

Detecting and living with an arrhythmia – the patients perspectives



Arrhythmia Alliance

www.aa-international.org

Arrhythmia Alliance

Arrhythmia Alliance (A-A) was launched in 2004 to raise awareness and highlight the deficiencies in the treatment and care of arrhythmia sufferers.

Supporting 100,000's members across the world, A-A works closely with medical professionals, policy makers, government, patients, carers, patient support groups and allied groups to:

- Provide support and information
- Advance the education of the medical profession
- Raise awareness amongst the general public
- Advocate for improved access to healthcare

Mission Statement

- “Every person affected by an arrhythmia will receive *information, support and rapid access* to appropriate treatment.”
Achieved through:

Awareness

Diagnosis & treatment

Improved
quality of life of those affected

Heart Rhythm Week



Arrhythmia Alliance organises an annual awareness week campaign which provides everyone with the opportunity to raise awareness and promote better understanding of heart rhythm disorders

- Know Your Pulse campaign was the cornerstone of Heart Rhythm Week
- Now Is The Time – Manifesto and report launched June 2015
- AF Awareness Week – last week of November



Know Your Pulse campaign



Overview: A broad campaign to encourage people to check their pulse and to promote the inclusion of routine manual pulse checks in clinical practice.

What has been achieved?

- Improved awareness and understanding amongst the general public of the importance of taking one's pulse as a first step to detecting AF
- Campaign endorsed by the Department of Health in the UK and by leading cardiology societies in other countries
- A powerful political campaign focused on AF, with public events hosted in national parliaments, schools, and other public areas in participating countries

Know Your Pulse

IT COULD SAVE YOUR LIFE

www.knowyourpulse.org

The poster features a photograph of a hand checking a pulse on a forearm against a solid red background. The text is white and centered.

International campaign

The Know Your Pulse campaign has been adopted across the world

- India
- USA
- South Africa
- Uruguay
- Argentina
- Colombia
- Mexico
- Denmark
- Saudi Arabia
- Sweden
- New Zealand
- China
- Australia & many more



Now is the Time campaign

Overview: A campaign to raise awareness of how to 'Detect, Protect and Correct' Heart Rhythm Disorders, presented at four parliament locations around the UK and Northern Ireland. Release of our Parliamentary manifesto, detailing the 'Chain of Survival' plus our seven task asks.

Our aim is to ensure that by 2020, 50% of sudden cardiac arrest victims in the UK, with a shockable heart rhythm, will return home alive and neurologically intact.



Now is the Time
1-7 June 2015
www.hearhythmweek.org



Heart Rhythm Congress



The annual Heart Rhythm Congress brings together all those with an interest in arrhythmias. The congress boasts a full programme of scientific sessions along with training courses, patient group conferences, live cases, industry sessions, a Patients Day and DoH and PCT meetings, with a trade exhibition running throughout.

Heart Rhythm Congress, 4-7 October 2015



AF Aware Week, 23-29 November

The aims of AF Aware Week are simple: **AF - Detect, Protect, Correct**

- AF Patient Voices video project
- Screening for AF in pharmacies and selected supermarkets
- In hospital screening events
- Petition launched to introduce routine screening for AF in over 65's and save lives from avoidable AF-related strokes



Awareness Raising – The Work of AF Association

Trudie C A Lobban MBE

Founder & CEO

trudie@afa.org.uk

www.afa.org.uk

NWAHSN June 2015

AF Association

- Founded in 2007 in response to enquiries; 50% of helpline calls AF related
- Provides information and support to those affected by AF
- All resources are medically approved, patient reviewed and endorsed



Today, alone

- 150,000 strokes per year in the UK¹
- 410 per day
- 17 per hour
- Within the next two hours:
 - 30 patients with AF will have suffered a AF-related stroke
 - 24 would have been known to be high risk of AF-related stroke
 - 18 should have been on an anticoagulant
 - 9 will go home
 - 15 will end up in residential care
 - 6 will die....

1 Townsend, N., et al. Coronary heart disease statistics. 2012

Wider impact on lives of those around the patient

“Just two years before his 60th birthday, we were watching TV and I had my head on his chest. I said ‘God, your heart is all over the place’, and laughed. Three weeks later my husband suffered a stroke caused by an undiagnosed arrhythmia, Atrial Fibrillation.”

