

Kirsten's story

Christmas 2003. After eating heartily my heart gave a few hiccups, with a surge of adrenaline, it scared me but I said nothing and carried on and a few days later it happened again.

After a few of these sessions I saw my GP who told me this was normal and something that just happens. They were frightening and I knew nothing about what they were there, why were they happening, anything at all. Time moved on and nothing changed, my GP said it was normal but referred me the local hospital where the consultant cardiologist gave a 24 hour electrocardiogram monitor. I was shown how to use it and wired up. I had to press a button when I felt a palpitation and after 24 hours return it to the hospital. The pads attached to me gave me a rash that took several weeks to clear by that time the results showed that I was, "still experiencing palpitations but they are really very short lived and only a couple of time a week. We have only documented super ventricular and ventricular ectopics which have been fairly infrequent, and I have reassures her that there is nothing wrong with her heart and discharged her back to your care, yours sincerely, consultant cardiologist."



My GP put me on beta blockers to see if that helped - I slept and couldn't get off the sofa to look after the children, I had to stop taking them, and I was put on diazepam.

On 27th February 2005 at about 8.00am I referred myself through Accident and Emergency with "palpitations" and was admitted for observation. I was ignored for several hours and then sent home, they decided I needed to come off all medication. I was traumatised and very scared. At 1.09am the next day, my husband's and son's birthday, I was back in Accident and Emergency admitted with palpitations and on examination found to have fast AF and sent to Cardiac Care Unit. I was wired for sound and put on an intravenous drip of Flecainide which put me into normal sinus rhythm and was started on Flecainide and Aspirin as regular medicines. Aspirin made me ill and was soon stopped as the gastritis was too severe.

I went home the next day in a state of nervous exhaustion and went to pieces, the anxiety was worse than ever and I couldn't cope with the fear of not knowing when the heart would work. I had lost all confidence in my body's ability to keep me alive and healthy.

It was not just a physical tiredness but an emotional and mental one. I could not eat or sleep properly and with the help of my family, relaxation therapies and more medication I took about 8 months to gain my confidence in my body and was able to get to some level of living "normally"

That anxiety has never completely gone and there is a shadow of that time always with me because I didn't cope. I was a neurotic middle aged woman being just over forty who should not think as much, get on with life and stop worrying.

The Flecainide worked for several years but slowly it began to let runs of fibrillations ran back into my life. In that time I looked after the children, my family, helped in school life as a cooking and

reading mum. My husband had been the head teacher and had moved school after a false accusation. Was the stress a precursor to the Atrial Fibrillation? We may never know.

I was seen 27th July 2005 in the cardiology clinic, I mentioned at this time that the palpitations which were still happening but short lived happened around the time of my menstrual period it was noted ,

“She is otherwise very well. Her exercise tolerance is good. She denies any symptoms of breathlessness. She was initially very anxious about her diagnosis but since then I understand she has been seeking counselling and is doing much better”. “She was unaware of why the aspirin was stopped, therefore have restarted it as it is important to her paroxysmal Atrial Fibrillation and I have added Omeprazole to her medications as she has previously suffered from indigestion. I am happy to discharge this lady back to your careyours etc”

I must have told her about indigestion etc and my intolerance to aspirin for her to mention the indigestion.

I found a counsellor who I met with as often as I could. He was probably a life saver - a wonderful mate and more of an angel than even having Reverend as a title allows him.

No one in the medical profession suggested a support network or any help with my mental well being.

I did it.

My internal state was sore and sick and unable to tolerate the drugs I was offered. I spent the morning nauseas and with fuzzy headed oblivion. I had realized that one of my main triggers to set off the Atrial Fibrillation was being sick, so one set the other off and the cycle of anxiety made the nausea and vomiting worse. I was finally “put on” cyclizine after nights of little sleep, anxiety and vomiting.

It helped a bit but didn't change the fact I was still ill mentally and physically

On 24th October 2007 in accident and emergency with another attack of A Fib. I had always been told that because the risk of a stroke I must go to the hospital for treatment. Although I was never offered Warfarin. I was found to be a patient increasing in symptoms for cardiology review. They did an ECG by which time I was having transient ectopic beats. My prescription was changed again and I was sent home, taking probably about 3 hrs. Most of the time I was alone with no nurse or Doctor input. But I was given the option of trying to stop Diltazem at some point just to see if the episodes reoccur.

