not spotted early on. It can get bigger over time and could burst (rupture), causing life-threatening bleeding

**Angina** Angina is chest pain caused by reduced blood flow to the heart muscles. It's not usually life threatening, but it's a warning sign that you could be at risk of a heart attack or stroke

**Aortic plaque** Plaques cause the narrowing of the Aorta and are a result of atherosclerosis

**Atrial fibrillation** Is a common heart rhythm disorder (arrhythmia) that causes an irregular and often abnormally fast heart rate

**Diabetes** is a lifelong condition that causes a person's blood sugar level to become too high

**Heart failure** also known as congestive cardiac failure (CCF) or left ventricular systolic dysfunction (LVSD), and refers to a weakening of the heart muscle

**High blood pressure** can also be known as hypertension, and can lead to heart disease and strokes if not suitably treated

**Myocardial infarction (MI)** commonly known as heart attack. This is where the muscle of the heart is damaged by a blockage in the circulation

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Section 8 -Health and exercise **Peripheral vascular disease** Is better known as poor circulation and is caused by a narrowing of the leg arteries

**Stroke** Is also known as cerebrovascular accident (CVA), a serious, life-threatening medical condition that occurs when the blood supply to part of the brain is cut off

**Transient ischaemic attack (TIA)** Is also called a mini stroke. Symptoms of stroke are experienced but there is no permanent damage to the brain

**Valvular heart disease** Is where the small tissue valves in the heart become damaged and affect the blood flow through the heart

#### Section 1 - Atrial fibrillation

#### 1. What is Atrial Fibrillation?

Atrial Fibrillation (AF) is the most common heart rhythm disturbance encountered by doctors. NHS 2011 figures suggest AF affects in excess of one million people across the UK, although this is considered to be an under estimation due to delayed detection and diagnosis. It can affect adults



of any age, but it is more common as people get older. In the over 65 year old age group, it affects about 10% of people. Atrial fibrillation is not a life-threatening heart rhythm problem, but it can be troublesome and often requires treatment.

Atrial fibrillation or AF occurs when chaotic electrical activity develops in the upper chambers or atria, and completely takes over from the sinus node. As a result, the atria no longer beat in an organised way, and pump less efficiently. The AV node will stop some of these very rapid impulses from travelling to the ventricles, but the ventricles will still beat irregularly and possibly rapidly.

#### 2. What might have caused my AF?

AF is very common and the number of individuals that are affected is increasing. There are a number of possible causes of AF. There is no question that there is a clearage-related incidence of AF. This would therefore imply that there is a powerful element of wear and tear involved in the development of this heart rhythm abnormality.

AF can also be triggered by high blood pressure. Occasionally, developing AF may be linked to genetics. Most people who develop AF will have an intrinsic genetic predisposition, accordingly other family members will have modestly increased risk. The risk is at such a level that no modifications to screening strategies are indicated.

Some patients have an underlying problem with the thyroid gland. When a patient first presents with AF, it is important that the doctors check the level of the thyroid hormones in the blood through a simple blood test. In most patients, this is not the cause but it still needs to be checked.

Some patients have an underlying problem with the structure of their heart which causes AF. Accordingly, all individuals with AF should have an echocardiogram (echo) to look at how the heart is in terms of its size, structure and its function.

Other people may have an infection which causes the heart to go into AF, either temporarily or permanently.

# 3. Why do I have AF? I am quite fit and healthy in all other ways.

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 family history can explain the development of AF. It has also become apparent that high levels of exercise can in fact enhance the risk of AF if the individual is otherwise predisposed.

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

### 4. What symptoms do you normally get during an episode of AF?

Experienced physicians who meet patients with AF are surprised by the substantial variability in the way they are aware of their fibrillation. Some patients have very rapid AF and get very few symptoms; while others have infrequent short bursts of paroxysmal AF (multiple episodes that cease within seven days without treatment).

The types of symptoms individuals experience include an awareness of the heartbeat (palpitations) and a general feeling that things just are not right in the chest.

