The Patient Voice in a modern NHS

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Founder & CEO

AF Association Patients Day
9 October 2016
"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

www.afa.org.uk
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 is 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

www.afa.org.uk
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.

A staggering 30% of those diagnosed with AF were UNDER 60 years of age.

30% <60 years old
41% 61+ years old
29% 71+ years old

43% received screening following symptoms
13% experienced a TIA or stroke

Symptoms included
- Palpitations - 65%
- Fatigue - 59%
- Breathlessness - 50%
- Light-headedness - 46%
- Anxiety - 40%
- Frequent urination - 30%
- Chest pains - 18%
- Excessive sweating - 18%
- Syncope - 8%

However...

7% had NO SYMPTOMS at all
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."
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

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

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