

ACT on AF Friday – Friday 26 November 2010

AF Patient Charter – By patients, for patients

The Atrial Fibrillation Association (AFA) is the UK's leading charity which focuses on raising awareness of Atrial Fibrillation (AF) by providing information and support materials for patients and medical professionals involved in detecting, diagnosing and managing AF.

AF is an abnormal rhythm of the heart involving the upper chambers of the heart – the atria. It is the most common sustained electrical disturbance of the heart, occurring in about 1-2% of the total population. The prevalence of this condition increases with age and over the age of 80, about 15-17% of the population is affected. Although there is a higher incidence of AF in men, women are at more risk of forming clots in the heart, and these clots can result in a stroke. AF is associated with five-fold increased risk of thrombo-embolic strokes, and these are often severe leading to long term disability or death. The annual cost of AF to the total NHS budget is a staggering £1.8 billion.

Unfortunately, awareness and understanding of heart rhythm disorders amongst many health professionals is low, so the patient is not currently receiving an appropriate and joined up journey of care across levels of service provision. This results in poor detection rates and sub optimal treatment for AF patients. AF is not currently prioritised despite its rising prevalence and significant contribution to stroke risk amongst patients. Furthermore, it is estimated that by 2050, 2% of the population will have AF. This is why we are working to ensure improved prevention, diagnosis and management of the condition.

It is our belief that patients should have a greater say in their care and we are therefore calling on the Government to prioritise AF, and for the NHS to ensure that there is better diagnosis and treatment options available to patients with AF. This will also ensure that patients are offered the restoration of quality of life and the ability to participate in society again; whether that is caring for one's family, earning a living or contributing in another way.

The Government has embarked on an ambitious programme of reform for the NHS, and is committed to shared patient decision making – 'no decision about me without me'. The AFA believes that patients are best placed to inform the care they should receive, and their patient journey. AFA held a patient workshop to agree a series of practical and pragmatic recommendations that support 'no decision about me without me', and to agree minimum standards of care that patients must receive. This Atrial Fibrillation Patient Charter sets out 10 recommendations to be adopted and implemented in the course of the NHS reform programme.

We would urge service providers - PCTs and GP Commissioners to consider the 10 recommendations, and we stand ready to work in partnership with all health service providers to deliver these goals.



Trudie Lobban MBE
Founder & CEO

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1. Atrial Fibrillation is the most common heart rhythm disorder, with more than 840,000 diagnosed cases across the UK, and with possibly as many more undetected. Yet, patient friendly information about Atrial Fibrillation (AF) is limited.
 - We call on service providers to ensure patients are provided with, and sign posted to, multi-media, medically approved sources of reliable information and support ideally endorsed by the Department of Healthⁱ. We support the early development of a Patient Decision Aid on Atrial Fibrillation by NHS Direct.
2. Early diagnosis of AF should actively be encouraged. Identifying and treating AF at an early stage will deliver significant cost benefits.
 - A local AF strategy, in line with best practice models and toolkits from the NHS Heart and Stroke Improvement Programmes, and adapted following involvement by local patient representatives, should be developed by PCTs and GP Commissioning consortia, and adhered to.
 - Patients want their condition to be fully understood and appropriately administered at all stages of the care pathway. We therefore call on health service providers to ensure better joined up working between primary and secondary care to ensure that patients receive appropriate treatment throughout the care pathway.
3. AF led to an estimated 851,095 GP visits, 575,000 hospital admissions and 5.7 million bed days in 2008, and the cost to the NHS is in excess of £1.8 billion. Early detection, diagnosis and appropriate medical management does lead to fewer appointment and admissions, saving the NHS money and individuals long term ill-health.
 - We call for service providers to deliver a public information campaign to raise the general public's awareness of AF and pulse checks through the ACT initiative:
 - Ask** could AF affect you?
 - Check** your pulse.
 - Talk** to a medical professional.
4. Pulse checks are quick, simple and extremely low-cost. The importance of pulse checks should be widely publicised and undertaken both inside and outside of medical practices.
 - Service providers must ensure they make Pulse Checks compulsory within the local delivery of NHS Health Checksⁱⁱ.
 - Existing Health Promotion campaigns in schools and community groups must educate people how to measure their pulse.
 - Opportunistic screening programmes (such as pulse checks in flu clinics) have been shown to deliver immediate cost savings by preventing strokeⁱⁱⁱ.
5. AF is the single most relevant risk factor for Stroke, increasing an individuals' risk by five-fold and being responsible for at least 20% of all ischaemic Strokes. Furthermore AF related Strokes have the worst prognosis for severe disabling and mortality rates.
 - Three quarters of AF related Strokes could be prevented, thus ensuring considerable savings are made by PCTs. We call upon service providers to ensure patients have access to high quality information regarding AF-Stroke risk and anti-coagulation options, and that patients are routinely assessed by informed practitioners^{iv}.

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6. Incidence of AF is set to rise 2.5 fold by 2050, and needs far more management in primary care, which we anticipate could be a positive outcome from GP commissioning.
 - We call on service providers to deliver AF rapid access clinics, led by community-based AF specialist nurses. These clinics would link with local GP centres to ensure that patients are diagnosed and treated closer to home in a timely and cost effective manner.
7. Improved awareness and use of new and innovative technologies would help to identify and diagnose AF at the earliest opportunity.
 - Local services should engage to ensure emergency electrocardiograms (ECGs) are made available in community health settings. Copies of ECG readings should routinely be given to patients to ensure that they have full benefit of joined up informed care at all stages of their treatment pathway.
 - The development of new anti-arrhythmic medicines that regulate the heart beat, are the first new treatments for AF licensed in over 20 years. These novel treatments have far fewer side effects, lead to a reduction in hospitalisation and incidence of stroke, and improve long term cardiac health in AF patients. Service providers must ensure that clinicians are able to prescribe these treatments to appropriate patients.
8. It is imperative that examples of NHS and clinical best practice for the early identification and treatment of AF are widely shared, along with up-to-date clinical information.
 - Examples of best practice from the NHS Heart and Stroke Improvement programme should be disseminated across the NHS, and adapted and implemented by service providers in line with local priorities.
9. The Government must make AF a national NHS priority.
 - Atrial Fibrillation must be recognised as a priority in the NHS Outcomes Framework; incentives provided in the Quality and Outcomes Framework (QOF); and minimum standards for the commissioning of AF patient care, through a NICE Quality Standard for AF.
10. Awareness and understanding of heart rhythm disorders amongst many health professionals is low, which too often leads to disorders going undetected.
 - We call for service providers to ensure continued medical professional education about the diagnosis, communication and aftercare of patients with AF, as part of medical professionals' CPD. This should be part of all GPs in-service training and the Royal College of GPs should advance it.

ⁱ http://www.eoe.nhs.uk/downloadFile.php?doc_url=1278861979_xVgv_high_impact_change_1_detecting_atrial_fibrillation.pdf

ⁱⁱ www.knowyourpulse.org

ⁱⁱⁱ The support and resources offered by Atrial Fibrillation Association (www.atrialfibrillation.org.uk) would be ideal in supporting PCTs to achieve this.

^{iv} GPs should be engaged to use the CHADS₂ / CHA₂DS₂VASc and GRASP-AF risk assessment tools already endorsed by the Department of Health and NHSI Heart and Stroke