



The Patient Voice in a modern NHS

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Founder & CEO

AF Association Patients Day
9 October 2016

The patient voice in a modern NHS

“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



1948: The NHS is there for us from the moment we are born. It takes care of us and our family members **when we need it most**

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

Patient engagement

21st century Vision is partnership



Between professionals
(who can be scary)



and patients (who can feel
unsure, scared... and unwell)

2012: The NHS Constitution
“No decision about me, without me”

How you can get involved

Share your story

Patient stories are an important way of providing great reassurance, support and advice to others who have the same condition. This where we really need your help.

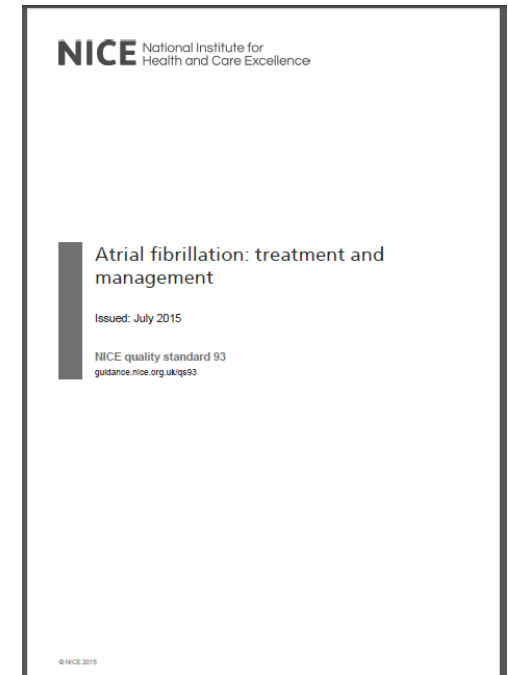
Would you be willing to share your story?



The National Institute for Health and Care Excellence (NICE)

NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

- Join a committee
- Attend a meeting
- Take part in focus groups
- Join the public involvement programme



Delivery of care

Discuss your treatment options

Discussing your treatment options will help you to understand why one option may be beneficial over another.

If at any time you have questions or concerns, do not hesitate to contact your doctor.



Become a volunteer

There are a wide range of opportunities for volunteers across AF Association. Whatever your motivation you will find that volunteering for AF Association is both challenging and rewarding.



The All-Party Parliamentary Group on Atrial Fibrillation (APGAF)

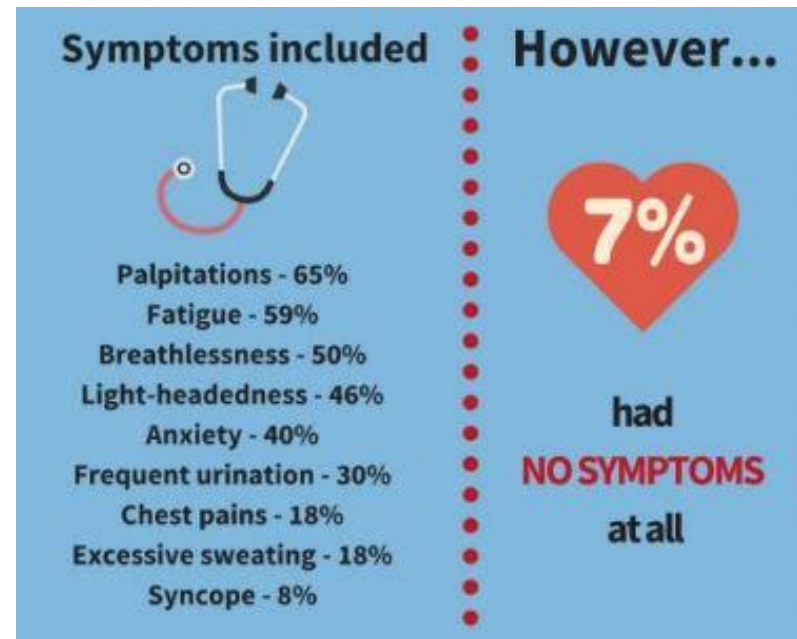
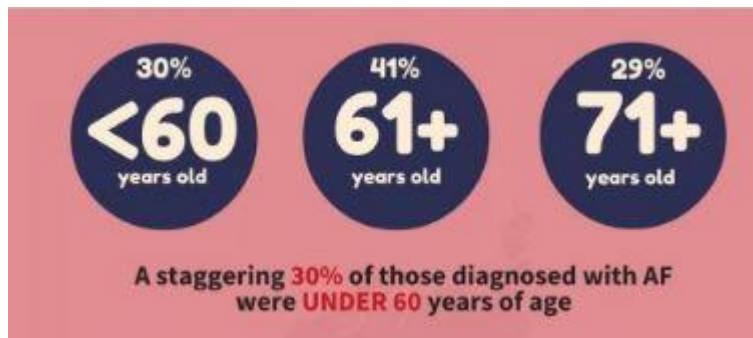


