



HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

Welcome to Action for AF

Just because you have atrial fibrillation (AF), does not mean you have to suffer a lower quality of life. This resource is designed to help you understand how the disease can affect your quality of life so you can speak to your doctor about what you can do to live your best life possible.

Start using this tool today by identifying what stage along the AF pathway you may be experiencing and then explore what other resources are available to you here to better manage the disease.



I HAVE BEEN DIAGNOSED WITH AF BUT I AM
NOT RECEIVING STROKE PREVENTION THERAPY



I HAVE AF AND I AM BEGINNING
ANTICOAGULATION THERAPY



I HAVE AF AND I AM ON ANTICOAGULATION
THERAPY BUT I AM EXPLORING OTHER OPTIONS



I HAVE AF BUT I HAVE DISCONTINUED
ANTICOAGULATION THERAPY



I HAVE AF BUT I DO NOT UNDERSTAND
WHAT THERAPY I AM ON

(1)





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

I have been diagnosed with AF but I am not receiving stroke prevention therapy

Click below to explore resources to help you better manage AF.

My doctor has diagnosed me with AF, but I have not started any kind of therapy to prevent AF-related stroke.

My doctor did not seem very concerned about my AF-related stroke risk so I do not feel it is a high priority at this time.



CLICK HERE TO LEARN WHEN AND WHY YOU NEED TO
RECEIVE AF-RELATED STROKE PREVENTION THERAPY



CLICK HERE FOR AN OVERVIEW OF
AF TREATMENT OPTIONS





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

I have AF and I am beginning anticoagulation therapy

Click below to explore resources to help you better manage AF.

My doctor has diagnosed me with AF and has prescribed therapy to prevent AF-related stroke.

Even though my doctor told me I could have a stroke because of my condition, I would still like more information about my risk and how the therapy may affect my lifestyle.



CLICK HERE FOR AN OVERVIEW OF
AF TREATMENT OPTIONS





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

I have AF and I am on anticoagulation therapy but I am exploring other options

Click below to explore resources to help you better manage AF.

My doctor has diagnosed me with AF and I am on therapy to prevent AF-related stroke but I want to know if there are other options.

The therapy I am on is inconvenient for my lifestyle and I do not know if it is helping me.



CLICK HERE TO LEARN IF YOU ARE PROPERLY
ANTICOAGULATED



CLICK HERE FOR AN OVERVIEW OF
AF TREATMENT OPTIONS





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

I have AF but I have discontinued anticoagulation therapy

Click below to explore resources to help you better manage AF.

My doctor has diagnosed me with AF and I was on therapy to prevent AF-related stroke but I stopped my therapy.

The therapy I was on was inconvenient for my lifestyle and I was not sure if it was helping me.



CLICK HERE TO READ SOME COMMON REASONS
WHY INDIVIDUALS DISCONTINUE THERAPY



CLICK HERE FOR AN OVERVIEW OF
AF TREATMENT OPTIONS





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

I have AF but I do not understand what therapy I am on

Click below to explore resources to help you better manage AF.

Are you unsure what kind of therapy your doctor prescribed you?

The “Overview of AF Treatment Options” may help you to better understand what therapy you are on and then you can see if any of the four common stages on the left sound like you.



CLICK HERE FOR AN OVERVIEW OF
AF TREATMENT OPTIONS





Stage-Specific Materials

Overview of AF Treatment Options



AF can be treated in various ways, such as by slowing down the heart rate (how fast your heart beats, also known as your pulse) with beta-blockers or calcium-channel blockers. Other AF treatments address the heart rhythm (the regularity of the pulse) with antiarrhythmic medications, like sodium channel blockers and potassium channel blockers.

There are also therapies that help to prevent AF-related stroke, such as anticoagulants and antiplatelets.^{1,2} The most common therapy for AF-related stroke prevention, until recently, were vitamin K antagonists (VKAs)³ but newer medications, known as non-vitamin K oral anticoagulants (NOACs),⁴ have been shown in studies to be generally as or more effective and as safe or safer than VKAs. Furthermore, NOACs are typically more convenient as they do not require routine monitoring and are less impacted by foods, alcohol or other medications.⁵

Please note that aspirin is no longer recommended as a safe and effective stroke prevention therapy option for individuals with AF, unless you are unable to take oral anticoagulants.⁵ If you are taking aspirin for stroke-prevention without trying oral anticoagulants, speak with your doctor as you may be at increased risk of having a stroke.

When thinking about treatment options that are right for you, it is important that you consider the quality of life factors that have the biggest impact on you. Be sure to complete the [My Quality of Life Check](#), and take the results to your next doctor's appointment to discuss what therapy is best for you based on your specific lifestyle.





Stage-Specific Materials

When and Why Do I Need to Receive AF-Related Stroke Prevention Therapy



A stroke can be very debilitating. When a clot travels to the brain and stops blood flow to a part of the brain, the affected part can suffer severe damage.⁶ It is very important to understand this risk and to discuss it with your physician. The negative effects of a stroke can be life-long and affect not only you, but also your family and friends.

Your doctor can calculate your stroke risk by using a well-known measurement called the CHA₂DS₂-VASc score. If the score indicates that you are at increased risk of stroke, your doctor may discuss initiating anticoagulation therapy with you.⁷

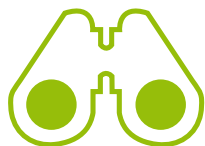
AF-related stroke risk can be reduced by about two-thirds through the appropriate use of anticoagulation medications.⁸ By taking it regularly you are reducing your risk of having a stroke.⁶





Stage-Specific Materials

How Do I Know if I am Properly Anticoagulated



Depending on what therapy you are taking for AF-related stroke prevention, you may be monitored regularly to ensure you are taking the right dose and have enough medication in your body to prevent your blood from forming clots too soon. For example, if you are taking a vitamin K antagonist (VKA), you would have to be monitored regularly. The ability of VKA to make the blood less likely to clot (measured by the International Normalised Ratio – INR) can be affected by a number of factors, such as food and other medicines. Regular monitoring ensures that the INR is not too low (risk of clots) or too high (risk of bleeding).⁸ Newer therapies like non-vitamin K oral anticoagulants (NOACs)⁵ with less variability in their effects, do not require regular monitoring.⁶

By taking your anticoagulation therapy regularly you are reducing your risk of having a stroke.⁶

It is important to take your anticoagulation therapy as prescribed by your doctor to keep your risk of stroke as low as possible.⁶ If you are experiencing AF symptoms, like shortness of breath, your heart beating rapidly, tiredness, dizziness or chest pain, speak with your doctor. AF can also be “silent,” and not have any symptoms.⁹ While you may feel your condition is under control, blood clots may still form so it is important to continue your anticoagulation therapy even if you are not experiencing symptoms.⁶





Stage-Specific Materials

Common Reasons Why Individuals Discontinue Therapy



If you are not following your anticoagulation therapy properly, it may be for various reasons.

Maybe you are:

- Experiencing side effects; or
- You feel your therapy is too complicated to follow; or
- You don't think you have a high risk of having a stroke at your age; or
- It is affecting your everyday quality of life too much.

AF affects individuals differently and your path through AF is your own. It is important to identify potential barriers that may be having an impact on your therapy plan and that could be putting you at unnecessary risk. [The Quality of Life Check](#) can help you pinpoint which quality of life factors are most important to you.

Additionally, use [The AF Pathway Diary](#) to write down questions for your doctor and keep track of times when your anticoagulation therapy has interfered with your life.





My Quality of Life Check



Research shows that patients and doctors often do not think about how AF and therapies for AF-related stroke prevention affect patients' everyday activities. Quality of life factors are important to consider as they can have an impact on whether individuals stay on treatment. Each person has a different experience with AF; therefore, different quality of life factors will be important to different individuals.

