

AF – My experience of diagnosis and ongoing treatment

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Having first been diagnosed in August 2012, I have devoured every piece of information I can to glean more details about the disease and its treatment.

I was fortunate to have been given the web address for the AF Association. I immediately joined the Association and studied all the information available on the website. I especially value the experiences from other AF sufferers and took comfort from their stories and that I could so easily identify and relate their experience to my own.

I would never have thought that I would have a close understanding of the terms cardiologist, arrhythmia, ECG, angiogram, sinus rhythm, AF and anticoagulant.

Initial symptoms

With hindsight, it is relatively easy to spot the signs that all was not as it should be. However, unlike other sufferers, I was not conscious of experiencing any palpitations or episodes of an arrhythmia attack.

The first time I could easily point to being unwell was at the end of July 2012, when I was holidaying with my family at my static caravan in Porthcawl, South Wales. As is normal, we had a fairly hectic time with walks for the dog and keeping my 7-year-old grandson occupied. Following these bouts of exercise I suffered extreme shortness of breath and swelling of my lower legs and ankles. I should mention that I was due to be admitted to hospital for a hip replacement operation in August. As a result, I decided to wait until after my holiday and the pre-admission checks before raising the matter with my GP or surgeon.

Although I mentioned above that I did not notice anything amiss until July, some further background to my family circumstances during 2012 should help to clarify the situation with regards to symptoms.

Family background 2012

In February 2012, my partner was diagnosed with gall bladder cancer. It was advised that it would not be possible to have an operation to remove the gall bladder as the cancer had already spread to parts of the liver and lymph nodes. The oncologist and surgeon both advised that a combination of chemo and radiotherapy could help to keep the tumor at bay but it was

impossible to say for how long. The course of treatment could not start until my partner was well enough to undertake the extensive necessary sessions.

To cut a long story fairly short, my partner never achieved a level of wellness that enabled chemo to start. In fact, she was admitted to a palliative care hospital in the April and remained there until her death the following July.

On a personal level, I was struggling to deal with her illness and also maintaining my commitments at work. I delayed having my hip replacement operation as I needed to maintain mobility (driving) for her appointments at the cancer centre in Cardiff. We lived in south Wales but I unfortunately had employment in Basingstoke, Hampshire. Until her illness and subsequent diagnosis I travelled up to Basingstoke on Monday mornings and returned usually Thursday or Friday evenings. Following her admission to the palliative hospital I was travelling daily to and from work, a journey of some 300 miles round trip, 3 hours each way. My own health conditions at that time could be summarised as a poor sleeping pattern and shortness of breath. This was a daily occurrence. I had GP appointments for regular checks during this time but it was thought that a combination of my partner's health and the stress of work and travelling was the reason behind my own symptoms...we know differently now!

My diagnosis and treatment

Following my partner's death, I decided to re-initiate the plans for my hip replacement operation. I had pre-admission checks on 10th August with the aim of admission for the operation on 17th August; it was during these checks that a problem was identified via ECG...the technician did not identify the irregular heartbeat to me, except to query whether I was undergoing treatment for such. I did not immediately think there was any cause for concern but took the queries to be part of the admission checklist. At any rate, I was due to have a GP appointment a few days later and so decided to bring the matter up with him at that time. And so the saga continues...

At my GP appointment, I mentioned the hospital checks and also the swelling on my ankles. He then checked this himself, along with my pulse rate and blood pressure. He wasn't happy with the results saying that he was concerned that the rate was 'on the high side', so he arranged for an immediate ECG to be carried out at the surgery. Following this, he again expressed concerns at the high heart rate and the irregular rhythm. Consequently he arranged for my immediate admission into the Emergency Assessment Unit (EAU) at the hospital. It was only then that I became concerned and somewhat anxious, which in itself increased the BP. On admission, further ECGs and BP readings were taken, with heart rate indicating 120-130 bpm. After

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numerous visits by registrars and consultant cardiologists, I was eventually advised of the probable cause of my condition. I was prescribed the beta-blocker metoprolol and aspirin and discharged with a follow-up review in 2 weeks.