Rarely an individual might suffer some chest discomfort and some get dizziness and more seldom a feeling that they might faint. If AF is more persistent then a general exhaustion and debilitation might be experienced. Some individuals do not experience any symptoms from AF. This is known as silent AF. Most seriously, Stroke is a life-threatening symptom of AF.

# 5. I have noticed the need to urinate has become more frequent. Is this a common symptom of AF?

This is a very common effect of AF and is related to what happens with a hormone that the atria (the smaller, 'upper' chambers of the heart) produce when AF occurs. It is nothing life-threatening, but will often continue for a while after the AF stops. Then as the body resets those hormone levels, the need to pass urine more frequently settles down. This is all quite normal and physiological.

#### 6. Where can I access information and advice about AF?

There are several sources available on the web that will help to guide you to ask the right questions about management of your AF. The AF Association website: www.afa.org.uk provides information which will help you understand your treatment and make sure you get the very best treatment. Contacting your GP/family physician is also a good place to start and they can put you in contact with AF specialists in your local area.

#### 7. My AF seems worse at night. Is this normal?

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 or 7 days). 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 e fficiently without much drug therapy or without an AF ablation, although these should also be considered, possibly as adjunctive therapies in conjunction with a pacemaker.

# 8. I have been diagnosed with AF. Is it likely that my children will also develop AF?

AF is a common condition and is widely regarded as being caused by a number of factors. Some diseases are determined by both intrinsic (often genetic) and extrinsic (usually environmental) influences. In AF, the relative importance of intrinsic and extrinsic factors changes as we get older.



In young people presenting with AF, genetic factors may be more powerful in terms of their influence on the expression of the disease than in older people. Of course, AF is an age-related condition and the very fact of aging itself may be the determinant of AF in a particular individual, combined with other factors that may have developed during their lifetime, such as the appearance of high blood pressure or obesity.

Accordingly, the impact of the expression of AF 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 influences, such as, the amount of alcohol consumed, or participating in an extreme amount of exertion.

# 9. Why does my AF come and go when others have it persistently?

The pattern of the AF and the way it affects individuals differs.

In some people the attacks go on for short periods of time then spontaneously revert to a normal rhythm. That is usually called paroxysmal AF. The reason that the attacks terminate as spontaneously as they do is often unclear.



However other people will be found to be in AF which is there all the time. This is generally referred to as persistent AF. This might have started in some patients as paroxysmal AF that has now become persistent.

In some patients, an attack will just start and never cease, and that again is referred to as being persistent. Ongoing research is endeavouring to find out why it is that paroxysmal becomes persistent in some individuals and not in others.

#### **Section 2 - Diagnosis**

### 1. I have been diagnosed with AF. What investigations would the doctor generally conduct on my first visit?

If you have AF, a doctor will first take your medical history, and ask you questions about your symptoms to try to identify possible causes. An examination would then be performed, keeping a particular eye on your blood pressure to see if there is any evidence of fluid overload caused by heart failure. They would listen to the heart to see if they can hear any murmurs that might indicate that there are problems with the heart valves and obtain an ECG which will provide the diagnosis. In a formal sense, AF cannot be diagnosed without conducting such an electrical ECG recording.

In selected patients, a Holter recording is taken as a secondary test, which is an ECG recording usually made over a period of 24 hours from a portable device. Additionally you will have some blood tests and a chest x-ray.

# 2. What are the main objectives that the doctor should discuss with me regarding the management of my AF?

There are three main issues that the doctor should consider. The most important thing is the risk of stroke.

This occurs because when a person is in AF, the atria (the top chambers of the heart) are fibrillating and not beating in a co-ordinated way. The lack of sufficient contraction means that the blood in parts of the atria becomes stagnant and can form clots. These clots can break off and travel anywhere in the body, but most worryingly, they can travel to the brain and cause a stroke. AF-related strokes are often more damaging than other kinds of stroke. A doctor will assess your personal risk of stroke when you have been diagnosed.

