

www.heartrhythmalliance.org

# Personalised arrhythmia management – from a patient's perspective

### Mrs Trudie Lobban MBE

Founder & Trustee

Improving Arrhythmia Management (2) 11 October 2016



## What can we achieve together?

- Awareness
- Patient education
- Advocacy
- Greater understanding amongst the medical profession of patients needs
- Stronger fund raising for research, education projects



# What do arrhythmia patients face?

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

"I rested my head on my partner's chest, and laughed – his heart was all over the place! Three weeks later he collapsed and I later learned he had suffered a stroke due to AF.

If only I had known what that irregular heart rhythm could be, I could have saved him. He was 58 years old, and we were planning for our future."



## **Patient Experience Factors**

Accurate and comprehensive information

Access to treatment

Streamlined care

More choice

One size does not fit all Patients at the heart of healthcare



## What Makes a Difference

- Timely and accurate diagnosis
- Easy access to appropriate therapy
- Reliable and helpful information
- Personal support and reassurance





# 21st Vision is Partnership

- Patients
- Physicians
- Politicians
- Commissioners
- General Public





# Consequences When This Does Not Happen



"I was rushed to A&E where they diagnosed me with atrial fibrillation. I was sent home with aspirin. Two weeks later I had a stroke." — Fiona

"In my 30s when I had my first palpitations, I went to my GP who assured me that 'it happens to everyone' and not to worry about it. I was finally diagnosed with AF at 59." – Christine





## **Good Practice**

# **Examples from the EU Healthcare Pioneers Report**



Correct: principles of best practice Improving the AF patient journey to optimise AF correction and improve symptoms and quality of life

Richard Schilling, Professor of Cardiology, Commercial and Strategy Director Barts Heart Centre, UK

TRUSTEE ARRHYTHIMIA ALLIANCE AND ATRIAL FIBRILLATION ASSOCIATION

Once the primary aims of managing AF have been achieved - detection of the problem, protection from

#### **Key Points**

 Once the primary aims of managing AF have been achieved - detection of the problem, protection from the major consequences of AF - then the management of AF should be largely focused on improving symptoms and quality of life.

Correct: case study Primary Care Atrial Fibrillation (PCAF) Service

#### Dr Dhiraj Gupta, Consultant Cardiologist/ Electrophysiologist,

THE LIVERPOOL HEART AND CHEST HOSPITAL, UK

The Primary Care Atrial Fibrillation (PCAF) service was first launched in Merseyside in June 2012 by Inspira Health Solutions in collaboration with clinicians at Liverpool Heart and Chest Hospital. It is an innovative consultant-led pathway that provides expert hospital-based resources within GP practices with the aim of improving the provision of anticoagulation treatments among high-risk AF patients. The service was developed in response to the fact that AF-related stroke-risk can be significantly reduced through appropriate treatment but, as NICE have estimated, 46% of patients that should be anti-coagulated are not. The service is available nationwide and as of November 2015, has been delivered in 364 GP practices within 84 CCGs across England, and in two Local Health Boards in Wales and in two Health Boards in Scotland.

#### The service comprises four phases:

In phase one, a comprehensive case note review is

#### **Key Points**

- Consultant-led pathway providing expert resources within GP practices with the aim of improving the provision of anticoagulation treatments among high-risk AF patients.
- · The PCAF service is available across the UK.
- The service has demonstrated a 96% uptake to anticoagulation within previously untreated high risk patients.
- In a sub-set of 1063 previously untreated patients, it is estimated that PCAF prevented around 30-35 strokes per year.
- As of Nov 2015, the service has been delivered in 364 GP practices across 84 Clinical Commissioning Groups in England.
- Educational legacy left within the GP practice following completion of the PCAF pathway.