Following are some factors that have been identified by experts as ones that may influence your quality of life and your ability to be adherent with your therapy for AF-related stroke prevention. Using the check boxes, mark which factors are most important to you and discuss them with your doctor.

Please check all that apply to you.

- | | |
|--|---|
| <p><input type="checkbox"/> Anxiety: Experiencing increased anxiety as a result of AF or therapy for AF related stroke affects your quality of life.</p> <p><input type="checkbox"/> Perceived stroke risk: Your understanding of how AF increases the risk of stroke can impact your quality of life.</p> <p><input type="checkbox"/> General health concerns: Having a long-term condition and feeling unhealthy, or having difficulty remembering things and concentrating due to increased worrying can have an impact on your quality of life.</p> <p><input type="checkbox"/> Knowledge: Your knowledge and understanding about your condition and your treatment plan can affect your quality of life.</p> <p><input type="checkbox"/> Disease symptoms: Experiencing symptoms related to AF, such as palpitations, dizziness or chest discomfort can impact your quality of life.</p> | <p><input type="checkbox"/> Side effects of your treatment: Treatment side effects you may experience, such as bleeding, blurry vision, dizziness, chest pain, bruising, and muscle aches, can affect your quality of life.</p> <p><input type="checkbox"/> Relationships: The trust that you have in your doctor, as well as maintaining good relationships with your friends, family, and partners can impact your quality of life.</p> <p><input type="checkbox"/> Other health conditions: Living with other conditions, such as arthritis, or high blood pressure can impact your quality of life.</p> <p><input type="checkbox"/> Therapy complexity: The complexity of AF treatment and stroke prevention therapy can impact your quality of life.</p> <p><input type="checkbox"/> Mobility: A decrease in your ability to participate in physical activity or travel (due to AF) can impact your quality of life.</p> <p><input type="checkbox"/> Age: The age at which you were diagnosed with AF can impact your quality of life.</p> |
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HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

About Action for AF

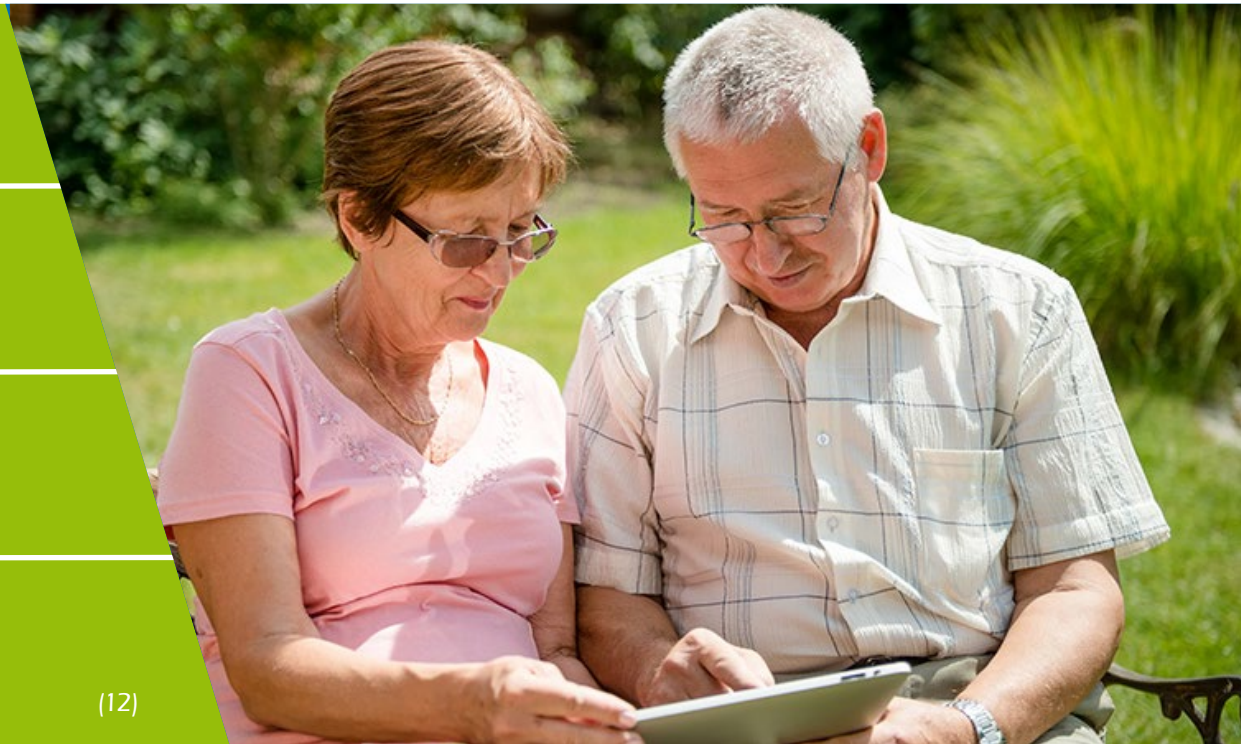
Click below to read about the Action for AF programme.

WHAT IS ACTION FOR AF

WHY IS ACTION FOR AF IMPORTANT

ABOUT THE ADVISORY BOARD MEMBERS

ACTION FOR AF: Q&A





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

Living with AF

Click below to read about Living with AF.

UNDERSTANDING THE PATHWAY OF AF

UNDERSTANDING THE LINK BETWEEN AF AND STROKE

BENEFITS AND RISKS OF ANTICOAGULATION FOR
AF-RELATED STROKE

WHY IS IT IMPORTANT TO TAKE MEDICINE THE WAY
MY DOCTOR PRESCRIBED

HOW AF AND AF-RELATED STROKE PREVENTION THERAPY
MAY IMPACT MY QUALITY OF LIFE

WHAT I NEED TO KNOW ABOUT AF: FACT SHEET

LIVING WITH AF: Q&A

(13)



Being Involved in Managing AF

Click below to read about Being Involved in Managing AF.

WHY IT IS IMPORTANT TO BE INFORMED
ABOUT HOW TO MANAGE AF

THE AF PATHWAY DIARY

HOW TO BE PREPARED FOR A DISCUSSION
WITH MY DOCTOR

HOW-TO GUIDE FOR TALKING TO MY FAMILY
AND FRIENDS ABOUT MY CONDITION





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

AF Carer Resources

Click below to read about AF Carer Resources.

**FAMILY AND FRIENDS
DISCUSSION GUIDE**

**UNDERSTANDING HOW QUALITY OF
LIFE IS RELATED TO AF THERAPY AND
MANAGEMENT**





HOME



ABOUT ACTION
FOR AF



LIVING
WITH AF



BEING INVOLVED
IN MANAGING AF



AF CARER
RESOURCES



ADDITIONAL
RESOURCES

Additional Resources

Click below to see Additional Resources.

FOR MORE INFORMATION, PLEASE
VISIT THE FOLLOWING PATIENT
RESOURCE WEBSITES:

- [AF ASSOCIATION \(AFA\)](#)
- [ANTICOAGULATION EUROPE \(ACE\)](#)
- [ARRHYTHMIA ALLIANCE](#)
- [AFIB MATTERS](#)





About Action for AF

Click below to read about the Action for AF programme.

