AF Association response to
The Health and Social Care Committee's follow-up inquiry on
Stroke Risk Reduction in Wales

20 September 2013

National Assembly for Wales

Health and Social Care Committee

Stroke risk reduction – follow-up inquiry

Evidence from AF Association – SFU 12

AF Association Response to the Health and Social Care Committee's Follow-Up Inquiry into Stroke Risk Reduction: 20th September 2013

Following our response and involvement in 2011, we are pleased to respond to the Committee following their recommendations of December 2011.

The AF Association is a UK registered charity which works with patients, carers, healthcare professionals, service providers and all other stakeholders, to:

- Increase awareness of atrial fibrillation (AF)
- Increase access to reliable and robust educational resources about AF and provide on-line, telephone, email and focused meetings to support all those affected by or managing this heart rhythm disorder
- Support timely access to appropriate treatment
- Ensure the patient experience and outcome is central to all heath services

My role within the AF Association is Deputy CEO.

The AF Association welcomed the 2011 Inquiry into Stroke Risk Reduction and its recommendations and is supportive of the Committee's continued focus on stroke risk reduction in Wales. The AF Association believes that recognising where there have been improvements, highlighting effective actions and identifying what further steps are needed to extend this work, are all essential in protecting the Welsh population from avoidable disability, suffering and premature death.

Jo Jerrome
Deputy CEO AF Association
www.afa.org.uk
01789 451 837

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As the 2011 Inquiry highlighted, atrial fibrillation (AF) is a major risk factor for stroke. Atrial fibrillation affects over 50,138[1] across Wales[2], with prevalence in some areas as high as 2.02% [3] (NHS average prevalence of 1.8%[4]). Aside from many other symptoms and consequences, people with AF are five times more likely to suffer a stroke[5]. Furthermore, AF-related strokes are more severe and cause greater disability than strokes in patients without AF. Half of patients will fail to survive ore than twelve months following a stroke[6]; while for many survivors, disability, fear of death and increased risk of a further stroke, become constant companions. AF and stroke not only devastate patient's lives but also the lives of their families and carers[7].

The AF Association welcomed **Recommendation One,** which included a specific focus on atrial fibrillation, within the National Stroke Delivery Plan (2012). However, while this called for greater partnership in promoting awareness of risk factors for stroke, the AF Association believes that much more is needed in particular in increasing public awareness of AF, signs, symptoms, and AF-related stroke risks. The AF Association would recommend greater use of existing materials and campaigns to empower a more far-reaching, national public and patient education campaign utilising all stakeholder channels. The 'Know Your Pulse' campaign is an appropriate and effective educational campaign, which empowers individuals to play a proactive role by being aware of the signs of AF and the importance of then talking with a healthcare professional in order to take appropriate action *before* a stroke occurs.

Patient empowerment is associated with improved clinical outcomes[8] and has been made central to the current focus of the NHS. As an AF Association member's account highlights, a lack of awareness around the very simple ways to detect AF can and do lead to tragic outcomes:

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[1] The Office of Health Economics, Estimating the direct cost of atrial fibrillation to the NHS in the constituent countries of the UK, 2008/2009
[2] AF Infographic – Wales: http://www.afinfographic.co.uk
[3] AF Clinic in Llanelli: Healthcare Pioneers 2011, http://www.atrialfibrillation.org.uk/files/file/Publications_Medical_Only/111026-JF-FINAL-Healthcare%20Pioneers%20Booklet.pdf
[4] GRASP-AF data 2013
[5] Wolf PA, Abbot RD, Kannel WB: Framington Study. Stroke 1991;22:983-8

[6] 5. The AF Report 2011
[7] White CL, Poissant L, Cote-LeBlanc G et al. Long term care giving after stroke J Neurosci Nurs 2006;38;354-60

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Jenni's husband was 58 years old:

" The stroke was caused by an undiagnosed heart arrhythmia. I say undiagnosed but that's not strictly true, just a few weeks before … I had my head on his chest and I said 'God your heart's all over the place', I never gave it another thought until three weeks later when the doctor in A&E asked if he had any known heart problems…"
(Full account:
http://www.atrialfibrillation.org.uk/files/file/Case_Studies/Jenny%20AFA%20Article.pdf)

Recommendation two

AF Association strongly supports the report's recommendation that the National Stroke Delivery Plan give clear reference to the prevention of a secondary stroke, however we feel more is needed to ensure this is carried out to maximum effect, and that individuals with AF are risk scored using validated schema such the European Society of Cardiology (ESC) approved and recommended CHA_2DS_2-VASc and HAS-BLED systems. Patients who have already suffered a stroke or TIA are at much greater risk of a second event and so it is critical to the person's outcomes, that preventative, effective therapies are initiated. Too often, current and validated recommendations such as those issued by ESC (AF Guidelines 2011 and 2012) are not implemented, with devastating outcomes:

'AF symptoms caused Jane to go to her local A&E where she was diagnosed with AF. She was discharged without any medication. Two weeks later she woke up without vision in one eye – she had suffered a TIA. She returned to hospital and this time was discharged with just a prescription of aspirin. Ten days later, she had a full stroke.'[9] (2012)

[8] Trummer U, Mueller U, Nowak P et al. Does physician-patient communication that aims at empowering patients improve clinical outcome? A case study. Pat Educ Couns 2006;61:299-306
[9] AF Association Health Unlocked Forum, 2012

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Far greater understanding of the vital importance of preventative therapy and validated tools that support clinical assessment need to be achieved to avoid suffering a preventable stroke. Increased adherence to guideline recommendations must also be central to managing stroke patients.

Recommendation four:

AF Association is supportive of this recommendation, although it does recognise that all healthcare practitioners should have and be aware of, clear guidance on identifying, risk assessing and managing AF.

