

On the 20<sup>th</sup> of December 2003 I was diagnosed with Atrial Fibrillation.

A short and very simple sentence but one that was to have a major impact on both my life and that of my wonderfully supportive wife.

I was a fit and healthy 47 year old man and all of a sudden I had been diagnosed with what sounded like a very serious heart condition. How did I arrive at this stage in my life?

In October 1979, newly married and my whole life in front of me I found myself at the GP. There was nothing specifically wrong but I was feeling generally out of sorts. The first thing he did was to take my blood pressure and it was higher than it should have been for a man of my age. There followed a visit to the local hospital for a whole suite of tests to discount any serious underlying condition which was all rather concerning for a young man who just didn't understand what was going on. Thankfully there was nothing seriously wrong and I was told that I had labile blood pressure which is blood pressure that can fluctuate abruptly and repeatedly. The recommendation was not to treat other than to keep an eye on my BP levels.

For the next nine years I went for a number of company sponsored medicals and at every one of them my blood pressure was either fine or on the high side of normal. This was the case up until June 1988, when at a medical my BP was found to be significantly raised but more worryingly my ECG displayed abnormal tracings.

I subsequently attended a Cardiologist who confirmed the ECG tracing and after an ultrasound scan determined that I had moderately severe thickening of the left ventricle, probably caused by persistently high blood pressure. I was prescribed Atenolol, to be taken daily (50mg) and asked to come back three months later.

This was devastating news but when I think back I am amazed at how positive I was in my reaction.

In the three month period leading up to my follow up consultation I took the view that anything was possible and removed from my mind any prospects of a poor longer term prognosis. I stopped drinking completely, continued to exercise and essentially got on with my life. For whatever reason but probably down to the Atenolol the results of my second ultrasound were very encouraging. Even during a relatively short period of time the thickening as identified previously had reduced quite a bit. My Cardiologist made no secret of his surprise but clearly I was being given a second chance.

Over the next few years I continued to attend regular general medicals and lived my life as normal but must confess to going back to drinking on a pretty frequent basis. During these medicals my ECG results seemed to revert back to normal and it was clear that the Atenolol was doing its job. I had my blood pressure checked by my GP on a regular 4/6 month basis and while it was never perfect it was better than had been identified previously. I returned for another ultrasound scan with my Cardiologist a few years later and he was able to confirm that the thickening had reduced and was almost back to absolute normality.

My blood pressure continued to read fairly high and as a result my GP added a few drugs to my daily prescription and things did begin to improve in this area as well, albeit it tended to remain higher than perhaps it should have been for someone of my age.

Fast forward to December 2002 and during an overseas business trip I began to feel very uncomfortable. I had begun to experience what could only be described as a queasiness in my stomach. I had no idea what it was but after a few days it went and I got on with life as normal. During 2003, I experienced a number of repeats of this feeling and it was only during one episode when on an exercise bike with a heart rate monitor I noticed that my heart rate was somewhat irregular and faster than normal. To this day my reaction to this situation really surprises me as I decided to ignore things.

I then became far more aware of my heart rate and on a number of occasions I recognised that things were clearly not right. Eventually just before Christmas 2003 the problem hit me again and at my wife's insistence I phoned my GP surgery and was very fortunate to get an immediate emergency appointment. During this consultation my GP diagnosed AF through an ECG.

I had no idea what this was but in discussion with the GP I was able to be assured that it was not a life threatening condition. He referred me to the Cardiologist I'd seen some years previously and I left looking to enjoy the Christmas period as much as I could in the circumstances.

I visited the Cardiologist in early January and he confirmed that my heart was essentially sound and free from heart disease and went through the condition in a lot more detail than I had before with my GP. He prescribed another change to my prescription and this did have an impact in the coming months in respect of my blood pressure which was now under control.