Jenny H

Family are forced to adjust to massive changes

- Communication
 - Mobility
 - Personal care

A financial, emotional and physical burden

Lack of information and awareness

Survey of 119 patients with documented chronic AF

- Unaware of AF as primary diagnosis: 37%
- Unaware that AF causes clots: 37%
- Unaware of AF & HF: 47%
- Unaware that AF leads to stroke: 47%
- Unaware of reason for warfarin: 48%

**2011 AF Association survey of symptomatic AF patients
found: Average time to diagnosis 28 months**

AF Experiences

“I found out I had AF after extensive tests post stroke.”

(Chris, AF patient, 29, 2013)

“There are worst things in life than death” (Eileen, AF patient, 2013)

“One GP admitted me to hospital and the other dismissed me with aspirin. I foolishly believed the second GP’s opinion and tried to return to my normal life, but after time, once again, the dizzy spells returned.

I decided to go through my private medical scheme at work and was referred to a senior cardiologist. He confirmed AF and put me on an oral anticoagulant and amiodarone.” (Jason, 41, AF patient 2013)



What do AF patients face?

- Challenge to diagnosis
- Lack of awareness
- For some, debilitating symptoms
- Complicated, ineffective and unequal access to therapies
- For some, stroke risk
- Psychological impact



A common message

"The arrhythmia is now with me 24 hrs per day, and while I am not unduly 'ill', it is ruining my life"

A - Alone

F - Frustrated

- What is needed?
- Timely & accurate diagnosis
- Reliable & helpful information
- Easy access to appropriate treatment

Yet, despite greater devastation of AF-related stroke, wider choice in therapy and emphasis on appropriate management from a policy perspective - **diagnosis and management of AF patients still remains poor**

Typical AF patient journey

Fear and confusion

Pre diagnosis, long and anxious search for explanation of symptoms



Relief and hope

Diagnosis, validation, control and hope



Despondency

Uninformed and unsupported, dismissal of symptoms, no grasp of what future might hold



Turmoil

Emotional distress, fear of stroke, loss of hope, unpredictable and invasive symptoms

McCabe PJ et al. J Cardiovasc Nurs 2011; Epub ahead of print

What makes a difference?



- Timely and accurate diagnosis
- Reliable and helpful information
- Support and understanding to manage worry, fear, debilitating symptoms
- Easy access to appropriate therapy
- **Detect, Protect, Correct!**

Factors affecting patient experience

Accurate and
comprehensive
information

Advice about all options
available

Access to treatments not
denied by local directive

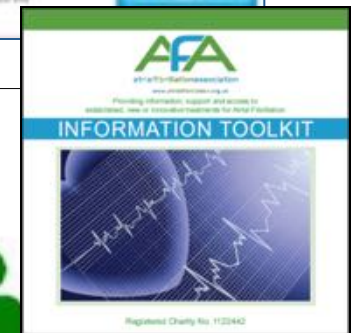
More streamlined care

More choice

Services that fit around
the patient and not the
patient fitting around
the service

Online Support – www.atrialfibrillation.org.uk

- Accredited online training
- Patient booklets and sheets
- Medical professionals area
- International specialists database
- Online message forum



The Heart of AF

- **AF Association's site**
The Heart of AF, is a central resource primarily for healthcare professionals to access the latest research, source information, share pathways/protocols and to be kept updated on established, new or innovative treatments and guidelines for atrial fibrillation (AF).
- www.heartofaf.org

THE
HEART
OF **AF**

The screenshot shows the homepage of the AF Association's website, 'The Heart of AF'. The header includes the AFA logo, the site title 'THE HEART OF AF', a search bar, and a 'Members Area Login' link. The main navigation menu lists: HOME, GUIDELINES, WHAT IS AF?, DIAGNOSTICS & TREATMENTS, SERVICE DEVELOPMENT, PROFESSIONAL DEVELOPMENT, LIBRARY, and EVENTS. The main banner features the site title and the tagline 'PROMOTING EXCELLENCE IN AF CARE' with a call to action 'LOG ON, SIGN UP, JOIN IN' and social media icons for Twitter, Facebook, Google+, YouTube, and RSS.

Welcome to The Heart of AF

AF Association's site - The Heart of AF, is a central resource primarily for healthcare professionals to access the latest research, source information, share pathways/protocols and to be kept updated on established, new or innovative treatments and guidelines for atrial fibrillation (AF).

UPDATE: On Wednesday 18 June 2014, the National Institute for Health and Care Excellence (NICE) issued an update to the clinical guideline on the management of AF, the first in eight years. Please click below to learn more about changes outlined in the guideline.

