

Seeking an Understanding

By Martin Harman

My name is Martin and I would like to share my story with you. I have suffered with AF for 3 years. I was first diagnosed back in October 2006 at the age of 33. I want to talk about how it has affected my life and the impact that's had on me. The symptoms of AF and what to expect are well known to sufferers, albeit they are unique to each and every individual. What is not often talked about is the mental and emotional impact AF can have on your life.

My journey started whilst playing football. I have always been a very keen sportsman and it has always played a major part of my life. One afternoon whilst playing football 3 years ago I sustained a bad knee injury that required surgery. I had the operation and the day after I was recovering at home when I began suffering from palpitations, excessive sweating, and dizzy spells. It felt like someone was tightening a strap around my chest and I was really short of breath. I thought nothing of it at the time and just assumed it was a side effect of the General Anaesthetic.

Two days later I was still having the symptoms and I got up to make a cup of tea when it hit me. The palpitations, the sweating, the dizziness, the room started to spin and I felt as if I was falling over. I could feel my heart thumping against my chest and I was very short of breath. That day I visited my local GP, I explained my symptoms to him and the first thing he did was check my pulse. I could see in his face that something was not right.

I had an ECG that confirmed I was in AF. I was admitted to hospital that evening for 4 days whilst I underwent various tests to try and identify if any underlying cause was triggering the condition. Ultimately they found nothing. The cardiologist I saw believes the episode was possibly triggered by the general anaesthetic. I am still sceptical about this as I have had 3 general anaesthetics previously without a problem and nobody can explain why.

I was eventually discharged and sent home (still in AF) and told, "See you in 3 months at the out patient clinic!" That was it, no information, no guidance, just an appointment for the anti-coagulation clinic. Thankfully, a staff nurse on the ward, simply out of her own kindness, found a BHF AF leaflet, but that was the only information I was given.

So the next 3 months I spent educating myself about AF, websites, chat groups and speaking to other sufferers.

The most difficult thing for me was coming to terms with what I had, the impact it was having on me and how it was affecting my life. It felt like my life had been taken away from me. I know that sounds dramatic, but at the time that's how I felt.

I was physically prevented from doing what I wanted, the things I took for granted, and then suddenly not being able to do anything that was tough to come to terms with. For 3 months my life consisted of my house, with the occasional 10 minute walk around the village! I went through so many emotions, anger and frustration, looking for someone to blame, wondering why this had happened to me! Did something go wrong? Was too much anaesthetic administered? Questions, Questions, Questions rolled over my mind, but without any answers.

I tried all different medications, different strengths, different combinations, but nothing worked. I remained in AF permanently for 3 months and could not even walk up the stairs without my heart rate racing! I was unable to work and I couldn't even walk for longer than 10 minutes.

My wife, family and work colleagues were very supportive of me at this time and I do think that was essential to aiding my recovery. You often forget about the people who have to sit and watch what is happening to you and they can't do anything to help, other than just be there for you, but that was enough.

My GP was fantastic, extremely understanding and was always supportive when I went to see him. We worked together with different medications in order to find one that would ultimately work and finally we did.

Amiodarone eventually got my heart under control and finally after 3 months reverted me back to NSR! The side effects were a long term concern, so I came off Amiodarone and began to use Flecainide alongside a beta-blocker. I had intermittent AF episodes along with prolonged attacks of ectopic beats. I was a regular visitor to my A&E department at the local hospital. Typically though, by the time I got to hospital the episode had passed!

Gradually I become stronger, eventually returning to work full time and I slowly started to exercise again. By early 2008 I had managed to put on the weight I had lost, was exercising daily and felt like my old self again. I still had episodes, but only occasionally. So, in discussions with my GP, I decided that I would stop taking my medication. I was offered ablation as a treatment, but I decided I wanted to try life without drugs first. I wanted to know if my body needed the drugs to control the occasional attacks. How would I know unless I stopped taking them? As I am relatively low risk because of my age and overall health other than the AF, he agreed and helped me. Warfarin was first, and then gradually over the next 3 months I came off all my medication. My symptoms are no worse, I still have the odd episode, but mine tend to be short, about 1 – 4 hours maximum and I get prolonged ectopic beats occasionally.