Anyway, over the coming weekend I kept being sick and generally felt unwell. The only change to my medication had been the beta-blocker and the aspirin so I called my GP who advised I stop taking both and to make an

appointment to see him on the Monday. This resulted in another admission to the EAU at the hospital and a further review of all my medication. So, for the AF I was prescribed bisoprolol and warfarin. My usual BP tablets were changed so that I only took lisinopril (ACE inhibitor). All other BP tablets were stopped. I also retained my gastric tablet Omeprazole. I was then discharged with a follow-up cardiologist appointment arranged four weeks later, at which time I would have another ECG and an angiogram at some point. This time, the combination of bisoprolol and the warfarin seemed to work and I settled down more or less into a regular routine of INR checks at the surgery backed up with blood tests for kidney function.

Following the cardiologist review, he confirmed the AF diagnosis (it is a really scary moment to hear the immortal words “you’ve suffered heart failure...”). He amended the dosage for the bisoprolol and added a diuretic (Furosemide) and a tablet to further boost kidney function (Spironolactone).

When the angiogram procedure was undertaken a few weeks later, it thankfully showed that all arteries were clear and so I did not need any stents or other bypass surgery.

Since then, I have been on regular INR reviews as dictated by the INR reading and am down to cardiologists review every 3-6 months. I have further reviews with the British Heart Foundation (BHF) cardiac team who provide monitoring service to the cardiology department at my hospital.

My medication remains at bisoprolol, warfarin, furosemide, spironolactone, lisinopril and omeprazole and I must admit to feeling quite good. I have been back at work since October 2012 following two months off on sick leave and am now pretty stable health-wise. The downside to all this though is that I do worry on occasion about trips away and the ‘what if something happens’ anxiousness that I’m sure everyone suffers from.

Another episode occurred in November 2012. This did not seem (to me anyway) directly related to my AF though. Whilst at home one weekend, we had settled down to our evening meal. I wasn’t feeling too good but was slightly agitated. I was experiencing pain in my chest on breathing-in, was sweating heavily and generally felt that something was ‘not quite right’. My son thought that I was having a heart attack and was all for calling 999 and an ambulance. However, the pain I was having didn’t seem to be heart-related as it was more on my left side

and not chest and felt similar to pulled muscles I'd suffered in my rugby playing days. What is it they say..."Dad knows best"! Anyway, as we only live 10 minutes away from the hospital, we went to A&E by car. Perversely, being a heart patient does have some advantages as I was in to see the triage nurse almost immediately. As they weren't sure at that point whether I was having a heart attack they administered some GTN spray onto my tongue. I underwent some ECG tests which gave a very high heart rate of 140+bpm, high blood pressure readings and they also took blood samples. A chest X-ray was also taken. When I did eventually see the doctor, the X-ray results showed I had contracted pneumonia in my lower left lung. This resulted in admittance to the EAU ward for two days and a further week on sick leave. I was prescribed a course of antibiotics to treat the pneumonia. However, one side effect was that one of the drugs (clarithromycin 500mg) acted as a blood thinner itself and so counter-acted with my warfarin. Thus, this dosage needed to be adjusted so that my blood didn't get too thin.

Eventually I recovered and, since then, have the regular reviews for INR checks and with my GP. Cardiologist team reviews are still maintained at 3-6 months. The help and support that I have received from the GP surgery and the BHF team at the Nevill Hall Hospital, Abergavenny has been exemplary and I am grateful for their on-going assistance and encouragement.

My orthopaedic surgeon has been kept fully apprised of the situation by my cardiologist. We have had health reviews and further scans on my hip and have decided to proceed with the replacement hip operation in August 2013. I look forward to this being a success and to hopefully be pain-free once more.

JOHN WILLIAMS

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