

# Atrial fibrillation and you







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

## **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 specializes 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 specializes 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



## **Diagnosis**

A diagnosis of atrial fibrillation can be a dramatic event and often comes as a surprise. It can be hard to come to terms with the diagnosis. 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 the AF, there will be a period of psychological adjustment and changes in how you may 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. 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



## **Getting to grips with medication**

In nearly all cases, a diagnosis gets 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. Remember that it can take time for your body to get used to a new medication. However, do not be afraid to ask for a medication review if you are not coping well on a particular drug.

#### **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. If this is a problem for you, discuss it with your clinician. There are 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 daily 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 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 be advised to take an oral anticoagulant.

Taking warfarin means that you have to be mindful of vitamin K in the diet. You will be advised about this and possible drug interactions. Vitamin K is a naturally occurring nutrient that plays a role in blood coagulation. Small amounts of dietary vitamin K are essential for maintaining good health. Vitamin K affects 'international normalized ratio (INR) levels. Vitamin K directly affects warfarin, so you must be careful to keep levels of the vitamin constant. Regular blood tests ensure that the right amount of warfarin gets 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). There are no concerns about INR (Internal normalized ratio) levels with these drugs - in other words, how well your blood can clot. However, you must take the tablets at the same time every day. If you think you have missed a dose, you must 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 or are at high risk of stroke, there is an alternative to medication. This alternative uses a procedure called transcatheter closure of the left atrial appendage. With this procedure, a medical closure device closes off the left atrial appendage (the primary source of blood clots in patients with AF), preventing clots from forming in the left atrial appendage or breaking free from it and traveling to the brain. Never make changes in your medication without seeking medical approval first.

#### **Surgical options**

In addition to medication, there are several procedures available to eliminate AF. There is cardioversion, which resets the electrical impulses in the heart by administering a controlled electric shock. Additionally, suitable patients may be eligible for ablation, whereby electrical impulses in the heart are blocked. AF Association has a range of booklets and information fact sheets that explain these procedures fully. They are available to read and download from our website: www.afa-us.org

## **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 experience 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 on everyone concerned.

It's always helpful to talk about your AF with a healthcare professional such as a GP; it can assist your medical team in understanding what helps you and adjust your medication if appropriate. If your GP suggests counseling or another form of psychological help, highly consider this optionadjusting on the personal front is important.

Cognitive Behavioral 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.

Meditation may also 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

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



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 symptomsevidence supports its benefits. There are apps available to download or search online for local meditation centers in your nearby town or city.

#### **Alternative therapies**

Far from being faddish 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.

While research into some complementary therapies is inconclusive, some AF Association members have shared the benefits they have received from yoga and acupuncture.

Studies support this as they have found gentle forms of yoga and breathing exercises can help patients with AF. Practicing yoga can lead to a slight drop in systolic and diastolic blood pressure, which provides a beneficial effect on heart rate. Yoga is easy to learn-and it can be practiced 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. It has a ripple effect on INR levels, affecting your warfarin dose. 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-everyone's metabolism is different. However, 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 say that a large meal can trigger AF, so it may be wise to eat smaller meals. If symptoms regularly come on at night, try not to eat past 7 pm.
- If you haven't already done so, drink less alcohol and eliminate smoking. Nicotine is a cardiac stimulant and is known to cause coronary heart disease. Your physician's office can direct you to a smoking cessation clinic.
- Replace tea and coffee with decaffeinated options such as Rooibos 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 to safeguard against clogged arteries that 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.

If you have paroxysmal AF, keep a diary of triggers. Recording details regarding when the symptoms appeared-whether after taking medication, if you had been feeling relaxed or panicky, perhaps you had been in a particular position, and the duration of the episode. Keeping such a diary can reveal a previously unnoticed pattern and highlight something you can avoid in the future.



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, cardiologist, or anticoagulation clinic. Someone with AF may need transportation assistance to and from appointments.