I have learned to understand the signs. I know what triggers my AF –it's the usual list you hear time after time, alcohol, caffeine, ya know all the stuff you like! - But I also suffer if I get overtired, or stressed. It doesn't mean I don't enjoy the occasional alcoholic drink or a few cups of coffee, but I have to be careful and it's about moderation and what works for me. I also make sure I am well hydrated drinking 2-3 litres of water a day. I found keeping a record of what I ate, drank and how I was feeling helped me notice the pattern and ultimately helped me to live a near normal life!

3 years on I am back to my normal self, no longer on medication, managing my condition and living a fairly normal life, with just the occasional setback on certain days. I am exercising daily and recently completed a Triathlon, which I raised over £1000 for the AFA charity! My ambition is to complete an Ironman competition before I am 40. That has been slightly halted as unfortunately 8 weeks ago I had to have further surgery to my injured knee that started this whole journey off, but thankfully this time with no complications like the last!

I am conscious that others may be listening and thinking "lucky you", but that is one of the reasons I wanted to share my story. I appreciate that I am one of the more lucky ones, perhaps not as symptomatic as some AF sufferers. Maybe because I am relatively young it is not so frequent and this may change as I get older, but for now, I intend to enjoy my life! I want to share my experiences with people, particularly younger people, in

order to try to help anybody out there who is going through what I went through, as I understand how difficult it is to live with and accept AF.

I have reflected a lot about the last 3 years and my battle coming to terms with AF. I believe that how I felt immediately after I was diagnosed did impair and hinder my recovery. The emotional impact it had on me brought out elements of my character that do not normally exist. They are not traits that I possess on a regular day to day basis. I became negative, pessimistic, defeated, not up to the challenge and that's not me. Normally my character lends itself to being positive, outgoing, a fighter, always motivated for a challenge. I did not know how to cope with these feelings, I felt like I was out of control.

My inability to do anything meant I accepted what I had and effectively gave up the fight. I had mentally decided I would have to live with things as they were and just adapted to how life "was going to be". I worried that something might have been missed in the diagnosis, what if something underlying does exist? This is my heart after all, I might die!

I also became obsessed with my condition. I bought pulse meters, checked my pulse and blood pressure every hour, I even recorded it on a spreadsheet! I began checking my pulse every few minutes, sitting and focusing on my heart beat, "is it out of rhythm, is it beating fast. I spent my days surfing the internet trawling every possible website available to fill my head with knowledge about AF!

This was all because the lack of information and support meant I had to fact-find myself and by trawling through the details I found, this became overwhelming and almost made me admit defeat. I focussed too heavily on the negative aspects and was unable to identify the positives. I had nobody to help balance that information and give me a perspective and even if they did, I am not sure I would have listened.

I shut myself away from normal every day life because I couldn't achieve the standard of living that I was used to and wanted to have. My life was AF and I was trapped inside an AF cocoon because that was all I had now and all I could live with.

So how did I change all that? The turning point was finally reverting back to NSR (normal sinus rhythm)

It was a major highlight, almost like the first positive point and made me realise that there was hope. That feeling of waking up and actually feeling normal for the first time in 3 months I could not put into words. This boosted my mood and gave me the inner strength to fight the condition and rebuild some kind of normality into my life. From that point I never looked back and continued to focus on what I could achieve despite having AF. I finally accepted the condition, but would not let it rule my life. I realised that what I needed to do was to modify the things I did, not cut them out altogether. My pace of life might not be what it was before, but the more I fought and accepted the condition, the more strength it gave me to achieve as much as I could.

I truly believe that with more information and support at the time of diagnosis, I would have recovered quicker and dealt with my condition a lot better. That is one of the reasons for me speaking here today. Attending the patient day last year and becoming involved with AFA has provided me with so much support and understanding and valuable information. I now want to give something back, help other sufferers who might be struggling to come to terms with what they have. I know in this room we have lots of sufferers who have suffered and are far more symptomatic than me. I also know from all the people I talk to and read about that they sometimes find it difficult to express how

they really felt. I don't feel embarrassed or ashamed of my feelings and what I went through, nor should anybody feel that way. I feel a little disappointed in myself, I feel I could have handled it better, but maybe it was something I had to go through in order to find the understanding and perspective to make me fight on and rebuild my life

They say time is a healer and fortunately for me that has been the case. I am lucky to have regained my quality of life back, and be able to do the things I want to do. That is something I remind myself of most days.

As for the future and my AF, well nobody knows and maybe in time it will get worse. For now, I will just continue to enjoy my life and be thankful for the quality I have regained as I will never forget the times without it.

Thank you for listening.