

Atrial fibrillation and you



Working to provide information, support and access to established,
new or innovative treatments for Atrial Fibrillation (AF)

Glossary

Antiarrhythmic drugs Drugs used to restore or maintain the normal heart rhythm

Anticoagulants Drugs which help to thin the blood, and reduce the risk of blood clots in the circulation

Arrhythmia Heart rhythm disorder

Arrhythmia nurse A nurse who is trained in heart rhythm disorders

Atrial fibrillation (AF) A heart condition that causes an irregular and often abnormally fast heart rate

CHA2DS2-VASc score A quick method to calculate individual risk of AF-related stroke and the need for anticoagulation

Cardiologist A doctor who specialises in the diagnosis and treatment of patients with a heart condition

Catheter ablation A treatment which destroys a very small area inside the heart causing an arrhythmia

Electrophysiologist (EP) A cardiologist who specialises in heart rhythm disorders

INR level Relates to the time that it takes for the blood to clot. This is relevant for people taking warfarin

Sinus rhythm Normal rhythm of the heart

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"I feel I have the information now to understand my AF"

Geoff, Aberdeenshire



Diagnosis

A diagnosis of atrial fibrillation (AF) can be a dramatic event and often comes as a surprise. It can be hard to come to terms with. A common response is “why me?” especially if you have been conscious of your diet and tried to be fit and active. Whatever the cause of AF, there will be a period of psychological adjustment following diagnosis as well as changes in how we think and behave.

At first, simply understanding your condition can be challenging, and that is before considering the wide range of treatment options available.

There have been many medical advances and innovations in the treatment of AF. The outlook for people with AF is excellent and there is every reason to believe that quality of life will be as good as anyone else's.

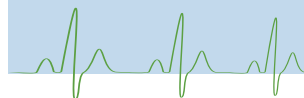
Whatever your situation, a diagnosis of AF is an ideal time to take stock of your health and lifestyle, and that is where this booklet comes in. There may be things you can do to reduce the impact of your condition and to look after your health and heart. There is not only life after diagnosis, but also a healthy and fit lifestyle with the right treatment.

On the following pages, we have set out how AF affects different aspects of your lifestyle management.



“After receiving treatment for AF, I am very, very happy and I am doing everything that I want to do.”

Paul, High Wycombe



Getting to grips with medication

Nearly always, a diagnosis will be followed by a consideration of medication to address various aspects of AF.

There is a period of adjustment with medication and finding the right combination of drugs for you. All drugs have side effects, and prescribing clinicians have to work with you to balance the benefits they bring with potential side effects. Do not be afraid to ask for a medications review if you are not coping well on a particular drug. Remember that it can take time for your body to get used to a new medication.

Rate limiting drugs

You may have been offered medication to regulate your heart rate. There are many types of such medication (e.g. beta blockers or calcium channel blockers). Some people notice increased breathlessness or fatigue and if this is a problem for you, discuss it with your clinician. There is a range of options within this family of drugs.

Rhythm control drugs

You may be offered medication to restore or maintain the heart's normal (sinus) rhythm. These medications are called antiarrhythmic drugs and can be either given on a daily basis to reduce the likelihood of further episodes of AF or on an 'as required basis' to restore sinus rhythm once AF has occurred ('pill in the pocket'). Commonly used drugs for this purpose are flecainide, amiodarone and dronedarone. These drugs can be particularly helpful for some who have an intermittent form of AF (paroxysmal AF). As these drugs are associated with some risks they are not for everyone; your consultant will be able to discuss these medications with you further.

Anticoagulation

Any risk of AF-related stroke will have been assessed following your diagnosis, depending on your 'CHA₂DS₂-VASc' score. It is likely (especially if you are over 65 years old) that you will have been advised to take an oral anticoagulant. Currently, five of these are approved for use in the UK - warfarin, dabigatran, rivaroxaban, apixaban and edoxaban.

Taking warfarin means that you have to be mindful about vitamin K in the diet and you will be advised about this, and about possible drug interactions. Vitamin K is a naturally occurring nutrient which plays a role in blood coagulation. Small amounts of dietary vitamin K are essential for maintaining good health. Vitamin K affects 'international normalised ratio' (INR) levels and this has a direct effect on a warfarin dose, so you have to be careful to keep levels of vitamin K constant. Regular blood tests ensure that the right amount of warfarin is being prescribed. The anticoagulation clinic is a source of helpful advice.