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

Partners/carers may find that increased demands on their time may mean they have to adjust 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

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

Joyce



## **Physical exercise**

Although AF is more common amongst older people, it can also occur in people who lead a physically active lifestyle, including endurance athletes. Exercise is a vital component of a healthy lifestyle. Exercising following a paced approach at a level 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. Daily walking is an excellent way of keeping fit. Scan the local paper, recreation centers, or library: you will also discover a wealth of activities like taichi, yoga sessions, or Zumba classes. There are also an infinite number of Online options to be foundfrom Yoga and Pilates to HII.

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.



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

Stuart

#### **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; 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.

## **Intimacy**

Anxiety about the impact of physical activity triggering and worsening AF is common. This can lead to feeling 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. It has cardiovascular benefits-increased blood flow, heart rate and deep breathing- and improves the circulation of oxygen and hormones to organs and muscles and waste product removal from the body. It also improves the cholesterol balance and burns calories.

Having intimate contact promotes overall stress reduction. It boosts the immune system and is linked to higher levels of an antibody (immunoglobulin A), which can protect us from getting colds and other infections. It reduces the risk of prostate cancer in men and helps to minimize a woman's risk of incontinence later in life. Intimate contact releases a hormone called oxytocin, the so-called love hormone, which promotes sleep (vital for maintaining a healthy weight and blood pressure). The deep relaxation that typically follows sex may be one of the few times people allow themselves to completely "let go" 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 uncomfortable for patients to talk about but remember, your doctor and nurses are professionals used to talking about these subjects. They are there to offer you the information and advice you need.

AF can contribute to erectile dysfunction. This symptom sometimes leads to diagnosis in the first place. If you are thinking about using a drug to treat erectile dysfunction (ED)-talk to your doctor. They know your medical history and will know of any possible drug interactions that require monitoring. Having said this, it is not uncommon for AF patients to safely be prescribed erectile dysfunction medications.

## **Traveling**

#### 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 immunizations 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 favorable terms for AF sufferers.

It is a good idea to carry a medication alert card or wear a medical ID bracelet or necklace during the trip. These items can state your medical condition, any implanted devices you may have, the medication you take, and your doctor's contact details. Likewise, a digital ID can also carry vital 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 traveling. Be aware of INR test centers 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. Studies show that they can reduce swollen ankles and the risk of deep vein thrombosis (DVT). They come in a variety of sizes and different levels of compression. Flight socks are available from pharmacies, airports, and many retail outlets. Compression stockings must be measured and worn correctly because ill-fitting stockings could 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 no reason why you cannot travel, including long-haul.

Pack more medication than you will need on the journey in your carry-on 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 carry-on 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 your to walk through the security scanners or whether you need to be manually hand searched.

- Get up and stretch your legs while traveling 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.comAtrialFibrillationAssociationUS, and Twitter: @AtrialFib\_US.

Our Patients Day is held every Fall and is well received by members. You are invited to join us to hear presentations by top cardiologists, electrophysiologists and other healthcare professionals on a range of AF topics including latest developments, and treatment options.

For support groups call or email the AF Association @ info@heartrhythmalliance.org

#### 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** (843)415-1886 www.afa-us.org

**Arrhythmia Alliance** (843)415-1886 www.heartrhythmalliance.org

### **AF Association resources**

AF Association has a wide range of booklets and fact sheets 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 mail 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 appreciated.

Our Newsletter AFA Today is published twice a year. Our e-bulletin updates are monthly. Please provide us with your contact details if you wish to receive the updates to info@afa-us.org

"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







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



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Published October 2014 Reviewed February 2023





Finger on your Pulse: is our new library of educational video resources. Medical Experts share their knowledge and address specific concerns and patients share their experience living with the various conditions and treatments.

www.fingeronyourpulse.org

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

Acknowledgments: AF Association would like to thank all those who helped in the development and review of this publication. Particular thanks are given to Francesca Lobban.

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