

I have said to Jo on more than one occasion that I would like to share my experience with fellow Atrial Fibrillation patients and contribute “My Story” to our magazine. Somehow time has moved on and this now appears more as a diary of the last four years, written over a similar time period.

I am a single person, now 67, and have always lived alone. Naively, I thought I could manage my AF in my usual independent way that I had always controlled my life, thus far. Slowly I lost that self confidence as fear of the unknown crept in and became part of every day. Recently there has been a television campaign promoted by the British Heart Foundation, which I recall states “you think of nothing else”, which believe me is so true.

I was diagnosed in 2003, after I went into AF post-operatively following surgery for something completely unrelated. With such a busy working lifestyle and a lot of stress attached, my working day almost always exceeded the norm. There was little time to recognise how I was feeling physically. In hindsight, I could say, yes, I was tired and fatigued a lot of them time. Breathless on the stairs, and grabbing a quick meal sometimes gave me a strange indigestion-like feeling in my chest, but I really didn't relate this in any way to the symptoms of AF. Being something I knew nothing about at the time, I put it down to work and work alone. I cannot therefore suggest when my AF first appeared; if it was present prior to the operation or triggered by the surgery or anaesthetic. By now, with retirement due, work seemed the last of my concerns, with considerate employers I brought things forward.

July 2003: my surgeon referred me directly to a cardiologist. Following the usual 24 hour halter monitor and echo tests, he confirmed I had AF. This was all new to me, I had never heard of AF!

Naively, I didn't ask questions, I am sure he explained everything fully, but how much of this I absorbed on the day I don't know. My one thought was “something wrong with my heart”. My dad had died at 64 of coronary heart disease, and I had been told as a child about both his parents dying young of heart related illness.

I was initially prescribed Flecainide to treat my AF; at this stage a catheter ablation was not discussed. Within a very short time I developed an itchy rash on my forearms and lower legs, one of the many side effects of my medication. However we carried on to see if things would settle down, which in fact, I understand from the following 24 hour tapes, played its role in regulating the AF. However, the rash persisted and after some three months I was changed to Propafanone. The rash slowly disappeared but new side effects presented themselves. Finally I settled on Sotalol, the lesser of three evils – much to my dentist's dismay as I started sucking peppermints (sugar!) to alleviate the nausea after my morning tablet.

We probably all share similar experiences over what seems an endless period of time. Adjusting to a suitable medication, what is right for one is not right for another, particularly if, like me, you have never been ill, to suddenly be reliant on medication and adjust your body accordingly was a whole new experience. Hopefully, when the new drug Dronedronone becomes available later this year (2009) AF patients won't have such a difficult transition.

Some six months on, I had taken a new part time job with far fewer hours, and no stress or worries. Visits to my cardiologist were three or six months apart and not a lot had changed. Fatigue and breathlessness were part and parcel of every day. Strangely, it was only now that I was really more aware of any palpitations or flutters as they happened.

January 2007. My first ablation. Although the procedure was fully explained to me by my cardiologist in a previous consultation, like always all crucial questions I should have asked went from my head. I am sure he covered everything; what happens during an ablation, the risk involved and post-operation recovery time at home. My hospital experience was not a pleasant one. On the day I had an exceptionally long wait by myself, contemplating what was in store, which didn't help matters whatsoever. Throughout, I was extremely frightened – this was not what I had expected. Where was the self confident me? Even to be called by my name would have helped. Apart from the earlier consultation, my own personal preparation (totally inadequate) was to read a leaflet that came with the video I had purchased from BHF, showing a patient undergoing an ablation (no worse than going to the dentist, they said), then to pretend to everyone I knew exactly what was going on. Oh, and I did stack my refrigerator as I knew I wouldn't be rushing to the shops in a hurry.

Next morning I came home with the usual discharge papers, but with no contact for help or support thereafter. My next meeting with the cardiologist was in eight weeks time. Back on Sotolol and now aspirin to alleviate the clot risk.

In early 2007 the Atrial Fibrillation Association didn't have their helpline operational. Having struggled to find anywhere at all, I cannot emphasise enough the need for support and reassurance in those early days. Personally, my trust and reliance on an old friend's help was completely lost a day after coming home. To be told I was ill-advised and entered into the whole procedure quite flippantly was certainly no way to begin a period of recovery, particularly when so vulnerable. Best friends, I thought, should be there to support you, not destroy your personality and undermine confidence. My cardiologist's PA/secretary was my sole contact. She gave me wonderful support and listened sympathetically. A few words of reassurance amid her busy day were greatly appreciated. (Thank you so much.) Somewhere at the bottom of my discharge notes I found the name Arrhythmia Alliance, which later led me to find AFA, my constant contact of friends and on-going supporters to this day.

I do urge everyone to use the support lines which are now in place. They are there to alleviate our fears and concerns, and manned by skilled people 24/7. Reassurance is like getting a great big hug and saying everything is alright, which I certainly needed at the time, yet couldn't find.

For me, recovery time was very slow. I felt unwell for a lot longer than I had expected, and found I was quite wheezy and breathless a great deal of the time. You also have to bear in mind that you are dealing with four hours of anaesthetic. I returned to work three weeks after my ablation.

Waiting time to see the cardiologist and get your results is “forever”. My April appointment finally came round, to be told, “These things don’t always work first time round” – I assumed I was back in AF, but didn’t ask.