WHAT IS ACTION FOR AF

WHY IS ACTION FOR AF IMPORTANT

ABOUT THE ADVISORY BOARD MEMBERS

ACTION FOR AF: Q&A





About Action for AF

What Is Action For AF



Action for AF is a programme that has been developed by the Bristol-Myers Squibb/Pfizer Alliance, in partnership with an independent advisory board, including experts from the AF Association (AFA), AntiCoagulation Europe (ACE) and Arrhythmia Alliance. The programme was created to help individuals living with Atrial Fibrillation (usually referred to as AF) and their family and friends, better understand how to manage AF and AF-related stroke risk. It provides tools and resources to improve communication between patients and doctors. Research shows that oftentimes patients and doctors do not think about how this condition and AF-related stroke prevention therapy can affect an individual's quality of life. Therefore, when developing **Action for AF**, leading experts came together and consulted scientific research to identify the specific lifestyle triggers that might have an impact on individuals living with AF—these are called quality of life factors. The programme will provide you with information and tools to help support you while you learn how to navigate your life with AF. As everyone has unique experiences, your “AF Pathway” will be specific to you.

The aim of this programme is to:

- Provide individuals living with AF information about AF and AF-related stroke risk, and help them identify how they can better manage their condition and what AF-related stroke prevention therapy option is best based on their lifestyle;
- Help doctors better understand the patient perspective and what it is like to live with AF and provide resources to improve how patients and doctors talk to each other about the condition;
- Support individuals with family or friends that have AF to understand the condition, the related stroke risk and how to help them best manage the condition.

For additional information, please look at the **Action for AF: Q&A**.



Action for AF

Saving lives, preventing AF-related stroke



About Action for AF

Why is Action for AF Important

What is AF-Related Stroke Risk



AF is the most common heart rhythm disorder.¹ If you are living with AF, you may have a higher risk for having a stroke, also called a “brain attack,” where the oxygen to an area of the brain has been disrupted.² AF causes an irregular heart rhythm, which allows the blood to pool and form into a clot in the heart. These clots are at risk of breaking away and flowing through the blood stream until they cause a blockage leading to a stroke.³ AF is the leading cause of ischaemic or embolic stroke. This is why it is important for individuals living with AF to be active in their stroke-risk management.

Your doctor and AF patient groups, like the AF Association (AFA), AntiCoagulation Europe (ACE), or Arrhythmia Alliance are good resources for information about AF-related stroke prevention. You should also speak with your family and friends about how they can help you prevent AF-related stroke.

For more information, visit the following patient groups:

- [AF Association \(AFA\)](#)
- [AntiCoagulation Europe \(ACE\)](#)
- [Arrhythmia Alliance](#)
- [Afib Matters](#)

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



About Action for AF

Shared and Informed Decision Making

Shared and informed decision making is a collaboration between a patient and his or her doctor to make healthcare decisions together.⁴ During this process, the patient and doctor look at the available scientific evidence, as well as the patient's personal values and preferences in order to come to a decision that is best for the patient.⁴

Shared and informed decision making respects both the doctor's expert knowledge and the patient's right to be fully informed of all care options and the potential harms and benefits. This process provides patients with the support they need to be fully involved in care decisions, while allowing providers to feel confident in the care they provide.⁴

For individuals living with AF, it is important to understand shared and informed decision making because each individual will have different experiences based on his or her personal lifestyle.

This programme includes tools and resources to help you identify triggers in your life that are having an impact on your condition and your quality of life. These tools and resources are also designed to support you in discussing these triggers with your doctor to help you make the right decisions regarding your AF-related stroke prevention therapy.

[Click here](#) to explore some tools that will help you prepare for your next doctor's visit.





About Action for AF

About the Advisory Board Members

Who is Involved in Action for AF



The Action for AF programme has been developed by a group of leading experts in Europe who came together to form an advisory board. This advisory board consists of people from two of the largest European AF patient groups, as well as a leading AF physician. They helped create these materials and provided expert advice that you will see throughout this resource.

Meet Our Advisory Board



Professor John Camm is a renowned cardiologist and AF expert who holds various roles of high esteem, including positions with the European Society of Cardiology and [The Arrhythmia Alliance](#) (President). He also was the lead author of the European Society of Cardiology's AF management guideline update published in 2013.

"Patient education is the key to comprehensive and effective treatment of atrial fibrillation – the Action for AF programme is designed to put the patient at the centre of medical care and ensure success."

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



About Action for AF



Trudie Lobban is the founder and Chief Executive Officer of the [AF Association \(AFA\)](#). Trudie sits on a number of European medical boards and steering groups, including the International Alliance of Patients' Organisations (IAPO), European Heart Rhythm Association (EHRA) and the Arrhythmia Alliance: The Heart Rhythm Charity.

"The AF Association exists to provide information, support and advice to thousands of individuals affected by AF worldwide. We are glad to be part of this unique programme to educate and improve awareness amongst patients, carers and health care professionals that will lead to improved quality of life for patients."



Eve Knight is the Chief Executive Officer and founder of [AntiCoagulation Europe \(ACE\)](#). Eve is a member of several European groups including The European Action for Stroke Prevention Alliance, The All Party Thrombosis Group in the UK and The European Task Force looking at bleeding risk assessments in AF patients.

"I'm proud to be involved in this unique programme as Action for AF focuses on the patient's quality of life and helps improve the dialogue between patients and clinicians, which is one of the most important things that can take place in the management of AF."



Action for AF

Saving lives, preventing AF-related stroke



About Action for AF

Action for AF: Questions and Answers



Q. What is Action for AF?

A. Action for AF is a programme that has been developed by the Bristol-Myers Squibb and Pfizer Alliance to help you better understand how to manage AF and AF-related stroke risk. The programme provides tools and tips to help you manage your condition, prepare for your next doctor's visit and identify what lifestyle factors could be having an impact on your quality of life.

Q. Who developed Action for AF?

A. The Bristol-Myers Squibb and Pfizer Alliance, in partnership, with the Action for **AF advisory board**, developed the Action for AF programme. The advisory board is made up of people from two of the largest European AF patient groups, as well as a leading AF physician. This resource includes links to documents, factsheets, brochures and other materials from AF-related patient groups if you would like to learn more or find more information about AF and AF-related stroke risk.

Q. Who is Action for AF for?

A. Action for AF is a programme that supports individuals living with AF and AF-related stroke risk, as well as anyone who has a friend or family member with AF and wants to learn more about the condition and how they can help prevent AF-related stroke.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



About Action for AF

Q. Why is Action for AF an important programme?

- A. This programme is important for individuals living with AF because it provides information about AF and AF-related stroke risk. The programme is unique in that it helps individuals living with AF identify where they are in the [AF pathway](#), what triggers could be having an impact on their quality of life and how they manage their condition.

Q. How do I benefit from the programme?

- A. The programme gives you free materials to learn more about how to better manage your AF to prevent AF-related stroke and allows you to share this resource with others living with AF. Specific tools and pages, like the [My Quality of Life Check](#), can be downloaded or printed to make it easy to take with you to the doctor's office.

Q. How is Action for AF different from other programmes that are currently available?

- A. Action for AF is a unique programme that focuses on helping individuals with AF understand what impact AF and AF-related stroke prevention therapy may have on their quality of life and empowers them to talk with their doctors about them.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

Click below to read about Living with AF.

UNDERSTANDING THE PATHWAY OF AF

UNDERSTANDING THE LINK BETWEEN AF AND STROKE

**BENEFITS AND RISKS OF ANTICOAGULATION FOR
AF-RELATED STROKE**

**WHY IS IT IMPORTANT TO TAKE MEDICINE THE WAY
MY DOCTOR PRESCRIBED**

**HOW AF AND AF-RELATED STROKE PREVENTION THERAPY
MAY IMPACT MY QUALITY OF LIFE**

WHAT I NEED TO KNOW ABOUT AF: FACT SHEET

LIVING WITH AF: Q&A





Living with AF

Understanding the AF Pathway



Atrial fibrillation (AF) is the most common type of heart rhythm disorder that at first can come and go, but very often turns into a chronic condition that remains with you throughout life from the time of diagnosis.^{1,2} Individuals living with AF may have a higher risk for stroke because the irregular heartbeat allows for the blood to pool and form a clot in the heart, which can travel in the bloodstream toward the brain and cause a stroke.³

A variety of factors, such as age, diet and state of mind, may affect your quality of life and how you manage your disease. These factors can change as you continue living with the condition, therefore your pathway with AF may be different from others. It is important to understand where you are along the path, so you can manage the condition the way that is best for you. This section explores common stages along the AF pathway to help you, your family member or friend stay healthy, while living the life you want to live.

