

It's time to talk about AF

**Identifying and managing Atrial Fibrillation in order to
reduce stroke risk.**

Based on the Report of an independent inquiry commissioned by NICHHS.



WHY AF IS IMPORTANT... ROSALEEN'S EXPERIENCE

Meet Rosaleen Fearon from Newry. Rosaleen was lucky as her atrial fibrillation (AF) was diagnosed when she was admitted to hospital to receive treatment for a fractured back.

"I didn't understand at the time. I remember the nurse taking my pulse and saying the doctor will probably want to have a chat with you about your heart. I didn't take this diagnosis serious at all and just continued life as normal thinking I was healthy."

"I was put on medication and was told to take 2 Apixaban tablets per day. Unfortunately, a friend told me she didn't bother with the two tablets and I had heard others saying this too, so I just took one of them instead of both."

Rosaleen didn't understand the seriousness of the condition and didn't understand the importance of taking her blood thinning medication. Then tragedy struck in June 2018.

"I don't remember very much about the day I took my stroke. I was making the bed and thought I'd tripped over the pillowcases, but I'd collapsed. The next thing I remember is waking up in the Royal Victoria Hospital and being told I'd had clot retrieval surgery."

"I didn't know it was possible I could have a stroke because of AF but I remember the GP telling me quite firmly that the second tablet would have helped prevent the stroke."



Rosaleen Fearon from Newry

Rosaleen believes strongly in playing an important role in her care and is a great champion for awareness and education. Since her stroke, she has completed NICHS' Post Rehabilitation Exercise Programme (PREP).



A MESSAGE FROM DECLAN CUNNANE, CEO OF NICHS



Engaging as we do with people every day, NICHS staff regularly witness the devastating impact of AF on thousands of local people. Through our work we have met numerous people

who were only diagnosed with AF after their stroke and whose stroke may well have been prevented if they had been identified earlier.

In the past three years we have been leading by example. We introduced AF testing as part of our health checks, and we delivered a public awareness campaign to raise the profile of AF and the associated stroke risk.

We believe **it's time AF was prioritised.** To help focus 'hearts and minds' we commissioned an independent inquiry in 2019 to help us gain a better understanding of the key issues and identify solutions relating to AF detection and management.

An Advisory Panel was established to enable the appointed researcher, Dr Niamh Kennedy, to regularly consult and seek advice from several healthcare professionals (HCPs) from across Northern Ireland with differing backgrounds.

The Inquiry was extensive, running from March 2019 to January 2020. Over nine months, 40 service users and 100 Health Care Professionals were engaged

through questionnaires and 18 one to one interviews.

This evidence, combined with feedback from engagement with service users about their lived experience within NICHS Stroke Groups, was collated and formed the core part of discussions in three roundtable discussions which have informed the development of the report.

We would like to extend our thanks and appreciation to everyone that has helped contribute to the inquiry especially people living with AF who shared their personal stories and to the Advisory Panel.

NICHS looks forward to working in partnership to ensure the recommendations from this report are taken forward to improve the outcomes and experience of people living with AF and to improve the population health by detecting undiagnosed AF which will significantly reduce preventable strokes in Northern Ireland.

Declan Cunnane
Chief Executive, NICHS



WHAT IS ATRIAL FIBRILLATION?

Atrial Fibrillation (AF) is one of the most common types of irregular heart rhythm and occurs when additional irregular electrical messages develop in the atria (upper chambers of the heart). These irregular messages make the atria quiver or twitch (fibrillation).

Symptoms, risk factors & treatment of AF

Symptoms

Sometimes people with AF have no symptoms and their condition is only detectable during a medical examination or by having a health check. Those that do, can experience palpitations, dizziness, shortness of breath, tiredness or fatigue.

As many as 40% of people with AF do not experience symptoms (asymptomatic AF), however, their risk of stroke is unchanged.