The second strategic consideration is symptom control. The main issue with AF in terms of its day-to-day impact is on quality of life, and this can vary quite substantially in individual patients. For some AF has little impact upon their quality of life and in others the impact can be overwhelming. There is no obvious and direct relationship between the ECG appearances representing the electrical disruption of the rhythm and the extent to which individuals experience symptoms.

The final issue the doctors should consider is the potential impact the AF is having upon heart function in general. It might be that AF has emerged with relatively few symptoms but has over a period of time lead to damage to the main pumping chambers of the heart, the ventricles.

Accordingly an echocardiogram should be obtained to see if that has indeed occurred. It might be that more aggressive treatment is required in individuals where some impact upon heart function is observed.

# 3. I have persistent AF and I recently presented to my doctor. What are the key issues that should be considered in my case?

The most important decision is how high your risk of stroke is, and what should be done about this. This is covered in more detail in the following section. If you have recently been found to have persistent AF, common opinion would be to try to get you back to normal rhythm. This should not be immediately applied because if one tries to correct the rhythm in patients who have been in AF for an uncertain period of time, that can increase the risk of thromboembolic events and may precipitate a stroke.

Accordingly, the right course of action is for the doctor to start the individual on an anticoagulant drug, to thin the blood, and at the same time give a drug such as a beta blocker (but not sotalol), digoxin or a calcium channel blocker (verapamil or diltiazem). See AF Association's Atrial fibrillation (AF) drug information booklet.

The reason to add these latter drugs is to slow the response of the ventricle pleural to the AF, which should help the symptoms to some extent in the short term. The reason for an anticoagulant is to reduce blood clot risk and also allow the doctor to plan for a cardioversion that would normally be carried out once an individual is stable on these drugs. See AF Association's Cardioversion of AF booklet. Upon the first presentation with AF, drugs like amiodarone and sotalol should not be started until an anticoagulant is in place and stabilised. Once things are more controlled and stable then a cardioversion should be considered.

#### Section 3 - Stroke and risk

### 1. Will having AF increase my risk of other conditions?

The main problem with AF is the risk of blood clot formation and the precipitation of stroke. It is obviously the most feared consequence, and therefore after discussion and, once appropriate tests have been completed, a proper judgment needs to be taken as to whether warfarin or another anticoagulant should be started.



The other problem with AF is that in the occasional patient it appears to cause heart failure and that again should be carefully considered. An echocardiogram is extremely useful in quiding consideration and treatment of that possibility.

# 2. I have high blood pressure and AF. 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?

Generally, warfarin is an extremely well tolerated drug. However, there is a subset of patients who, for a variety of reasons, find they are unable to tolerate warfarin. There are other types of oral anti-coagulant drugs that you can take that have been shown to be just as effective as warfarin in protecting against AF-related stroke. These medicines are called DOACs (Direct-acting Oral Anti Coagulants). They work on different parts of the clotting system and require less monitoring than 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 usually involves a catheter-based procedure not dissimilar to ablation from a patient's perspective.

See AF Association's Ablation for atrial fibrillation (AF) booklet. The procedure is now available at several regional cardiac centres in the United Kingdom and, in selected patients, may become the approach of choice.



#### 3. What is a DOAC and what are the different ones?

Direct-acting Oral Anti Coagulants (DOACs) are a newer class of anticoagulant drugs that, like warfarin, can help inhibit clot formation. The drugs are dabigatran, rivaroxaban, apixaban and edoxaban. Compared to warfarin, DOACs carry out their function more rapidly and effectively, and then reduce their anticoagulation effects more quickly. Routine monitoring and dose adjustments of DOACs is less important than for warfarin, as they have more predictable anticoagulation activity.