Dabigatran, rivaroxaban, apixaban and edoxaban are sometimes known as 'new' or 'novel' oral anticoagulants (NOACs), or 'non-vitamin K antagonists' (NVKAs). Whilst there are none of the considerations about INR levels with these drugs, it is essential that you take the tablets at the same time every day. If you think you have missed a dose, it is important that you wait until the time of the next dose before taking it again.

If you have an upcoming procedure such as a dental extraction, medical procedure or surgery, ask your clinician for advice about whether you should discontinue your anticoagulant beforehand. Remember that bleeding is normal and anticoagulation slows down but does not stop your blood from clotting.

For patients who are unable to tolerate anticoagulation for medical reasons, there is a procedure called transcatheter closure of the left atrial appendage. An alternative to medication for patients with AF at high risk of stroke is to close off the appendage with a medical closure device. The device is designed to close the left atrial appendage (which is known to be the main source of blood clots in patients with AF), preventing clots from forming in the Left Atrial Appendage (LAA), or breaking free from it and travelling to the brain. **Never make changes in your medication without seeking medical approval first.**

Surgical options

As well as medication, there are several procedures available which can eliminate your AF. There is cardioversion, which resets the electrical impulses in the heart by administering a controlled electric shock. Suitable patients may be offered ablation, whereby electrical impulses in the heart are blocked. AF Association has a range of booklets and information fact sheets which explain these procedures fully, and all of them are available to read and download from our website:

www.afa.org.uk

Psychological impact and coping

The experience of a fast or irregular heart rhythm can trigger a cycle of anxiety, increased adrenaline, a further raised heartbeat, and more anxiety. This can be distracting and disabling for some people.

Depression is a natural and common reaction to a diagnosis of AF and can have far reaching effects for everyone concerned.

It is always helpful to talk about your AF with a healthcare professional such as a GP. This can help them to understand what helps you and adjust your medication if appropriate. If your GP suggests counselling or another form of psychological help, do consider this option. Adjusting on the personal front is really important.

Cognitive Behavioural Therapy (CBT) can be very effective in helping to address anxiety and depression related to conditions like AF. This talking approach can help you to understand the things that trigger and contribute to your experience of AF related emotional reactions, and to develop more adaptive ways of responding to your condition. CBT is available as an NHS treatment and is provided by Improving Access to Psychological Therapies (IAPT), or it may be available in your local cardiology service. There are free online resources devoted to CBT and meditation.

Meditation may help to reduce the severity or frequency of AF episodes if stress seems to be a trigger.



"My advice is – don't feel alone. There are so many people out there with this."

Paul, Huddersfield

"I joined the online Support Forums, I don't feel alone - it really helps to hear others' experiences"

Gary, Essex



Mindfulness is a branch of meditation which has grown in popularity over the last few years. It involves concentration on the senses and the present moment.

Meditation and relaxation can help you cope with stress-related symptoms, and evidence supports its benefits. There are apps available to download or search online for local meditation centres in your nearby town or city.

Alternative therapies

Far from being faddy or 'new age', steps to promote emotional wellbeing can complement the more 'visible' forms of treatments prescribed by clinicians in the form of drugs. It can have a significant role to play in finding a holistic answer.

Whilst research into some complementary therapies is inconclusive, some AF Association members have talked about the benefits they have received from yoga and acupuncture, and The National Institute for Health and Care Excellence (NICE) has acknowledged that some complementary therapies can be beneficial.

Studies have found that gentle forms of yoga and breathing exercises can help patients with AF. Practising yoga can lead to a slight drop in systolic and diastolic blood pressure and can have a beneficial effect on heart rate. Yoga is easy to learn, and it can be practised while sitting in a chair.

Many health food products (e.g. ginger, ginkgo biloba, ginseng and St John's Wort) can affect the blood clotting process, prolong bleeding, and affect INR levels in patients on warfarin, so it is best that patients seek advice from their doctors if they use these products or are thinking of using them.

Healthy eating

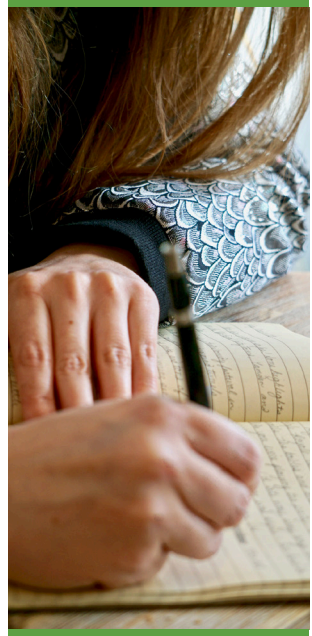
If you are on warfarin, you need to be mindful of the vitamin K content in food, because this has a knock-on effect on INR levels, and this in turn affects your dose of warfarin. Please refer to our Warfarin and diet factsheet for further details.