Risk factors

The exact cause of AF is unknown, but it's more common in men and risk increases with age. Risk factors are associated with AF, include:

- high blood pressure
- heart failure
- valvular heart disease
- previous heart attack
- thyroid disease
- diabetes
- chronic lung disease
- sleep apnoea
- kidney disease
- excessive alcohol consumption
- obesity
- smoking



Treatment

Treatment to alleviate symptoms can include medication to help control the heart rate or rhythm or to help reduce stroke by preventing blood clots.

Traditionally warfarin would have been prescribed but there are a range of newer anticoagulants.

Other treatments include:

- **Cardioversion** - which aims to restore normal rhythm by delivering a controlled electric shock.
- **Catheter ablation** – a surgical procedure where any areas producing the abnormal rhythm are destroyed by radiofrequency, after which sometimes a pacemaker is needed.

“I took control of my life, health and AF. But it effected by head. I felt really shook by it.”

Male, 66, Belfast

THE IMPACT OF AF IN NORTHERN IRELAND

AF is one of the most common irregular heart rhythms. People over the age of 40 years have a lifetime risk of one in four of developing AF.

As age is a risk factor for AF, and the elderly population is growing rapidly, the number of people living with AF is predicted to increase. The prevalence of AF roughly doubles with each advancing decade of age.

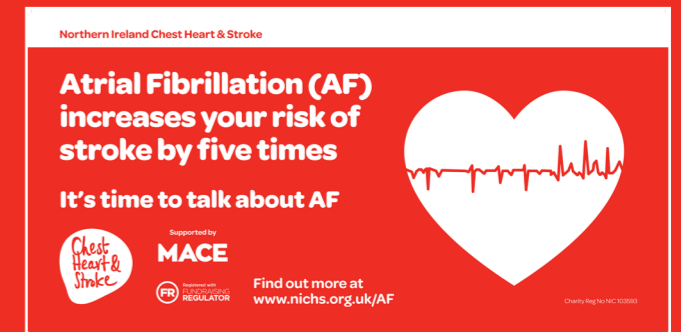
Within a decade, Northern Ireland will be facing greater numbers of people living with AF, which will impact on an individual's quality of life, Health & Social Care and society.

There is huge concern that the lack of early detection and management of AF, will impact on the number of people developing a stroke. This is apparent as recent Sentinel Stroke National Audit Programme (SSNAP) data indicates, that despite the total number of strokes falling, the number of strokes that were AF related has increased from 18.9% to 23% in Northern Ireland.

One of the clearest ways of preventing a stroke is the detection and management of underlying conditions such as AF.

“Requires innovative digital solutions integrated into the clinical pathway for diagnosis and monitoring.”

Cardiologist



Artwork from NICHHS awareness campaign

- Nearly **40,000 people (80%)** have been diagnosed with AF.
- It is estimated there are **10,000 people** undiagnosed.
- AF can increase the risk of stroke **by 5 times** (more than any other cardiovascular risk factor).
- Between **30-40%** of people may not be aware they have AF until they have a stroke.

THE NEXT STEPS

NICHS commissioned an independent Inquiry to examine how to improve the identification and management of AF in order to reduce stroke risk.

This is an Executive Summary of that Report.

Summary of the key recommendations

Working in partnership with key stakeholders, including the Department of Health we should:

1. Develop an AF strategy for Northern Ireland.
2. Aim to identify 85% of people with AF by March 2023 and 90% by 2025.
3. Create a clear clinical pathway for AF.
4. Invest in technologies in clinical practice to detect AF and monitor treatment.
5. Increase AF detection rates by targeted case finding based on AF risk factors.
6. Address the echocardiograms (ECG) waiting list issue including tackling any workforce issues.
7. Provide information and education to people living with AF.
8. Prioritise improving adherence to treatment for existing AF patients to prevent future strokes.
9. Commission the Public Health Agency to identify the most effective methods to raise public awareness of AF.

Inquiry findings

Awareness:

The inquiry found there was a low understanding of AF and that people didn't understand the seriousness of the condition. This was highlighted in research carried out both before and after NICHS's public awareness campaign. Even when people knew what AF was, the message about being at greater risk of developing a stroke was lost as many felt it was something that only affects older people and therefore was not relevant to them.