Both DOACs and warfarin are equally effective, but DOACs are less influenced by diet and medications compared to warfarin. Most DOACs do not currently have a reversal agent unlike warfarin; nonetheless, the short half-lives of DOACs will result in its effects swiftly receding. Specific reversal agents are available for dabigatran (praxbind, idarucizumab) and apixaban and rivaroxaban (ondexxya, andexanet alfa) but there is currently no specific authorised reversal agent available for edoxaban. The situations in which a reversal agent may be required are in practice extremely rare.

# 4. If I would like to change to a DOAC, what is the best way to go about it?

If a patient wants to consider changing from warfarin to a DOAC then they can approach their GP and simply ask for their advice. There are specific national guidelines on who is eligible for the DOACs - these are produced by NICE. If you fulfil those criteria, then also, if you are on warfarin and you are not in the right range with the INR measurements over 60-70% of the time when it is measured then the warfarin is not doing what it needs to do and a DOAC would almost certainly be better.



See the AF Association Preventing AF-related stroke: anticoagulation booklet for more information.

#### **Section 4 - Treatment**

#### 1. How is AF treated?

Drugs are currently the most common treatment for AF, and they aim to alleviate symptoms and reduce the likelihood of stroke. Commonly prescribed medicines to reduce or relieve palpitations include sotalol, flecainide, amiodarone, and beta blockers. Warfarin is an oral anticoagulant and is the most common medication to reduce the risk of stroke. There are also newer oral anticoagulants which are used to reduce risk of stroke: dabigatran, rivaroxaban and apixaban.

For many patients, medications may not reduce symptoms, or they produce side effects that may actually prove to be worse than the symptoms arising directly from the AF. Physicians may choose to perform an electrical cardioversion, a procedure in which high-voltage current is delivered through pads positioned on the chest wall. Cardioversion will often 'shock' the heart back into its regular rhythm.

For patients undergoing surgery for other types of heart disease, including coronary artery surgery or mitral valve repair, an additional procedure called surgical ablation may be performed to treat AF. This procedure involves making multiple, strategically placed incisions, or lesions, in the upper chambers of the heart. These lesions are intended to isolate and stop the abnormal electrical impulses that cause AF, thereby restoring the heart to normal sinus rhythm (NSR). For many patients not needing surgery, a less invasive procedure called catheter ablation is now thought by many specialists to be the most appropriate treatment. In 2006, the National Institute for Health and Care Excellence (NICE) voiced its support for catheter ablation as a treatment for AF, and in 2012 the European Society of Cardiology (ESC) followed suit.

# 2. I have been found to have AF and have few symptoms. Do I actually need any treatment?

In individuals who do not have any obvious or intrusive symptoms of AF, the main decision is whether or not they need to take anticoagulants (warfarin or a DOAC) to reduce their risk of stroke. Recent ESC guidelines and NICE no longer recommend aspirin as an AF-related stroke prevention measure unless there is a history of conditions such as coronary heart disease or heart attack.

Heart failure is also an effect of AF that may need treating even if your AF itself causes few symptoms. An echocardiogram will assess the pumping function of your heart. If your heart is not pumping as effectively as it should, your doctor may prescribe medications including ACE inhibitors, beta blockers and mineralocorticoid antagonists. In addition, high blood pressure has been found to be a contributor to heart disease and also AF. If diagnosed, this will need to be controlled, often with tablets.

### 3. Are there any treatments that can be applied to cure me of AF?

For many individuals, the treatment of choice is catheter ablation. Radiofrequency catheter ablation is particularly effective in patients with paroxysmal AF where cure rates of 80% are achieved. In patients with persistent AF, the cure rate for a first procedure is lower, but with improvements in special equipment and techniques as well as a greater understanding of the condition, this is continually improving. Some patients require more than one ablation procedure to eradicate their AF.

The question of ablation is something you should raise with your doctor.

# 4. If I have an ablation, will I feel better immediately?

Whether you will feel better immediately after an ablation depends on a number of things. A single ablation normally cures some arrhythmias so one would expect an immediate improvement if the symptoms were happening a lot before the ablation.