Do Any of These Five Common Stages Sound Like You?

1. I have been diagnosed with AF but I am not receiving stroke prevention therapy

- My doctor has diagnosed me with AF, but I have not started any kind of therapy to prevent AF-related stroke. My doctor did not seem very concerned about my AF-related stroke risk so I do not feel it is a high priority at this time.
 - [Click here](#) to learn when and why you need to receive AF-related stroke prevention therapy.
 - [Click here](#) for an overview of AF treatment options.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

2. I have AF and I am beginning anticoagulation therapy

- My doctor has diagnosed me with AF and has prescribed therapy to prevent AF-related stroke. My doctor told me I could have a stroke because of my condition, so I would like more information about my risk and how the therapy may affect my quality of life.
 - [Click here](#) for an overview of AF treatment options.

3. I have AF and I am on anticoagulation therapy but I am exploring other options

- My doctor has diagnosed me with AF and I am on therapy to prevent AF-related stroke but I want to know if there are other options. The therapy I am on is inconvenient for my lifestyle and I do not know if it is helping me.
 - [Click here](#) to learn if you are properly anticoagulated.
 - [Click here](#) for an overview of AF treatment options.

4. I have AF but I have discontinued anticoagulation therapy

- My doctor had diagnosed me with AF and I was on therapy to prevent AF-related stroke but I stopped my therapy. The therapy I was on was inconvenient for my lifestyle and I was not sure if it was helping me.
 - [Click here](#) to read some common reasons why individuals discontinue therapy.
 - [Click here](#) for an overview of AF treatment options.

5. I have AF but I do not understand what therapy I am on

- Are you unsure what kind of therapy your doctor prescribed you? The [Overview of AF Treatment Options](#) may help you to better understand what therapy you are on and then you can determine if any of the four common stages above sound like you.
 - [Click here](#) for an overview of AF treatment options.





Living with AF

Understanding the Link Between AF and Stroke

Understanding AF-Related Stroke Risk



Individuals with AF have a heart rhythm that is not normal. The delays between the beats create a risky situation for those individuals who have AF because with each delay of the heartbeat, the blood can pool, or join together in a clot inside the heart,³ much like when you cut yourself and a clot forms to stop the bleeding. In this case though, the clot can be dangerous. When the heart beats again, this clot can dislodge and go into the general circulation and end up in the brain. If it does, the result can be a stroke.³

Individuals with AF have a five-fold increased risk of stroke compared to those with a normal heartbeat.⁴ Across 28 European countries, it's estimated that there are 8.8 million people with AF⁵ and there are almost one million strokes each year, making it the second leading cause of death worldwide.⁶

Individuals living with AF can reduce their stroke risk by about two-thirds by taking anticoagulation therapy. Anticoagulants prevent the blood from clotting too soon when the heart does not beat in its normal rhythm. These medications are very effective in stopping this process and therefore, greatly reduce the risk of AF-related stroke.⁴

The most common therapy for AF-related stroke prevention is a type of medication called Vitamin K Antagonists (VKA).⁷ VKAs work by acting on the liver to prevent the formation of proteins that go on to create fibrin, which is the basic component of a clot. VKAs require regular monitoring to ensure the dose is correct for the individual as it can be impacted from time to time by factors such as certain foods, alcohol and other medications. If you are taking a VKA, you

[Please scroll down to continue reading on the following page.](#)



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Saving lives, preventing AF-related stroke



Living with AF

will typically be required to visit a clinic every few weeks to check whether your blood has been thinned (anticoagulated) enough without putting you at risk for major bleeding (when it is too thin).⁴ However, VKAs are not right for everyone, which is why there are other options available.⁷

Newer medications, known as non-vitamin K oral anticoagulants (NOACs),⁸ have been shown in studies to be generally as or more effective and as safe or safer than VKAs. Furthermore, NOACs are typically more convenient than VKAs as they do not require routine monitoring and are less impacted by foods, alcohol or other medications.⁹

You should talk to your doctor about what therapy is best for you based on your specific lifestyle. [Click here](#) for a helpful guide to prepare for a discussion with your doctor about your stroke risk and what therapy is best for you to reduce your stroke and bleeding risk. Before your doctor's visit, you should also complete the [My Quality of Life Check](#) to find out which quality of life factors are most important to you right now and take the results to your next appointment.





Living with AF

Benefits and Risks of Anticoagulation for AF-Related Stroke Prevention

What is an Anticoagulant



Anticoagulants are medications that help prevent blood from clotting by making it “thinner.” A very important benefit of anticoagulants in AF is that they greatly decrease the risk of blood pooling together into a clot when the heart beats in an abnormal rhythm. By not allowing the blood to clot too soon, these medications reduce your risk of a clot going to your brain and causing a stroke.⁴

Blood clotting is the process that stops bleeding after a cut or an injury.¹⁰ Since anticoagulants block this process, there is a greater risk of bruising and bleeding. Bleeding is the primary complication of anticoagulants; however, the bleeding risk of each medication varies. Studies have shown variable efficacy in reduction of stroke risk and bleeding risk among different anticoagulants,⁷ therefore, it is important to discuss these traits with your doctor to understand the benefits and risks related to these medications. **If you are prescribed an anticoagulant to reduce your stroke risk, be sure to ask your doctor:**

- Whether to stop or discontinue anticoagulants when you need surgery;
- How to stop bleeding if you are cut or injured.

In order to understand which individuals might bleed more from using anticoagulants, experts have created the HAS-BLED score. This tool provides a measure to understand the risk of bleeding when using anticoagulants.¹¹





Living with AF

Why is it Important to Take Medicine the Way My Doctor Prescribed

Understanding the Impact of AF-related Stroke



A stroke can be very debilitating. When a clot travels to the brain and stops blood flow to part of the brain, that part can suffer severe damage.¹² It is very important to understand this risk and to discuss it with your doctor.

The negative effects of a stroke can be life-long and affect not only you, but also your family and friends. However, AF-related stroke risk can be reduced by about two-thirds through the appropriate use of anticoagulation medications.⁴

It is important to take medications as prescribed by your doctor. If the medication you are taking is interfering with your life, discuss this with your doctor. [Click here](#) to read a guide to help you in that discussion.

The Role of Therapies in Reducing AF-Related Stroke Risk

Individuals living with AF can reduce their stroke risk by taking anticoagulation therapy. If you do not take your anticoagulation therapy as your doctor prescribed it, it is possible that your blood may pool and form a clot in the heart, which may travel to the brain and cause a stroke.⁴

Newer medications, known as non-vitamin K oral anticoagulants (NOACs),⁸ have been shown in studies to be generally as or more effective and as safe or safer than VKAs. Furthermore, NOACs are typically more convenient than VKAs as they do not require routine monitoring and are less impacted by foods, alcohol or other medications.⁹ Also, patients who receive VKA often are not properly anticoagulated, losing some of the stroke prevention benefits.¹²

Please scroll down to continue reading on the following page.



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Saving lives, preventing AF-related stroke



Living with AF

When considering therapy options that are right for you, it is also important that you consider the quality of life factors that have the biggest impact on you. For example, patients being treated with VKAs face many limitations impacting their quality of life including:

- Diet restriction;
- Potential complications resulting from interactions with other treatments;
- The need for regular blood tests to monitor the level of anticoagulation in the blood.