Visit NICE website to download guideline in full | Download NICE Patient Decision Making Aid | Download NICE Implementation Collaborative (NIC) Consensus Statement | Visit AF Association's Care AF website

Latest News

- 14.04.2015** Benefits of a new class of oral anticoagulant [Read more >](#)
- 07.03.2015** National Audit of Cardiac Ablation 2013-14 [Read more >](#)
- 04.02.2015** FDA Approves New Oral Anticoagulant From Daiichi Sankyo [Read more >](#)

AF Treatment Guidelines

Professor A John Camm, an AFA Trustee, outlines the latest guidelines for the treatment of AF. [Find out more >](#)

AF in Primary Care

Dr Matthew Fay discusses the challenges atrial fibrillation presents in a primary care setting. [Find out more >](#)

Nurse-led AF Clinics

Find out more about the role of a nurse-led AF clinic and how it fits into the care of an AF patient. [Find out more >](#)

View Recent Videos

- The aspirin conspiracy in AF
- AF and Anticoagulation

External Links

- AF Rehabilitation Tool
- AF Stroke Risk Calculator
- Atrial Fibrillation Association
- British Heart Rhythm Society
- Heart Rhythm Specialists
- Left Atrial Appendage Occlusion

AF stroke risk calculator



AF STROKE RISK CALCULATOR



If you have AF, click here to calculate your personal risk of suffering a stroke



What has been achieved?



- User friendly, simple tool which appeals to patients as well as physicians
- Improved understanding by AF patients of their risk of stroke
- Helps ensure each patient receives a thorough assessment of their stroke risk in accordance with clinical guidelines
- Starting point for discussion between patient and all treating physicians about AF and risks of stroke with AF, helping improve continuity of care throughout the care pathway
- Positive feedback received to date from physicians and AF patients



The All-Party Parliamentary Group on AF (APGAF)



Healthcare Pioneers Booklet

The 2015 Healthcare Pioneers report was developed by the AF Association and endorsed by the All-Party Parliamentary Group on Atrial Fibrillation (APGAF). This report identifies best practice in the diagnosis, treatment and care of patients with atrial fibrillation (AF).



The AF Report

- Anticoagulation Europe (ACE), the Atrial Fibrillation Association (AFA), and all those who endorse the recommendations in this report, call for an urgent focus on AF within the National Health Service (NHS), and call specifically for six actions that will improve and extend the lives of UK AF patients. If implemented, these actions will prevent thousands of fatal and debilitating cases of stroke; saving hundreds of thousands from stretched healthcare budgets

www.preventaf-strokecrisis.org



A report for patients and those who care for them

A report for healthcare professionals

A report for policy makers and purchasers

www.preventaf-strokecrisis.org



Patient education

To ask questions, seek opinions, know the choices available, feel reassured to return and ask again

- Telephone helpline
- Information resources to empower patients
- Website & social media
- Patient group meetings
- CPR & AED training / placements
- Signposting to arrhythmia specialists
- Articles, newsletters

Know Your Pulse in four steps

- 1** To check your resting pulse rate in your wrist, sit down for 3 minutes beforehand. Remember that any stimulus taken before the reading will affect the rate (such as coffee or nicotine). You will need a watch or clock with a second hand.
- 2** Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.
- 3** With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the string tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.
- 4** Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

Record your pulse here

Day	Heart rate	Activity (top after line)
1		
2		
3		
4		
5		
6		
7		

Appropriate management has a positive impact for everyone

- Nobody chooses to become a patient
- Information empowers the patient to access appropriate help
- To feel in control of making informed choices
- Protects those who care for them
- Management of arrhythmias restores the patient to a person, giving back to society



Signposting patients to achieve better health outcomes

- Heart Rhythm Specialists website
 - Rapid Access Clinics, healthcare professionals and centres of heart rhythm expertise located on global map
 - Open to patients and healthcare professionals

www.heartrhythm-specialists.org



What can we achieve together?

Improved quality of life



Patient education



Awareness



Advocacy



Understanding amongst the medical profession of patients needs

Restoring a patient to a person

“I understand that AF increases my risk of stroke. My clinician has involved me in the decisions around treating and managing my condition and supports me to access the best quality care to suit my lifestyle. I feel empowered to take control of managing my condition with the support of my healthcare professional. I have sufficient information and support to help me ask the right questions and manage my condition effectively. I know I’m not alone as I can network with other patients. I feel optimistic and hopeful for the future”.

(Elizabeth, AF patient, 2013)

In conclusion

✓ **Detect**

✓ **Protect**

✓ **Correct**



Arrhythmia Alliance™

The Heart Rhythm Charity

www.heartrhythmcharity.org.uk

trudie@heartrhythmalliance.org

www.aa-international.org

www.afa-international.org