The All-Party Parliamentary Group on Atrial Fibrillation (APGAF) champions awareness of Atrial Fibrillation (AF) from within the heart of Westminster.

Next meeting – 16th November 2016

Screening for AF

We surveyed nearly 4000 patients regarding routine screening for AF.



Screening for AF

Those with persistent AF felt that screening would have identified AF sooner



The majority of patients were in favour of AF screening with handheld ECGs

Patients also believed that healthcare professionals needed to be better educated about AF symptoms



Patient Quotes

"Detected on visit to doctor as I was short of breath and suspected a chest infection. Screening would have caught it sooner."

"I had been told by several medical professionals in the past few years that I had an irregular pulse but no one ever acted like it was anything to be concerned with."

"Although I told my GP two years prior that I thought my palpitations, lightheadedness, chest pains and vertigo were heart related, I was fobbed off with 'you have a vitamin deficiency'."

"We need education for the public and doctors. Atrial fibrillation should not be dismissed."

"AF screening should be added to the annual medical check up for all patients."

"A screening program detected my atrial fibrillation."

Write to your MP & CCG

AF Association is calling for an early review of the UK National Screening Committee's (NSC) policy on screening for atrial fibrillation (AF) in the over 65s.

For a template letter to send to your MP and CCG please email vicki@afa.org.uk



AF Aware Week

21-27 November 2016

Detect

AF by a simple pulse check

Protect

against AF-related stroke
using anticoagulation therapy
(not aspirin)

Correct

AF by access to appropriate
treatment options



Display and share information about AF and Know Your Pulse in your local centres, which provide support and information.

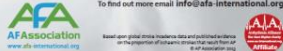
Every 15 seconds
someone suffers an
AF-related stroke

Detect AF by a simple pulse check
Protect from AF-stroke using anticoagulation (not aspirin)
Correct AF by speaking to your doctor to discuss treatment and medication options

To find out more email info@afa-international.org

AFA
AF Association
www.afa-international.org

Based upon global stroke incidence data and published evidence on the proportion of strokes caused by AF from the AF Association survey



Know Your Pulse

IT COULD SAVE YOUR LIFE

www.knowyourpulse.org




Know Your Pulse in four steps

- 1 To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants 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 strings tension directed 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	Time	Rate	Activity
1			
2			
3			
4			
5			
6			
7			



These materials can be collected today from the AF Association stand near reception.

www.heartrhythmalliance.org

STARS

Syncope Trust And Reflex anoxic Seizures®

Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures.



@BlackoutsTrust



blackoutstrust

Arrhythmia Alliance™

Working together to improve the diagnosis, treatment and quality of life for all those affected by arrhythmias.



@KnowYourPulse



Arrhythmia Alliance

AFA

AF Association®

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



@AtrialFibUK



Atrial Fibrillation Association





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Hear
Rhythm
Congress



Save The Date

01 – 04 October 2017
The ICC, Birmingham UK

Providing education and training to promote diversity and improved technology for all involved in the treatment of arrhythmia patients.

www.heartrhythmcongress.org

info@heartrhythmcongress.org