For those who are not on warfarin, there are no hard and fast rules when it comes to diet because everyone's metabolism is different, but some people have reported that the following steps can reduce symptoms if they have paroxysmal AF (episodes that stop within 7 days without treatment):

- Some people say that a large meal can trigger AF, so it may be wise to eat smaller suppers, no later than 7pm, if symptoms regularly come on at night.
- Drink less alcohol, and if you haven't done so already, try to cut out smoking. Nicotine is a cardiac stimulant and it is also known to cause coronary heart disease. Your local GP surgery will be able to signpost you to a smoking cessation clinic.
- Replace tea and coffee with decaffeinated options such as red-bush tea, which is available from most supermarkets.
- Chocolate contains naturally occurring stimulants which can trigger an episode of AF in some people.
- Cut down on salt, especially if you suffer from high blood pressure.
- Follow a low fat diet and watch your cholesterol intake so that you safeguard yourself against furred arteries which might restrict blood flow.
- Grapefruit is 'arrhythmogenic' at high dose and affects the heart's 'QT' wave (electrical timing pattern) so it might be wise to avoid it.
- Some studies have suggested that foods including cheeses, some beans, processed meats and pickled foods may trigger an episode of paroxysmal AF in some people.

If you have paroxysmal AF, it is a good idea to keep a diary of triggers, recording things like whether the symptoms appeared after taking medication, if you had been feeling relaxed or panicky, perhaps you had been in a certain position, and the duration of the episode. Keeping such a diary can reveal a previously unnoticed pattern and highlight something you can avoid in future.

It has been discovered that there is an increase in drinking and hospital visits for AF in a large population. Acute alcohol consumption or 'binge drinking' carries a higher risk of an episode of atrial fibrillation; this also includes a higher risk of experiencing a first episode of atrial fibrillation among individuals never previously diagnosed with the condition.



Always consult a doctor, dietician or arrhythmia nurse specialist before making significant changes to your diet.

Caring for someone with AF

Because there are few or no visual signs that someone has AF, it can be difficult for others to appreciate what someone with AF is going through. Psychologically, the heart is what keeps us alive, and coming to terms with AF and a possible risk of stroke can take time for both patient and carer. A problem shared is a problem halved, so the saying goes, and a willing ear can make a huge difference.

A diagnosis of AF will mean more visits to the GP, a cardiologist, or perhaps an anticoagulation clinic and someone with AF may need lifts to and from appointments.

It can be difficult to appreciate the impact of AF on the patient because it is not a visible condition, and if in addition the patient is in denial, they may not see the importance of taking their medication and may skip doses.

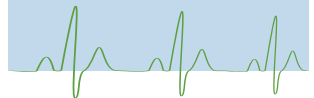
Partners may find that increased demands on their time will mean that they have to make adjustments to their schedules.

"I was devastated when my husband was diagnosed with AF, but with all the support we've had from AF Association, we are confident and reassured about the future."

Marie, Portsmouth

"Thank you for your help, you've given me the knowledge and strength to support my husband in his recovery of a stroke"

Joyce, Norfolk



Driving

Check the small print on your car insurance policy. Having AF should not restrict whether or not you can drive, but you should inform them of your diagnosis, and not disclosing this could render your policy invalid. If the terms of the policy are not beneficial to you, it might be time to change to another insurance company.

The official DVLA guidance for drivers is subject to change at short notice, and so their website will have the most up-to-date requirements or restrictions, including how soon you can drive after a cardioversion or catheter ablation. Please check the DVLA website for current guidance.

Choose and book

This is an NHS service whereby you can choose a hospital or clinic when you and your GP agree that you need an appointment, and you can discuss clinically appropriate options that are available for treating your medical condition. Using an Appointment Request Letter reference, you can choose any hospital in England funded by the NHS (including some independent hospitals) if it is linked to the Choose and Book system.

Choose and Book gives you time to consider your choices and lets you fit your treatment around existing commitments. You can check your referral status, change and cancel appointments easily by phone or on the internet, and get appointment confirmation. Any follow up appointments are arranged by the hospital themselves.