Be sure to complete the [My Quality of Life Check](#), and take the results to your next doctor's appointment to discuss what therapy option is best for you based on your specific lifestyle.

How Do I Know I am Taking My Anticoagulation Therapy Properly?

Your doctor can calculate your stroke risk by using a well-known measurement called the CHA₂DS₂-VASc score. If the score indicates that you are at increased risk of stroke, your doctor may discuss initiating anticoagulation therapy.¹³ You should receive information about how to take your therapy properly in consultation with your doctor, for example when and how often you should take it.



Depending on what therapy you are taking for AF-related stroke prevention, you may be monitored regularly to ensure you are taking the right dose and have enough medication in your body to prevent your blood from forming clots. For example, if you are taking a VKA, you would be monitored regularly.⁴

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

The ability of VKA to make the blood less likely to clot (measured by the International Normalised Ratio – INR) can be affected by a number of factors such as food and other medicines. Regular monitoring ensures that the INR is not too low (risk of clots) or too high (risk of bleeding).⁴ Newer therapies like non-VKA oral anticoagulants (NOACs)⁸ show less variability in their effects and do not require regular monitoring.¹²

It is important to take your anticoagulation therapy properly to keep your risk of stroke as low as possible.⁴ If you are experiencing AF symptoms, like shortness of breath, your heart beating rapidly, tiredness, dizziness or chest pain, speak with your doctor. AF can also be “silent,” and not have any symptoms.¹⁴ While you may feel your condition is under control, blood clots may still form so it is important to continue your anticoagulation therapy even if you are not experiencing symptoms.⁴

You may not feel differently by taking anticoagulation therapy because it does not take away the symptoms you may have with AF, but by taking it regularly you are reducing your risk of having a stroke.⁴

For various reasons, you may not be following your therapy properly:

- Maybe you are experiencing side effects;
- Maybe you feel your therapy is too complicated to follow;
- Maybe you don't think you have a high risk of having a stroke at your age;
- Maybe you do not think it affects your everyday quality of life too much.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

AF affects individuals differently and your path through AF is your own. It is important to identify potential barriers that may be having an impact on your therapy plan and that could be putting you at unnecessary risk of stroke. [My Quality of Life Check](#) can help you pinpoint which quality of life factors are most important to you.

Additionally, use [The AF Pathway Diary](#) to write down questions for your doctor, and keep track of times when your anticoagulation therapy has interfered with your life.





Living with AF

How AF and AF-Related Stroke Prevention Therapy May Impact My Quality of Life

What Are Quality of Life Factors



Research shows that individuals often do not have a good understanding of AF and AF-related stroke risk, including therapies for AF-related stroke prevention.

This lack of understanding can have an impact on their quality of life. Quality of life factors are important to consider as they can have an impact on whether individuals stay on treatment. Therefore, expert opinions and the latest scientific research were consulted to identify specific factors that have an impact on the quality of life of individuals living with AF. Each person has a different experience with AF; therefore, different quality of life factors may be important to different individuals.

Understanding the Impact of AF and AF-Related Stroke Risk on Quality of Life

When thinking about the impact that AF has on your daily life, it's easy to become overwhelmed about how to manage the condition and prevent AF-related stroke.

Following are some points to consider that have been identified by experts as ones that may influence your quality of life and your ability to be adherent with your therapy for AF-related stroke prevention:

Please scroll down to continue reading on the following page.



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Living with AF

Anxiety: Experiencing increased anxiety as a result of AF or therapy for AF-related stroke prevention affects your quality of life. If you have a lot of anxiety or emotional stress, you may be distracted and not be taking your anticoagulation therapy properly.

Perceived stroke risk: Your understanding of how AF increases the risk of stroke can impact your quality of life. If you don't believe your stroke risk is very significant, you may not be taking your anticoagulation therapy properly.

General health concerns: Having a long-term condition and feeling unhealthy, or having difficulty remembering things and concentrating due to increased worrying can have an impact on your quality of life. If you feel you generally are in poor health, or if you have trouble remembering things, you may not be taking your anticoagulation therapy properly.

Knowledge: Your knowledge and understanding about your condition and your treatment plan can affect your quality of life. If you don't feel like you have a good understanding of AF or AF-related stroke risk, you may feel you do not need therapy and therefore may not be taking your anticoagulation therapy properly.

Disease symptoms: Experiencing symptoms related to AF, such as palpitations, dizziness or chest discomfort, impacts an individual's quality of life. If you are experiencing AF symptoms, you may be focusing on treating those and not focusing on taking your anticoagulation therapy properly.

Side effects of your treatment:

Treatment side effects you may experience, such as bleeding, blurry vision, dizziness, chest pain, bruising, and muscle aches, can affect your quality of life. If you are experiencing side effects from your anticoagulation therapy, such as bleeding, you may be concerned about continuing to take it.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

Relationships: The trust that you have in your doctor, as well as maintaining good relationships with your friends, family, and partners can impact your quality of life. If you have a good relationship with your doctor and he/she involves you in treatment decisions, that may impact how you feel about taking anticoagulation therapy.

Other health conditions: Living with other conditions, such as arthritis, hypertension, or others can impact your quality of life. If you have other existing conditions, you may be focusing on treating those and not focusing on taking your anticoagulation therapy properly.

Therapy complexity: The complexity of AF treatment and stroke prevention therapy can impact your quality of life. If your anticoagulation therapy is complex, you may not be taking it properly.

Mobility: A decrease in your ability to participate in physical activity or travel (due to AF) can impact your quality of life. If your anticoagulation therapy requires frequent monitoring and interferes with your travel, you may not be taking it properly.

Age: The age at which you were diagnosed with AF can impact your quality of life. If you were diagnosed with AF at a younger age, you may not be concerned about your stroke risk and may not be taking your anticoagulation therapy properly.

You should evaluate how these factors may be affecting your quality of life and talk about them with your doctor at your next appointment.





Living with AF

What I Need to Know About AF: Fact Sheet



Two large European patient groups that focus on AF, AF Association (AFA) and AntiCoagulation Europe (ACE), both have resources about AF that you can access through their websites. We have also provided links to different fact sheets that may be useful to you from these sites.

- [What is Atrial Fibrillation?](#)
- [Causes of Atrial Fibrillation](#)
- [Symptoms](#)
- [Types of Atrial Fibrillation](#)
- [Risks of Atrial Fibrillation](#)
- [AF-Related Stroke](#)
- [Definitions and Abbreviations](#)
- [Everything You Need to Know About AF](#)





Living with AF

Living with AF: Q&A

Understanding AF Treatment and Management Options



Q. What is AF?

- A. Atrial fibrillation, or AF, is the most common, sustained cardiac arrhythmia (irregular heartbeat).¹ It is estimated that at least 8.8 million individuals in the European Union have AF.⁵

Q. Is AF a life-threatening condition?

- A. AF can be considered a life-threatening heart rhythm problem because individuals living with AF have a greater risk of stroke and heart failure compared to those with a normal heartbeat. AF related stroke-risk can be minimised with proper anticoagulation therapy.⁷ Learn more about AF related stroke-risk [here](#).

Q. Is AF a genetic disease?

- A. Yes, there are familial and genetic components to AF. Research has found that children of individuals with AF have approximately twice the risk of developing the heart rhythm disorder.¹⁵

Q. What are the causes of AF?

- A. The cause of AF is not fully understood. It is age related – the older you become the more likely you are to develop AF. However, AF is more likely to occur in individuals who have other conditions, such as:
- High blood pressure;
 - Heart failure;
 - Coronary artery disease;
 - Mitral heart valve disease (caused by valve disease from birth or acquired later in life);
 - Long-standing lung disease;
 - Congenital heart disease (abnormality of the heart since birth).