"I had never heard of AF and now I'm left with effects from my stroke and if my AF had been detected I would never have had my stroke." Male, 76, Dungannon

Targeted Detection:

Our research revealed that, 86% of Health Care Professionals believe there should be some form of AF detection programme. AF has clear risk factors (assessed by CHADSVASC score) and a targeted approach, using existing clinics and reviews, would be an effective way of reaching patients. In addition, with technology (AF detection devices) people can be tested in a time efficient way.

"Large numbers of patients on stroke wards have undiagnosed AF, this is an important and relatively easy way of potentially reducing stroke incidence and cost." Stroke Physician

Treatment and management of AF

The inquiry identified several concerns with treatment and management:

1. Over 30% of people with AF are not on the appropriate medication.
2. Poor medicine management - there are concerns with adherence as it is estimated that in the long term, 40-60% of people with AF may be non-adherent to their direct oral anticoagulant (DOAC) therapy.

3. The inquiry found that two in five people with AF only received a brief description to inform them of their AF and just half felt they had a good understanding of their condition.
4. In one to one interviews, several people with AF mentioned how isolating it was, citing the impact of lack of information about their condition.
5. The inquiry found that two in five HCPs identified the lack of resources as a significant challenge to treatment and care for people living with AF.

People living with AF are equally at a similar risk of stroke as people living with diabetes. It is imperative that people with AF are provided with similar information and education as people living with diabetes have access to.

Service transformation

The inquiry explored several areas, and identified the following:

1. **Need for good practice and innovation**
The inquiry provided the opportunity to share good practice and innovation. In addition to AF clinics, the need to invest in technology was apparent. AF detection devices and technology for service users to better manage their condition would deliver both improved health and possible financial savings.
2. **Importance of an AF pathway**
67% of Health Care Professionals stated they did not believe there is an effective care pathway in place for AF. A lack of resources (cost, staff and capacity) is also creating barriers to providing a more consistent approach to the effective management of AF.

The inquiry identified the importance of developing a clear clinical pathway.

3. Investing in AF stroke prevention and management

The inquiry has highlighted the financial impact of AF on the individual, Health & Social Care and society. It is imperative that there is investment in early detection and management of AF (stroke prevention).

The current situation cannot continue. In addition to the evidence concerning poor detection of AF, the waiting list for cardiology is considerable and for echocardiograms has doubled from approximately 10,000 in 2016 to 20,000 in 2019.

Conclusions

While there are examples of good practice, there is not enough being done to increase early detection of AF. Equally, the management of those who have been identified with AF is not as good as it should be.

NICHS call on the Department of Health, and all key stakeholders, to drive forward the recommendations of this Report. Doing so will help reduce death and disability from stroke.

First and foremost, the Department must take the lead in devising and, with the help of the Trusts, implement a new pathway for AF. This can act as the foundation for future change as the other recommendations are pursued over time.

Advisory Panel:

1. **Dr John Winter** - Chairperson & GP Lead of the Ards Integrated Care Partnership
2. **Dr Brian Gallen** - Consultant Stroke Physician and Geriatrician, South West Acute Hospital and member of NICHS Governance Board
3. **Michael Jackson** - Lead Pharmacist for Cardiothoracic Services, Belfast Health and Social Care Trust
4. **Neil Johnston** - Public Affairs & Policy Manager, NICHS
5. **Dr Niamh Kennedy** - Lecturer in Psychology, Ulster University
6. **Clare Murray** - Lead GP Pharmacist, East Belfast Federation of Family Practices

About Northern Ireland Chest Heart & Stroke

NICHS's vision is a Northern Ireland free from chest, heart and stroke illnesses. Established in 1946, we work with people of all ages across the country, delivering vital care and prevention services and carrying out extensive research into how to prevent these conditions, alongside 'on the ground' support.

As a charity, we are committed to supporting thousands of local people living with chest, heart, and stroke conditions to keep well through COVID-19. With almost 90% of our services funded by you, we need your help to continue 'Still Caring through COVID'.



Nearly 90%

of our work relies on donations from the public.

Without your support we couldn't be here making a difference.

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