Physical exercise

Although AF is more common amongst older people, it can also occur in people who have lead a physically active lifestyle, including endurance athletes. Exercise is an important component of a healthy lifestyle. Exercising according to a paced approach at a level with which you are individually comfortable is sensible from a cardiovascular and emotional perspective. Your GP will have advice about the excellent benefits of being physically active.

'Use it or lose it' is more than just a catchy phrase. Prolonged periods of inactivity can be as harmful as overly strenuous exercise: moderation is the key. Walking regularly is an excellent way of keeping fit. Scan the local paper, leisure centres or library and you will discover a wealth of activities like tai-chi, yoga sessions or zumba classes and also an infinite number of online classes, from yoga and pilates to HIIT.

If you would like to try more strenuous exercise such as sports or going to the gym, please discuss this with your clinicians before participating.

Swimming

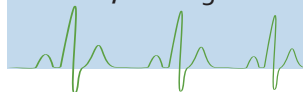
Swimming is a great aerobic exercise. If you have been enjoying it for some time with no ill effects, It is probably fine for you to continue. Humans are adapted for life on dry land and immersing the body in water squeezes blood from the extremities towards the chest. Cold water can have the same effect, as it causes surface blood vessels to narrow as a natural response in order to conserve heat. This may have implications for blood pressure and AF.

Be mindful of your condition if you notice signs and symptoms of slow heart rate, AF, or feeling faint.



"I was afraid that AF would put an end to my passion for running, but I went on to run the London Marathon!"

Stuart, Wokingham



Intimacy

Anxiety about the impact of physical activity on triggering and worsening AF is common. This can lead some people to feel worried about the safety of sexual activity. Losing interest or confidence in sex can affect you and your partner if you are in an intimate relationship. It can also affect how you feel about yourself and life in general.

Having a loving and satisfying sexual relationship is safe and indeed recommended by doctors.

Sexual activity is a form of exercise, and it has cardiovascular benefits including increased blood flow, heart rate and deep breathing. All of these improve circulation of oxygen and hormones to organs and muscles, as well as the removal of waste products from the body. It improves the cholesterol balance and burns calories.

Having intimate contact promotes overall stress reduction. It boosts the immune system and has been linked with higher levels of an antibody (immunoglobulin A), which can protect us from getting colds and other infections. It reduces risk of prostate cancer in men and helps to minimise a woman's risk of incontinence later in life. It releases a hormone called oxytocin, the so-called 'love hormone', and this promotes sleep which is linked with other benefits such as maintaining a healthy weight and blood pressure. The deep relaxation that typically follows sex may be one of the few times people actually allow themselves to completely let go, surrender and relax.

If you have concerns about having sex following a diagnosis of AF, you can always discuss this with your doctor. The topic of sex can be difficult for patients to talk about, but remember that your doctor and nurses are used to talking about these things and they are there to offer you the information and advice you need.

AF can contribute to erectile dysfunction – in fact this symptom sometimes leads to diagnosis in the first place. If you are thinking about using a drug to treat this, talk to your doctor, because they are aware both of your medical history and any possible drug interactions which might require monitoring. Having said this, it is not uncommon for AF patients to be safely prescribed erectile dysfunction medications.

Travelling

Before you go

Discuss with your doctor. They know your medical history, so they are always the best person to advise you.

- Tell them how long you are going away for and which country you are visiting.
- Ask if you need to take any precautions.
- Ask if any immunisations are necessary and whether they interact with anticoagulation.
- If prescribed warfarin, discuss self-monitoring options for INR while away.
- Ask them if any significant local time changes will make a difference to how you take medication.
- Discuss any other particular concerns which you may have.

Ask AF Association about travel insurance companies who have favourable terms for AF sufferers.

Now that the UK has left the EU the Government are issuing a Global Health Insurance card. Please go to <https://www.gov.uk/global-health-insurance-card> for further information.

It is a good idea to carry a medication alert card or wear a medical ID bracelet or necklace during the trip. This can state your medical condition, any implanted devices you may have, medication you take, and your doctor's contact details. Digital ID can carry a lot of information on your condition. Ask AF Association for a free anticoagulation alert card.

If you are on warfarin, take advice from your anticoagulation clinic on change of diet while travelling. Be aware of INR test centres or discuss with your doctor self-monitoring for INR while away.

Wearing flight socks (also known as compression stockings during journeys of four hours or more helps blood flow and studies show that they can reduce swollen ankles and the risk of deep vein thrombosis (DVT) significantly. They come in a variety of sizes and there are also different levels of compression. Flight socks are available from pharmacies, airports and many retail outlets. It is vital that compression stockings are measured and worn correctly because ill fitting stockings could actually increase the risk of DVT. Take advice on size and proper fitting from a pharmacist or healthcare professional. With anticoagulation, your risk of developing a clot or DVT is low and there is no reason why you cannot travel, including long-haul.