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

AF can also be associated with:

- Thyroid gland disorders;
- Pneumonia;
- Lung cancer;
- Pulmonary embolism;
- Carbon monoxide poisoning;
- Alcohol or drug abuse or misuse.

Sometimes individuals develop AF for no explainable reason. When there is no known cause this is known as “Lone AF” or “idiopathic AF.”¹⁶

Q. What are the symptoms of AF?

A. Some AF patients do not experience any symptoms and the AF is only discovered at a routine medical examination or after a health problem. However, for those who do, the most common symptoms are:

- Palpitations (or awareness of the heartbeat), which may be rapid;
- Tiredness;
- Shortness of breath;
- Dizziness;
- Chest pain.¹⁴

Q. Who is affected by AF?

A. AF can affect adults of any age, but it is more common as individuals get older. AF occurs in around one in 10 adults over 65 years old.¹ Currently, there are at least 8.8 million individuals in Europe living with AF.⁵

Q. How is AF treated?

A. AF can be treated in various ways by slowing down the heart rate (how fast your heart beats/your pulse) or by correcting your heart rhythm (the regularity of the pulse).¹⁸

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

Q. How do I know if I, a family member or a friend has AF?

A. The simplest way to detect AF is to check your pulse. If the rhythm of the beat seems irregular, this may indicate you have AF. It is very important to check with a doctor to find out whether you do actually have AF, because there are other conditions that also cause an irregular pulse. An electrical recording of your heart beat is needed to confirm the diagnosis.¹⁷

Q. What is AF-related stroke?

A. The irregular rhythm of the heart due to AF can cause the blood to pool together to form a clot in your heart. It is these clots that are at risk of breaking away and flowing through the blood until they cause a blockage in the brain, which is a stroke.³

Q. Why is it important to understand AF-related stroke risk?

A. Patients with AF experience a five-fold increased risk of stroke compared to those with a normal heartbeat.⁴ As a result, across Europe with a combined population of 500 million, there are almost one million strokes each year, making it the second leading cause of death worldwide.⁶

Q. How do I prevent AF-related stroke?

A. You can prevent AF-related stroke by taking anticoagulation medication that works to prevent stroke by slowing down the clotting process of the blood.¹⁸ You can also prevent stroke by taking treatment to correct your AF. Even if treatment stops, the AF may come back so assessment for stroke risk is still very important.¹⁸ If you are unable to take an oral anticoagulant, ask your doctor about other options that may be right for you.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

Q. What are the different therapy options available for AF and AF-related stroke prevention?

- A. There are different treatment options for AF that control your heart rhythm, such as anti-arrhythmic medications (i.e. sodium channel blockers and potassium channel blockers), procedures and devices. AF can also be treated by slowing down the heart rate with beta-blockers or calcium-channel blockers.

There are also therapies that help to prevent AF-related stroke, such as anticoagulants and antiplatelets.^{18,19} The most common therapy for AF-related stroke prevention, until recently, were vitamin K antagonists (VKAs)⁷ but newer medications, known as non-vitamin K oral anticoagulants (NOACs),⁸ have been shown in studies to be generally as or more effective and as safe or safer than VKAs. Furthermore, NOACs are more convenient than VKAs as they typically do not require routine monitoring and are less impacted by foods, alcohol or other medications.⁹ When thinking about treatment options that are right for you, it is important that you consider the quality of life factors that have the biggest impact on you and the condition. Be sure to complete the [My Quality of Life Check](#), and take the results to your next doctor's appointment to discuss what therapy is best for you based on your specific lifestyle.

Q. How do I know I am on an anticoagulation therapy that is right for me?

- A. When considering therapy options that are right for you, it is important that you consider the quality of life factors that have the biggest impact on you and the condition. Be sure to complete the [My Quality of Life Check](#), and take the results to your next doctor's appointment to discuss what therapy is best for you based on your specific lifestyle.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

Q. Are there any common side effects associated with anticoagulation therapies?

A. The most common risk of anticoagulation therapy is bleeding.⁷ If you are prescribed an anticoagulant to reduce your stroke risk, ask your doctor about:

- Whether to stop or discontinue anticoagulants when you need surgery;
- How to stop bleeding if you are cut or injured;
- What to do if you have “nuisance” bleeding, such as a nose bleed or more obvious bruising.

Q. How do I know I am properly anticoagulated?

A. Depending on what therapy you are taking for your stroke risk, you may be monitored regularly to ensure you are taking the right dose and have enough medication in your body to prevent your blood from forming clots too soon. For example, if you are taking a VKA, you would have to be monitored regularly.⁴ The ability of VKA to make the blood less likely to clot (measured by the International Normalised Ratio – INR) can be affected by a number of factors such as food and other medicines.

Regular monitoring ensures that the INR is not too low (risk of clots) or too high (risk of bleeding).⁴ Newer therapies like non-VKA oral anticoagulants (NOACs)⁸ show less variability in their effects and do not require regular monitoring.¹² You may not feel differently by taking anticoagulation therapy because it does not affect your AF symptoms but by taking it regularly you are minimising your risk of having a stroke.⁴

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Living with AF

Q. Is it a problem if I am taking treatments for other medical conditions?

- A. Sometimes medications you take for other conditions can interact with anticoagulation therapy, particularly if you are taking a VKA for AF-related stroke prevention.⁴ You should talk to your doctor about what other conditions you have and whether the therapy you're taking is right for you.

What Resources Are Available

Q. What resources are available to me about AF?

- A. This programme provides you with educational information about AF and AF-related stroke. You can also ask your doctor for more information and tools to help you manage your condition.

Q. Where can I go to find further information?

- A. For further information outside of this resource, visit the following pages:
- AF Association's (AFA) "[Living with AF](#)" page to learn about real individual's experiences;
 - AntiCoagulation Europe's (ACE) "[Everything You Need to Know About AF](#)" page;
 - Arrhythmia Alliance's "[Patients](#)" page.





Being Involved in Managing AF

Click below to read about Being Involved in Managing AF.

**WHY IT IS IMPORTANT TO BE INFORMED
ABOUT HOW TO MANAGE AF**

THE AF PATHWAY DIARY

**HOW TO BE PREPARED FOR A DISCUSSION
WITH MY DOCTOR**

**HOW-TO GUIDE FOR TALKING TO MY FAMILY
AND FRIENDS ABOUT MY CONDITION**





Being Involved in Managing AF

Why is it Important to be Informed About How to Manage AF

What is Shared and Informed Decision Making



Shared and informed decision making is a collaboration between a patient and his or her doctor to make health care decisions together.¹ During this process, the patient and the doctor look at the available scientific evidence, as well as the patient's personal values and preferences to come to a decision that is best for the patient.¹

Shared and informed decision making respects both the doctor's expert knowledge and the patient's right to be fully informed of all care options and the potential harms and benefits. This process provides patients with the support they need to be fully involved in their care management, while allowing doctors to feel confident in the care they provide.¹



Why is it Important to Understand AF and AF-Related Stroke Risk and Take an Active Role in Managing it

If you have AF, you should understand the condition because the more you know, the better prepared you are to be able to prevent AF-related stroke. It is important to work with your doctor to understand your stroke risk and to come to a shared decision about what stroke prevention therapy is right for you based on your personal lifestyle and other factors that can affect your quality of life.

Read the [How to be Prepared for a Discussion with My Doctor](#) guide for tips on how to prepare for your next doctor's visit and how to start having shared and informed discussions.



Action for AF

Saving lives, preventing AF-related stroke



Being Involved in Managing AF

The AF Pathway Diary



This diary may be a helpful tool for individuals living with AF who want to take charge of their condition. It can also serve as a useful resource to help you feel confident when speaking with your doctor and assist you in having informed and shared decision making.