For others, it is quite common to get some symptoms in the first few weeks or months after an ablation (occasionally even worse than before the ablation), but it could still settle down and be successful in the long term. Migraine symptoms can occur after any ablation for a number of reasons, but particularly after AF ablation. If people have a prior history of migraines, then simply the process of going through a procedure can upset this.

Again, specifically with AF ablation there is a theory that the puncture through the atrial septum (the bit of tissue between the two 'upper' chambers of the heart) may be a trigger for the migraine, and once the septum seals itself over the next few days/weeks the migraines settle.

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

With paroxysmal AF, it may well be that interventions such as decreasing alcohol intake, losing weight and generally increasing fitness levels and controlling blood pressure, are effective in controlling AF. Even if a lifestyle modification approach is considered as the first line strategy for symptoms, then this should not change a proactive medical approach in measures to reduce the risk of stroke with anticoagulants.



Having said this, it would be encouraged that there are lifestyle modifications in all patients with AF, as these are likely to lead to a better overall outcome in terms of quality of life and prognosis of whether or not other interventions are applied.

See the AF Association Atrial fibrillation (AF) patient information booklet.

#### Section 5 - Medication

# 1. I have paroxysmal AF. What drug treatments are available to help alleviate my symptoms?

The aim of the available drug treatments is to reduce the frequency and duration of the AF episodes. There are three types of drug that are used for what is called rhythm control in patients with AF. In many ways, the simplest drugs to use are beta blockers. These interrupt the action of adrenaline and stimulatory nerves on the heart. Some beta blockers are relatively simple such as atenolol, metoprolol and bisoprolol, whilst others are somewhat more complex such as sotalol. Sotalol is complex in that it also has direct electrical actions on the heart. The problems with beta blockers are that in some patients they can cause tiredness, mood upset and, in both men and women, may be sexually disruptive. Some patients, however, tolerate beta blockers extremely well and they can be very effective in the management of their AF.

Some individuals, such as those who have already got a slow pulse, may not be suitable for beta blockers, and therefore they cannot be used.

Doctors may also suggest flecainide, a drug widely used in the United Kingdom. Flecainide is usually well tolerated and can be highly effective in treating AF.

In the first few days after it is started, there may be symptoms of dizziness and blurred vision but these generally resolve. Sometimes doctors will prescribe flecainide alongside a beta blocker or calcium blocker (e.g. verapamil or diltiazem). The other drug in this category is propafenone. This has many of the features of flecainide but in addition it also has some beta blocking action. There are no particular advantages (or disadvantages) in starting propafenone in place of flecainide.

In patients who have hearts that are damaged in other ways, for example, who have coronary artery disease or have an abnormal echocardiogram, then flecainide or propafenone may not be suitable.

The third type of drug used for the treatment of AF is amiodarone. Though effective, amiodarone has side effects including increased sensitivity to sunlight, under- or over-activity of the thyroid gland, sleep disturbance and occasionally lung damage. However, many patients will tolerate amiodarone very well.

# 2. I have AF and would like to know how often my doctor should review the drugs that I am taking.

The assessment process for AF can be divided into three phases.

- 1. Recognition, diagnosis, and treatment plan;
- 2. Therapy and assessment of therapy;
- 3. Period of stability following more intense treatment.

In the first and second phases of the management of the condition, relatively regular reviews by the doctor are normally the order of the day. Once the main treatments have been deployed, then a follow up at six or 12 months is usual. At the end of that period, if symptoms are controlled and appropriate antithrombotic plans are in place, follow up may not be required on a regular basis.

See the AF Association Atrial fibrillation (AF) patient information for AF and Preventing AF-related stroke: anticoagulation booklets.