## **Good Practice**

## **International Examples**

Protect and correct: principles of best practice Organisational change to improve multidisciplinary coordi and optimise therapy options for patients with AF

Lluis Mont, Assistant Professor and Head of Arrhythmia Unit, Hospital Clinic

UNIVERSITY OF BARCELONA, SPAIN

A number of healthcare disciplines are involved in the management of AF patients and to maximise stroke prevention and symptom control it is important that all those involved are working towards the same goals and are following treatment guidelines. However, the various disciplines often work independently with little interaction and have varying levels of experience and knowledge about AF management. Structured guideline based management of AF is rarely implemented with consistency across the disciplines.

Limited resources can make it challenging to improve multidisciplinary coordination. When resources are limited it may be possible to still address disconnect between the various disciplines involved in AF management. Existing systems can still be used but with new organisational steps put in place to enhance interaction and education and share expertise across different healthcare disciplines. It may be that this is a gradual process that involves more and more disciplines / departments over time.

#### **Key Points**

- Atrial fibrillation is a highly disease managed by a nur disciplines.
- The healthcare profession: patients have varying leve knowledge and structured management of AF is rarel across all the disciplines.
- There are a number of difpathways and multidiscipl is limited with each discipindependently.
- Coordination of all the her can improve knowledge as guideline implementation enable the best possible to to patients with AF. This w AF-related stroke preventicontrol being achieved an population.
- · Multidisciplinary coordin-

Protect and correct principles of best practice AF outpatient clinic to improve patient access to protection against AF-related stroke and AF symptom control

Axel Brandes, Associate Professor, Consultant Cardiologist & Electrophysiologist, ODENSE UNIVERSITY HOSPITAL, DENMARK

Many AF-related strokes can be prevented and AF symptoms can be reduced/managed through effective oral anticoagulation therapy and symptom treatment. Yet a vast number of patients across Europe that are diagnosed with AF do not receive the oral anticoagulation therapy and symptom treatment they require and are left both symptomatic and at an increased risk of AF-related stroke. There are a combination of reasons for this poor management, some of which are addressed here.

Findings from across Europe indicate that evaluation and treatment of AF and AF-related stroke risk is variable and inconsistent. Many healthcare professionals involved in the treatment pathway have limited knowledge and experience in managing AF and stroke risk management and collaboration between disciplines often requires improved coordination. Adherence to guidelines and therefore use of recommended therapy and treatment has also been shown to be insufficient across Europe.

#### **Key Points**

- A vast number of AF patients do not receive the oral anticoagulation therapy and symptom treatment they require and are left both symptomatic and at an increased risk of AF-related stroke.
- AF patient access to evaluation, symptom treatment and protection against risk of AFrelated stroke is variable and inconsistent.
- Patients with AF are seen by members
  of the healthcare team with varying
  levels of experience and knowledge and
  multidisciplinary collaboration is often limited.
- Structured guideline based management of AF is often not implemented resulting in available therapy options not being offered to patients with AF.
- Patient involvement in the management of their disease and associated stroke risk needs to be maximised.
- . An AF outpatient clinic provides a channel for:



# Healthcare Pioneers Showcasing Best Practice in AF April 2015

This report serves as an update to the 2011 edition of Healthcare Pioneers.

You can collect your copies from the exhibition area.









# 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 – 16<sup>th</sup> November 2016



## **AF Aware Week 21-27 November**

**Detect** AF by a simple pulse check

**Protect** against AF-related stroke

using anticoagulation therapy

(not aspirin)

**Correct** AF by access to appropriate

treatment

Perfect the patient care pathway



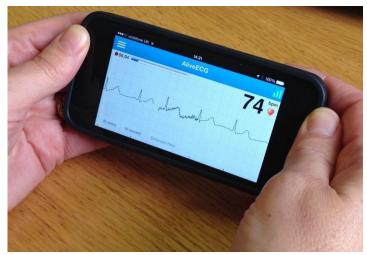


## **Call For Action**

Arrhythmia Alliance and AF Association are 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 <a href="mailto:vicki@afa.org.uk">vicki@afa.org.uk</a>







# www.heartrhythmalliance.org











www.heartrhythmalliance.org

### Trudie Lobban MBE

Founder & Trustee

trudie@heartrhythmalliance.org

07778 233999





### 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