This diary consists of an appointment sheet and a lifestyle tracker that you can print and take with you every time you meet with your doctor. The appointment sheet has:

- A contacts list for you to write down your doctor's, nurse's or other healthcare provider's information;
- Space for you to write down key questions to ask your doctor during the appointment;
- A medications list to inform your doctor about what medications you are currently taking;
- A general notes section to write down remarks from your doctor;
- Space for you to write down your next appointment date and time.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Being Involved in Managing AF

My Appointment Sheet

Date: _____

Time: _____

My Key Contacts

You can use this page to write down key contact details of your doctor, nurse or another healthcare provider.

Name	Phone	Address/Location	Notes

Key Questions to Ask Your Doctor

Use this space to write down questions to ask your doctor during the appointment. Sample questions:

1. I have read about different types of therapies for stroke prevention. What medication am I currently taking for my stroke risk?
2. Will the medication I'm taking now interfere with medications I take for other conditions?
3. I have to travel for work a lot. Do you think that will affect my therapy or put me at more risk for having a stroke?

Please scroll down to continue reading on the following page.





Being Involved in Managing AF

My Appointment Sheet (continued)

Notes from My Doctor

Use this space to write down any remarks from your doctor.

My Medications

You can note what medications you are taking and share and discuss this list with your doctor during your appointment.

Medication Name	Dose	When I Need to Take It

Next Appointment:

Date: _____

Time: _____

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Being Involved in Managing AF

My Lifestyle Tracker

When thinking about the impact that AF has on your daily life, it's easy to become overwhelmed about how to manage the condition and prevent AF-related stroke.

Following are some quality of life factors we have identified to help you keep track throughout the AF pathway. Before your next doctor's visit, be sure to review the following list and mark down when one of the factors listed is having a particular impact on your quality of life.

Using the check boxes, mark which factors are most important to you and take them to your doctor to discuss your overall quality of life. You should revisit these factors on a regular basis as the factors that are most important to you may change over time as you continue along the AF pathway.

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



Being Involved in Managing AF

- ☐ **Anxiety:** Experiencing increased anxiety as a result of AF or therapy for AF-related stroke prevention affects your quality of life. If you have a lot of anxiety or emotional distress, you may be distracted and not be taking your anticoagulation therapy properly.
- ☐ **Perceived stroke risk:** Your understanding of how AF increases the risk of stroke can impact your quality of life. If you don't believe your stroke risk is very significant, you may not be taking your anticoagulation therapy properly.
- ☐ **General health concerns:** Having a long-term condition and feeling unhealthy, or having difficulty remembering things and concentrating due to increased worrying can have an impact on your quality of life. If you feel you generally are in poor health, or if you have trouble remembering things, you may not be taking your anticoagulation therapy properly.
- ☐ **Knowledge:** Your knowledge and understanding about your condition and your treatment plan can affect your quality of life. If you don't feel like you have a good understanding of AF or AF-related stroke risk, you may feel you do not need therapy, and therefore may not be taking your anticoagulation therapy properly.
- ☐ **Disease symptoms:** Experiencing symptoms related to AF, such as palpitations, dizziness or chest discomfort, impacts a patient's quality of life. If you are experiencing AF symptoms, you may be focusing on treating those and not focusing on taking your anticoagulation therapy properly.
- ☐ **Side effects of your treatment:** Treatment side effects you may experience, such as bleeding, blurry vision, dizziness, chest pain, bruising and muscle aches, can affect your quality of life. If you are experiencing side effects from your anticoagulation therapy, such as bleeding, you may be concerned about continuing to take it.
- ☐ **Relationships:** The trust that you have in your doctor, as well as maintaining good relationships with your friends, family, and partners can impact your quality of life. If you have a good relationship with your doctor and he/she involves you in treatment decisions, that may impact how you feel about taking anticoagulation therapy.
- ☐ **Other health conditions:** Living with other conditions, such as arthritis, or high blood pressure can impact your quality of life. If you have other existing conditions, you may be focusing on treating those and not focusing on taking your anticoagulation therapy properly.
- ☐ **Therapy complexity:** The complexity of AF treatment and stroke prevention therapy can impact your quality of life. If your anticoagulation therapy is complex, you may not be taking it properly.
- ☐ **Mobility:** A decrease in your ability to participate in physical activity or travel (due to AF) can impact your quality of life. If your anticoagulation therapy requires frequent monitoring and interferes with your travel, you may not be taking it properly.
- ☐ **Age:** The age at which you were diagnosed with AF can impact your quality of life. If you were diagnosed with AF at a younger age, you may not be concerned about your stroke risk and may not be taking your anticoagulation therapy properly.

Date: _____



Action for AF

Saving lives, preventing AF-related stroke



Being Involved in Managing AF

How to be Prepared For a Discussion With My Doctor



Shared and informed decision making is a collaboration between a patient and his or her doctor to make health care decisions together. It is important to make shared and informed decisions with your doctors/carers because as a patient, you should be fully informed of all care options and the potential benefit and harm. This process provides patients with the support they need to make the best individualised care decisions, while allowing doctors to feel confident in the care they provide.

Talking to your doctor about your quality of life is an important part of making informed and shared decisions. Understanding what quality of life factors are important to you will help you and your doctor determine what the best therapy options are to improve your quality of life and prevent AF-related stroke.

You can prepare to have a shared and informed discussion with your doctor by using the following tips:

- Write down any questions you want to ask before your visit;
- Be prepared to take notes – bring a pen and paper along to the appointment;
- Consider asking a partner, friend or family member to come with you to the appointment for support;
- Bring any key documents to share with the doctor (e.g., “My Lifestyle Tracker”).





Being Involved in Managing AF

How-To Guide for Talking to My Family and Friends About My Condition



Just as it is important to discuss your condition and your quality of life with your doctor, it is also important to talk about these topics with your family and friends. Not only can your family and friends provide you with emotional support throughout the AF pathway, they can also help you manage your condition by:

- Helping you think of questions to ask your doctor;
- Helping you identify which quality of life factors might be having an impact on your life;
- Accompanying you to your doctor's visit;
- Reminding you to take your medicine and of important appointments.

When you talk with your family and friends about your condition, they may have some questions about AF or about AF-stroke risk. Here are some common questions that you may get about your condition:

1. What is AF?
2. What does it feel like to have AF?
3. How do you get AF?
4. How do I know if I have AF?
5. Is it easy to treat?
6. Is it difficult to manage AF and AF-related stroke risk? Does it have a big impact on your day-to-day life?

To help you talk to your family and friends and provide them with information about AF and AF-related stroke, they can read the following materials or visit the [AF Carer Resources](#) section:

- [Family and Friends Discussion Guide;](#)
- [What I Need to Know About AF: Fact Sheet;](#)
- [Why it is Important to be Informed About How to Manage AF.](#)



Action for AF

Saving lives, preventing AF-related stroke



AF Carer Resources

Click below to read about AF Carer Resources.

**FAMILY AND FRIENDS
DISCUSSION GUIDE**

**UNDERSTANDING HOW QUALITY OF
LIFE IS RELATED TO AF THERAPY AND
MANAGEMENT**





AF Carer Resources

Family and Friends Discussion Guide



Atrial fibrillation (AF) and AF-related stroke are serious conditions that can impact not only the individual living with it but also their friends and family. Being diagnosed with AF and living with AF-related stroke risk can be scary, however, when treated properly the condition can be well managed without having to make too many changes to your day-to-day life.

If you know someone with AF you might have some questions about the condition and how you can support them. This guide helps you to understand what your friend or family member might be experiencing and how the disease and therapy can have an impact on their quality of life.