"I was diagnosed with AF and had a consultant telling me I should go on warfarin and a GP telling me I didn't need to as my heart was still in NSR most of the time. I was offered cardioversion and I was waiting to go on the list. Within two weeks I had a clot form which went walkabout and I had a big stroke which left me unable to walk or talk." (Lesley[10])

It is important that primary care practitioners:

- Understand the impact and risks associated with AF and AF-related stroke
- Are fully aware and confident to use approved guidelines
- Have thorough understanding of the benefits of risk-reduction therapies and which therapies are appropriate for reducing the risk of an AF-related stroke
- Recognise the benefits of patient education and engagement in decision-making and how to discuss risks and benefits of treatment with patients

There is clear evidence that many AF patients are not being offered anticoagulation even when their risk factors are well documented[11]. It is essential that health care professionals (HCP) become better informed about:

- AF-stroke risk
- The near absence of a role for aspirin to reduce this risk
- How to effectively assess an AF patient

[10] AF Association Health Unlocked Forum 2013
[11] NICE AF: the management of atrial fibrillation. Costing report; Implementing NICE guidance. July 2006

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- The importance of at least an annual review to reassess AF-stroke risk

It would also be extremely beneficial if HCPs were encouraged to provide approved patient information or/and direct patients to the NHS Patient Decision Making tool[12] (PDA) or the forthcoming PDA being developed by NICE.

The provision of appropriate anticoagulation for patients with AF, in line with modern clinical guidelines, will save lives as well as NHS Wales resources[13]. While it must be the responsibility of every clinician to ensure that each patient in their care is treated in line with the most up-to-date clinical guidelines, nationally supported audit tools can provide an efficient and effective way to audit GP data, identify those at risk and who would benefit from appropriate therapy. We are aware that in Wales, an audit tool for AF has been developed - 'Audit Plus'. There is good evidence that a similar tool available in England, has been an influential tool in supporting primary care to find, assess and review current AF patients who are at increased risk of stroke but are not receiving an appropriate therapy.

Audit Plus has been developed for Wales and we believe, should be actively encouraged by the Health and Social care Committee along with the Welsh Assembly, to encourage review and improved management of all AF patients in Wales to reduce their risk of an AF-related stroke. Furthermore, the Audit Plus tool would support the '1000 Lives Plus' campaign and could be delivered through the Primary Care Quality Information Services 'How to Guide for AF'[14].

While changes to QOF in 2011 have been welcomed by the AF Association, further amends are required to be in line with ESC update AF Guidelines 2012, in particular, an amendment to aspirin as a therapy option in line with the updated guidance[15].

We also believe, that in line with the 2012 focused update of the ESC Guidelines for the management of atrial fibrillation, Left Atrial Appendix Occlusion (LAAO) should be considered as

[12] http://sdm.rightcare.nhs.uk/pda/stroke-prevention-for-atrial-fibrillation/
[13] NHS Improvement – Heart in association with NPSA: Anticoagulation for AF: simple overview to commissioning quality services, 2011
[14] http://www.wales.nhs.uk/sitesplus/888/page/59796
[15] http://www.escardio.org/guidelines-surveys/esc-guidelines/GuidelinesDocuments/Guidelines_Focused_Update_Atrial_Fib_FT.pdf

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an option for AF patients with thromboembolic risk who cannot be managed in the long-term using any form of oral anticoagulant[16].

Recommendation five
AF Association supported the Committee's recommendation to implement opportunistic pulse checks. Furthermore opportunistic screening is supported by ESC updated AF Guidelines 2012.

However despite recommendation and intention, while prevalence of AF continues to grow, measures to detect and diagnose patients are still insufficiently delivered. As a consequence, not only are asymptomatic AF patients failing to be detected and diagnosed, and so remain at high risk of a AF-stroke, but also individuals who are at increased risk of developing AF are not being shown simple self monitoring techniques to raise their own awareness of the possible onset of AF.

The implementation of an effective, low cost AF screening programme as reflected in the SAFE study[17] clearly showed the cost benefit of targeting known at-risk patients aged over 65 years or presenting in chronic disease clinics. For this to be effectively implemented on a national scale, a policy requiring:

- An audit of all patients in general practice to determine and flag those at AF and stroke risk
- Manuel pulse checks for all risk-flagged patients when visiting their local GP or a medical appointment
- Prompt access to an ECG

With the development of a number of highly effective, accurate, low cost and approved modern technologies that take simple ECG readings, even greater sensitivity within an opportunistic screening policy is now easily possible.

Without doubt, opportunistic screening would ensure timely identification of AF. As a direct consequence this would enable early intervention to manage the condition and its risk factors, resulting in a significant reduction in the number of AF-strokes suffered. 'Population based

[16] http://www.escardio.org/guidelines-surveys/esc-guidelines/GuidelinesDocuments/Guidelines_Focused_Update_Atrial_Fib_FT.pdf pg 2732
[17] SAFE study 2005

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opportunistic screening for AF – tried and evaluated business models for healthcare systems' is to be published by the AF Association in just a few weeks, intended as a supportive guide for service providers seeking to implement an opportunistic screening model. We believe opportunistic screening to be an integral part and first step to achieving a reduction in stroke and AF-related strokes.

In review of the 2011 'Inquiry into stroke risk reduction' the AF Association thanks and congratulates the Health and Social Care Committee for its work in bringing together the five recommendations. However, there remains an urgent need for coordinated action covering early awareness, timely diagnosis, implementation of audit and review and appropriate management of anticoagulation for all those at increased risk of ischemic including AF-related stroke.
We would now urge the Committee to ensure greater implementation of these areas across the whole of Wales.

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Deputy CEO AF Association
www.afa.org.uk
01789 451 837