I went off to spend the summer, get on with life, and decide if I wanted to commit to a second ablation. I was managing my AF with Sotalol and wanted some quality of life back again. Holidays were planned and I was enjoying my new job, having just fully got back into it. As summer wore on, all the symptoms of AF were naturally still there, and not wanting to be ignored. By late August I began counting down the weeks to my next appointment with the consultant in October 2007. It was agreed to repeat the procedure and I was booked in for a second ablation in early 2008.

Christmas came and went, with life’s little surprises. At our local carol service I began with my usual exuberance, only to find I had no puff to sing “Hark! The Herald”, let alone join in fully with the carols to follow!

January 2008: this time I knew more, or so I thought. Again, I took it on board alone. I walked over to the hospital, the same one as before, but with a completely different approach. A new Cardiac Care Unit had opened; I was welcomed, spoken to and reassured throughout. I still had a long wait but felt comfortable that someone knew I was there this time. Things don’t always go to plan; again I was very unwell for quite a long period afterwards. I had hoped to be back at work sooner and get on with my life, but this time it took longer to recover and without medication I was very frightened as to what could go wrong. It is very difficult to explain, but I did struggle alone. To readers of my story, please do not be put off by my experience. There is a good percentage of success following a single ablation procedure, and a considerably greater rate with repeats. My heart anatomy is just slight different and has not allowed this to happen.

I returned to work four weeks later. My walk to and from work necessitated a couple of rests, thank goodness for park benches! The groceries came home in small amounts; to carry any more exhausted me. As for changing the duvet or hoovering the flat, this was a big chore and required accompanying sit downs to say the least.

Like so many other AF sufferers, I have kept a daily diary, starting with my pulse rate every morning, to which there appeared to be no pattern whatsoever. Faster, slower tomorrow, uneven and so on. Recording daily events also helped me recall them in my all too brief consultations.

May I raise a point regarding the relationship between GP and specialist, which has been an ongoing topic of discussion at our meetings, as to whether patients with AF are better managed by arrhythmia specialists or the GP? As a private patient I was managed, and still am monitored, by my cardiologist, with interim visits to the GP practice.

My first experience with the practice was when medications were changed. Follow up letters were sent and I dutifully went back to my GP, only to be sent back to my cardiologist, wasting everyone’s time. I was given another appointment to see him and explained that I needed my prescription. In fact I think my doctor told me why I was there, as at this stage it was hard to speak with him and embarrassing to me that I

had not been able to insist more at the practice. I very much felt I had become the messenger between the two, a quite unnecessary exercise to specialist and patient alike.

The second time, and possibly more upsetting was following my second ablation. The GP was so supportive initially; I had three appointments during the first week, plus being sent back to have a 24 hour monitor as my heart rate was not at all stable. So consequently, this is where you turn to again, with my specialist appointment still three weeks away, on no medication and still feeling unwell, I wanted to be reassured. Having checked my heart rate and blood pressure, she suggested I should bring forward my appointment, telling me that my heart was dropping a beat and blood pressure differentiating between sitting and standing. I brought forward my appointment and preceded it with a 24 hour monitor. With these doubts in mind I went along expecting something to be wrong, and approached my consultation in a similar mood. I was probably at my lowest at this time, so to be told I was in normal sinus rhythm and three pulmonary veins were successfully ablated went over my head. I remember my doctor saying “no more nasty operations” and what should have been a happy occasion passed me by. I didn’t even say thank you for all his hard work and care. I left and went to my afternoon’s work – and cried a lot. To this day, I regret more than anything, not saying thank you at the right time.

From my own experiences I have learned, too late in hindsight, I made the mistake of not directing my concerns to my cardiologist throughout, the time between appointments is too long following procedures. On the other hand I didn’t want him to know I wasn’t managing, mainly from fear of the unknown. It is not always wise to burden your very busy GP. I now only consult my cardiologist and will continue to do so as I trust him implicitly.

I am writing now at the end of autumn 2009.

My cardiologist continued to support me. He patiently continued to seek other avenues to help alleviate my arrhythmia. Currently I am in sinus rhythm most of the day, but still experience Atrial Tachycardia from the fourth pulmonary vein which was unable to be ablated. I spent the greater part of the year free from medication and side effects, which felt so normal! However as the months moved on I began to feel palpitations. Consequently, I am back on Propofanone, with uncomfortable side effects. However, I am looking forward to changing to Dronedaronone in the New Year.

Good news though, during this year we have concluded why I still have an arrhythmia. With this comes peace of mind, and I somehow feel so much better.

20th December, 2009. I had to add this...I have just come home from this year’s carol service and I can sing again! Bliss!

It has taken me four years to try and piece my story together, pages and pages hand written during summers in the garden, or by lakes on my Swiss holidays. Each year has brought something new into my life – not always pleasant.

I now firmly believe there is no quick cure. Just be patient.

For me it has been very therapeutic to write. My first attempt to do anything like this, I've certainly shed a lot of tears in the process. Not being an emotional person previously, I found the whole experience overwhelmed my life in a way I had not know before. It was, and still is, difficult to deal with at times. Being a very private person, I usually hide my emotions.

In conclusion: I am extremely indebted to my cardiologist, having put my life in his care twice. I have sometimes found it difficult to talk with him, but that is improving over time. Do think of all the wasted consultation times, the questions I should have asked if I'd know more in the early days, and most importantly, not forgetting my "thank yous". So many good people out there are working tirelessly to help us all; I have nothing but praise for the whole cardiac fraternity and their associated bodies.