Frequently Asked Questions About AF

Q. What does an AF diagnosis mean?

A. Atrial fibrillation, or AF, is the most common sustained cardiac arrhythmia (irregular heartbeat).¹ It is estimated that 8.8 million individuals in the European Union have AF.² AF can be managed, however, it is important that people speak with their doctor about the best therapy option for them and what lifestyle factors could have an impact on how they manage and live with the condition.

Q. Is AF a life threatening condition?

A. AF can be considered a life threatening heart rhythm problem because individuals living with AF have a five-fold increased risk of stroke compared to those with a normal heartbeat.³ AF-related stroke risk can be reduced by taking an anticoagulation therapy.⁴ Learn more about AF-related stroke risk [here](#).

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



AF Carer Resources

Q. What are the causes of AF?

A. The cause of AF is not fully understood. It is age related – the older you become the more likely you are to develop AF. However, AF is more likely to occur in individuals who have other conditions, such as:

- High blood pressure;
- Heart failure;
- Coronary artery disease;
- Mitral heart valve disease (caused by valve disease from birth or acquired later in life);
- Long-standing lung disease;
- Congenital heart disease (abnormality of the heart since birth).

It can also be associated with:

- Thyroid gland disorders;
- Pneumonia;
- Lung cancer;
- Pulmonary embolism;
- Carbon monoxide poisoning;
- Alcohol or drug abuse or misuse.

Sometimes individuals develop AF for no explainable reason. When there is no known cause this is known as “Lone AF” or “idiopathic AF.”⁵

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



AF Carer Resources

Q. What are the typical signs and symptoms of AF?

- A. Some individuals living with AF do not experience any symptoms, and the AF is only discovered at a routine medical examination or after a health problem.⁶ However, for those who do, the most common symptoms are:⁵
- Palpitations (or awareness of the heartbeat), which may be rapid;
 - Tiredness;
 - Shortness of breath;
 - Dizziness;
 - Chest pain.

Q. What are the different therapy options available for AF and AF-related stroke prevention?

- A. There are different treatment options for AF that control your heart rhythm, such as anti-arrhythmic medications (i.e. sodium channel blockers and potassium channel blockers), procedures and devices. AF can also be treated by slowing down the heart rate with beta-blockers or calcium-channel blockers.⁷

There are also therapies that help to prevent AF-related stroke, such as anticoagulants and antiplatelets. The most common therapy for AF-related stroke prevention, until recently, were vitamin K antagonists (VKAs)⁴ but newer medications, known as non-vitamin K oral anticoagulants (NOACs),⁸ have been shown in studies to be generally as or more effective and as safe or safer than VKAs. Furthermore, NOACs are typically more convenient as they do not require routine monitoring and are less impacted by foods, alcohol or other medications.⁹

When thinking about treatment options that are right for you, it is important that you consider the quality of life factors that have the biggest impact on you and the condition. Be sure to complete the [My Quality of Life Check](#), and take the results to your next doctor's appointment to discuss what therapy is best for you based on your specific lifestyle

Please scroll down to continue reading on the following page.



Action for AF

Saving lives, preventing AF-related stroke



AF Carer Resources

Q. Is AF a genetic disease?

A. Yes, there are familial and genetic components to AF. Research has found that children of individuals with AF have approximately twice the risk of developing the heart rhythm disorder.¹⁰

Q. Should I make sure that my family and/or I are tested for AF?

A. The simplest way to detect AF is to check your pulse. If the rhythm of the beat seems irregular this may indicate you have the condition.¹¹ It is important to understand the signs and symptoms of AF and risk factors for the condition and to speak with your doctor about getting yourself or family and friends tested.

Q. How can I help to make sure that my friend or family member is taking their therapy properly?

A. If you have a friend or family member who has been diagnosed with AF, there are many ways you can provide support and help him/her best manage their condition, such as offering to accompany them to their doctor's appointment or giving them a friendly reminder to take their therapy. Understanding how therapies work will also help you to support your friends or family. To learn more about how therapies work [click here](#).

Q. How will AF affect family life?

A. An individual who is diagnosed with AF can live a normal life. For certain therapy options there are side effects and implications that could have an impact on an individual's quality of life. To understand what factors are most important to your friend or family member they can complete the [My Quality of Life Check](#) and take the results to their next doctor's appointment to discuss what therapies are best for their lifestyle.





AF Carer Resources

Understanding How Quality of Life is Related to AF Therapy and Management



Research shows that patients and doctors often do not think about how AF and AF-related stroke prevention therapies affect patients' everyday activities. Therefore, expert opinions and the latest scientific research were consulted to identify specific factors that have an impact on the quality of life of people living with AF. Each person has a different experience with AF; therefore, different quality of life factors may be important to different people.

If you know someone who is living with AF, it is important that you understand what quality of life factors are most significant to them – especially when it comes to managing the condition, and how they may change with time.

Below you will find a list of key quality of life factors you should be aware of. You can help to support your friend or family member by encouraging them to take the [My Quality of Life Check](#) to see which factors are the most important to them at this stage along the AF pathway.

What's more, you can remind them to take the results to their next doctor's appointment to discuss what therapy is best for them based on the impact those factors have on their quality of life.

Please scroll down to continue reading on the following page.



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AF Carer Resources

Key Factors that can Affect Your Friend's or Family Member's Quality of Life When Living with AF

All the below factors can have an impact on an individual's quality of life. Your friend or family member should evaluate how these factors may be affecting their quality of life and talk about them with their doctor at their next appointment.

Anxiety: When someone experiences increased anxiety (constantly worrying about their condition) as a result of AF or therapy for AF-related stroke prevention.

Perceived stroke risk: An individual's understanding of how AF increases the risk of stroke.

General health concerns: When someone has a long-term condition and feels unhealthy or has difficulty remembering things and concentrating due to increased worrying.

Knowledge: An individual's knowledge and understanding about the condition and the therapy plan.

Disease symptoms: When someone experiences symptoms related to AF, such as palpitations, dizziness or chest discomfort.

Side effects of your treatment:

Experiencing treatment side effects, such as bleeding, blurry vision, dizziness, chest pain, bruising and muscle aches.

Relationships: The trust a person has in his/her doctor, as well as maintaining good relationships with friends, family, and partners.

Other health conditions: When a person is living with other conditions, as well as AF, such as arthritis, or high blood pressure.

Therapy complexity: The complexity of AF treatment and stroke prevention therapy.

Mobility: A decrease in an individual's ability to participate in physical activity or travel due to AF.

Age: The age at which a person is diagnosed with AF.

To read more about quality of life factors, visit the [How AF and AF-Related Stroke Prevention Therapy May Impact My Quality of Life](#) section.

To learn more about AF, visit the [Additional Resources](#) section of the resource.



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Additional Resources

Click below to see Additional Resources.

FOR MORE INFORMATION, PLEASE VISIT THE
FOLLOWING PATIENT RESOURCE WEBSITES:

- [AF ASSOCIATION \(AFA\)](#)
- [ANTICOAGULATION EUROPE \(ACE\)](#)
- [ARRHYTHMIA ALLIANCE](#)
- [AFIB MATTERS](#)





Disclaimer

This programme is a service to medicine provided by the Bristol-Myers Squibb/Pfizer Alliance. It has been financed by the Alliance and developed in partnership with an independent Advisory Board, including experts from the Atrial Fibrillation Association (AFA), AntiCoagulation Europe (ACE) and Arrhythmia Alliance.

The information contained in this toolkit is general in nature and intended to provide a general overview of atrial fibrillation (AF) management for uses of the general public. It is not intended to replace in any way the opinion of a healthcare professional. For specific information about this pathology and/or detection, diagnosis, prognosis, administration and, where applicable, appropriate treatment for each specific case, please promptly consult a healthcare professional.



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Action for AF

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Action for AF

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