Pack more medication than you will need on the journey in your baggage in case you get delayed or in case you need to extend your trip.

During the journey

- Take more medication than is required with you in your hand luggage in case of travel delays or loss.
- Carry with you in hand luggage in case suitcases go missing.
- Carry a list of medications and doses.
- Carry a medication alert card or bracelet.
- If you have an implanted medical device ask airport security if it is safe for you to walk through the security scanners or whether you need to be manually searched/frisked.

- Get up and stretch your legs while travelling to reduce the risk of blood clots forming.
- Do anti-DVT exercises at least every half an hour. Raise your heels, keeping your toes on the floor, then bring them down again. Do this 10 times. Then raise and lower your toes 10 times.
- Carry water to counter the effects of dehydration.
- Wear loose comfortable clothes.
- Wear your flight socks throughout the flight.
- Drink alcohol in moderation or cut it out altogether, and avoid sleeping pills.
- Follow advice on how to take medication if on long-haul flights with significant time changes.

At your destination

- Keep as much as you can to your normal sleep pattern to avoid becoming over-tired.
- Try not to exert yourself more than you usually do. Pushing yourself too hard could trigger AF symptoms.
- Stick to your normal diet as much as possible. Alcohol and overeating can trigger AF.
- Get immediate medical help if you have unusual AF symptoms.

Enjoy your trip!

Your support

Feel free to join the conversation online at the **HealthUnlocked** forum:
www.healthunlocked.com/afassociation

AF Association is also on Facebook:
www.facebook.com/afassociation, and Twitter:
[@AtrialFibUK](https://twitter.com/AtrialFibUK).

Our Patients Day is held every autumn and is well received by members. There are presentations by top cardiologists, electrophysiologists and other healthcare professionals on a range of AF topics and it also gives patients an opportunity to ask questions and to talk to each other.

Regular patient groups are held around the country. Please call us for details.

Sources of advice and information

- Your cardiologist or electrophysiologist (EP)
- Your GP
- A pharmacist
- Arrhythmia nurse specialist
- Anticoagulation clinic
- The internet
- Good bookshops
- Libraries

Helplines and websites

AF Association
01789 867 502
www.afa.org.uk

Arrhythmia Alliance
01789 867 501
www.heartrhythmalliance.org

AF Association resources

AF Association has a wide range of booklets and factsheets on atrial fibrillation. Our publications are accredited by the AF Association Medical Advisory Committee and are endorsed by the Department of Health. They are reviewed and updated regularly as developments occur in the medical field.

AF Association resources can form the focus of discussion at appointments with your GP or cardiologist.

All of our publications are available on our website to download, read and print. We are always happy to post publications to our members. These are normally free of charge, but we rely upon donations to cover production and postage costs, and these are always gratefully received.

Our e-bulletin updates are monthly. Please provide us with your contact details if you wish to receive the updates to info@afa.org.uk

“We want you to know that a diagnosis of AF does not mean that, once properly treated, your quality of life should be unduly compromised, and we wish you all the best for a long, happy and healthy future.”

Trudie Lobban MBE,
Founder & CEO,
AF Association



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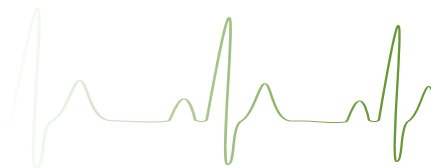
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This booklet has been written to support those diagnosed with an arrhythmia and their carers, who struggle to find information on this condition. Without donations and fundraising, we would not be able to provide support through our award-winning resources and helpline.

Please donate to support our vital work at
www.heartrhythmalliance.org/afa/uk/get-involved/donate



Working to provide
information, support
and access to
established, new or
innovative treatments
for Atrial Fibrillation (AF)



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"I found this booklet really useful, I've read it from cover to cover several times as it answers most of my questions about AF"

Kevin, Nottinghamshire

To view our patient resources, scan the QR code below:



Please remember that this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional. If you would like further information or would like to provide feedback, please contact AF Association.

Acknowledgments: AF Association would like to thank all those who helped in the development and review of this publication. Particular thanks are given to Dr Christine Baker, Dr Andreas Wolff, Dr Kim Rajappan and Dr Charlotte D'Souza.

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

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