#### Section 6 – Cardioversion

#### 1. What is an electrical cardioversion?

An electrical cardioversion is sometimes recommended for patients with persistent AF. The individual is first given anticoagulation therapy, if warfarin is used, it would be adjusted into the right (therapeutic) range (to make sure there is no clot in the heart) and is then given a general anaesthetic. Pads are placed on the chest and an electric shock is given across the heart whilst the patient is asleep. In many patients, this will restore normal rhythm. In those for whom the AF has been relatively short-lived, the normal rhythm may be restored for a considerable period of time. In fact, they may stay in normal rhythm well into the future. In those who have had AF for longer or who have structurally damaged hearts as indicated by echocardiography, the rhythm might go back to AF quite quickly after the cardioversion.

If the first cardioversion has worked but AF has emerged sometime thereafter, then a repeat cardioversion may be planned. Under those conditions, and in addition to warfarin, an antiarrhythmic drug may be started and applied in conjunction with a cardioversion to increase the chance of the normal rhythm being maintained over time. The drug that is usually used is amiodarone because that is the most effective. It might be that after a period of time the amiodarone can be stopped providing the heart has been maintained in normal rhythm.

See the AF Association patient information Cardioversion of atrial fibrillation booklet.

#### 2. When is the best time to seek advice from a specialist?

The management of AF is evolving. The recent guidance from the ESC indicate that the ablation of AF may now be considered as a potential first line therapy for those with AF who have a structurally normal heart. Therefore, it may be possible to seek early advice from a specialist in some cases with symptomatic AF. See AF Association Ablation for AF booklet for further information.

#### **Section 7 - Procedures**

# 1. Will I eventually need a pacemaker?

A pacemaker may be considered for patients with AF in whom drugs have previously been tried but have failed to reduce or stop the symptoms caused by the AF. A pacemaker may be implanted and once this is in place, or even at the same time, then the junction between the upper and lower chambers (the AV Node) is disconnected by using a catheter ablation procedure. This therapy is often referred to as ablation of the atrio-ventricular (AV) node or 'pace and ablate'.



This procedure has been in use for almost 30 years and has proven to be highly effective in many patients. Warfarin or other oral anticoagulants are likely to have to continue to prevent clot formation and reduce the risk of AF-related Stroke.

See the AF Association Pacemaker and AV-node ablation factsheet.

# Section 8 – Health, exercise, and relationships

# 1. I have recently developed AF. Is it safe for me to carry on attending my exercise classes and jogging twice a week?

The first step in terms of getting a management plan is proper medical assessment. Once that has been achieved and appropriate medication has been prescribed and/or interventions have been embarked upon, then physicians would generally encourage patients to return to full and normal activities and to maintain general cardiovascular fitness. Such a programme will provide the maximum long term advantage to patients.



Accordingly, we would advise individuals to attend exercise 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.

#### 2. Will AF affect my sex life?

People who have experienced heart problems can often worry about having sex. We know that people often reduce or stop having sex because they are frightened it may bring on further heart problems.

The bottom line is that exercise is good for the heart and sexual activity is just another form of exercise. So – opposite to peoples' worrying thoughts and fears - regular sexual activity can actually be good for our hearts!

# 3. I am aware that having AF increases the risk of strokes, possibly resulting in incapacity. Where can I learn more about an advance decision (living will)?

An advance decision (living will) is a decision you can make now to refuse a specific type of treatment at any time in the future.

This means that your family, carers, and healthcare professionals will know your wishes if you are unable to make or communicate those decisions yourself.

For more information please visit: www.nhs.uk.





Providing information, support and access to established, new or innovative treatments for atrial fibrillation



#### AF Association

**\( +44** (0)1789 867 502

✓ info@afa.org.uk

www.afa.org.uk

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"I was so anxious upon receiving a diagnosis of a new heart condition, I had so many questions and didn't know where to turn - thanks to the FAQ booklet by the A F Association, many of those questions were answered!"

Michael, Wiltshire

Please remember that this publication provides general information. You should always discuss and seek advice from your healthcare professional what is most appropriate for you.

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Founder and CEO: Trudie Lobban MBE, FRCP (Edin)

If you would like further information or feedback please contact AF Association.