Life went on for the next few years. I was hardly drinking and watched very carefully what I ate. It seemed clear that there were very specific dietary triggers that would cause an attack of AF and where at all possible I tried to avoid these as best as possible. I felt that excess dairy products were a trigger and completely avoided cheese and yoghurt. Caffeinated coffee was removed completely although tea didn't seem to be too much of a problem. Green tea was however to be avoided. I also believed that too much stress and tiredness were also factors but these are clearly much more difficult to control. Any attack tended to last 16-18 hours and they went as quickly as they arrived. I could always tell when it was about to kick in as I would start to get regular ectopic beats coupled with a severe bloated feeling in my stomach. In taking the Atenolol the actual attacks while very unpleasant were probably not as bad as they could be and more often than not my actual heart rate was not too high although it was irregular.

Fast forward again to December 2008 and the attacks were becoming more frequent.

In early January 2009 I went back to my GP to ask for another referral to the Cardiologist I had seen previously. This would seem to have been the best thing I had done for years. He again examined me in minute detail and again confirmed that my heart looked and sounded fine. Having personally built up a far better understanding of my condition in respect of my symptoms and what I considered to be the principal triggers, we were able to piece together the condition in a way we had never before. He was convinced that the condition was treatable and suggested that it was a manifestation of sino-atrial disease and not hypertensive disease and recommended a rather different drug regime. He suggested I slowly remove the Atenolol and replace it with two daily doses (25mg) of Flecainide.

Despite my GP's doubts I started to follow this course. I was also rather apprehensive given the bad press Flecaïnide had on the many on-line forums we all tend to go to when suffering any type of medical condition.

However all did not go well to begin with and my body did not like the removal of the Atenolol after 22 years. I don't believe I suffered any negative reaction to the Flecaïnide but the removal of the Atenolol was pretty rough. My resting heart rate was now faster than ever before when under Atenolol and I was finding the incidences of AF episodes increasing as were their severity. However, I did note that while there were more of them they were much shorter in duration and I was finding that they'd go after a couple of hours but only after taking an Atenolol as had been suggested to me.

I then opted to start taking the Atenolol (25mg) once again every morning and within a week I was finding things much better. I was still suffering ectopic beats and on occasion these were quite severe but I never felt that they were likely to lead to an AF episode. During another scheduled visit to the Cardiologist he confirmed that I had done the right thing in adding the small dose of Atenolol and recommended a third 50mg dose of Flecaïnide during each 24 hour period in an attempt to reduce the extra beats.

The long and short of the story is that I am now 19 weeks into an AF free period, probably the longest ever since I was diagnosed with AF. In addition the Ectopic beats are few and far between.

While not being cured I may have found a drug regime that keeps the condition under control. I don't think I will ever accept that the condition is fully under control let alone cured and without question I will continue to watch my diet and alcohol intake to ensure I don't do anything silly. While doing this though I have added a number of things back into my diet that I had earlier thought were triggers, although I am still wary of too much alcohol and dairy products. I am exercising much more with a degree of confidence I haven't had for many years and at age 53 am beginning to think seriously about starting hill walking and planning my first Munro.

I suppose all of this leads me to say to anyone reading this and wondering about their own condition is not to accept things. Always force the issue with your GP and insist on being referred if you think things are getting worse. I probably should have gone back to my Cardiologist earlier than I did but the fact is I didn't and to be honest it doesn't bother me that I may have had this improvement one or maybe two years earlier. My main thought process is to enjoy this time while always being on the alert to ensure that I do not do anything foolish that may bring on an episode.

What was it that made me start to force the issue again with my GP? That's easy. Over last Christmas when things were getting me down I joined the Atrial Fibrillation Association. I found the leaflets of great value as I did with the Newsletter. In particular the article on Catheter Ablation in the February 2009 issue really hit home to me and I actually wanted to follow up this option in going back to see my cardiologist. Had I not seen this article I really don't think that I would have taken any action at all.

If one person can get something out of this article then I'll be absolutely thrilled. Don't accept anything without a fight. I've been lucky – I know that and I also know that I could be hit with an attack tomorrow. I can live with that though. What I couldn't live with was not doing anything and on reflection that was half my problem. I had accepted there was nothing that could be done and accepted in my own mind that I was an invalid. What a load of rubbish. I was feeling sorry for myself and I needed a kick up the backside to take things head on and do something. Your Newsletter did that for me and for this I will be eternally grateful.

Nelson

14<sup>th</sup> August 2009.