I felt that my opinion was considered but with no specialist knowledge of cardiac drugs to fiddle my pharmacology alone was a lot to take on board.

This pattern continued and in June 2008 I was seen in clinic. In the letter my GP received the cardiologist talks in a disparaging way, when talking about me, “she feels her symptoms were precipitated by nausea” not Mrs. M. knows. She then lists the treatment at the time, “she has been nauseated since being on Flecainide 100mg BD and has recently started on Cyclazine and Lansoprazole to combat it (sometimes it worked) Diltazem XL 120mg was added to her treatment regime in November but she has had a breakthrough episode of palpitations since then.....

Reassuringly she has had a normal echocardiogram, scan and thyroid function test in the past..... I think a lot of her problems stem from the side effects.... Notably the Flecainide and I have suggested she discontinues this (she told me the 50 mg of Flecainide I had been on was no more than a homeopathic dose and probably didn't do anything) we have had a chat about future pharmacological treatment options at minimizing the frequency of her attacks... although she could try a higher dose of Diltazem she prefers to give Sotalol 80mg bd a go I suspect this decision is influenced by the fact she has joined an online patient support group... to be seen in 6 months."

The support group was the only place I had to go find people like me and was run by the Atrial Fibrillation Association. It was an angel sent from heaven and remains a great comfort and source of brains and laughter.

It was only after a further admission, which was a trauma from beginning to end, did I feel I got somewhere. On the 9th Oct 2008 I was admitted through Accident and Emergency with another attack. I waited for several hours in A&E to see if my Sotalol would do anything, then I was told they would put me on a beta-blocker drip and after 3 hours I was told that would not happen as there was none of the necessary drug in either of the two local hospitals. I was admitted to a medical observation ward and had further talks about not going back on Flecainide and the fact that I would need to go onto Flecainide to put me back into normal rhythm. I talked about how sick it had made me and was aware that if the hospital had the correct medication wouldn't need to be back on Flecainide.

I noted that it took about 5 hours before I was given anything to stop my blood clotting and this was after the drugs had been ordered by the Doctor but the ward staff had not had time to get them from Pharmacy or to administer them, both the Doctor and my husband had to "remind" staff. The care on the ward was nonexistent to many of the patients. The dignity of many was compromised and treatments were given to others such as urinary catheterization for the convenience of the staff.

I was barely observed and although my heart was still racing at about 140 beats per minute the monitor was removed by a nurse as it kept going off and the alarm made a lot of noise. Later the Doctor returned, reset the alarm and put the monitor on again.

I was told I would move to the cardiac care unit as soon as the steam cleaning was finished, I wondered was there an infection on the ward? After receiving my drugs at about 4.00pm I got to the ward at just after 7.00pm. Three darling older ladies gave me the low down on the ward and one gave up her bed so that I could have a bed space with a working monitor! The dust that fell when moving the monitor showed that no cleaning had taken place.

My family left and I rested fitfully through the night until at 5.00am the next morning I popped back into my normal sinus rhythm. I was given Flecainide again after a discussion with the nurse. I reminded everyone I can't tolerate it. The first Doctor who saw me said don't worry, keep on Sotalol and go home. It was only after a more specialized Dr I was offered a check ECG. It showed the Sotalol was affecting my heart beat and was causing long QT waves which could in turn give me an irregular heartbeat. He did however say I needed referring to Papworth, Hurray. About time.

So I saw the Electrophysiological Studies Doctor, and was put forward for Pulmonary Vein Isolation. He said wait till after Christmas, go on Warfarin and await a date to go in.

I asked my GP after Christmas who said wait until you get a date then go on Warfarin. I got a date but wasn't on Warfarin so I had to be put back in the pile for a while.

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About a month later and the Warfarin was going well except that the effect on my menstrual period. The entire bleeding in one morning and four days feeling sick and anaemic and a scared family. I had lost over 300mls of blood. Some more tests ensued to see if the ferritin in my blood was high enough. So now I was trying to eat when I could food with lots of iron in but without vitamin K in.

Weeks of being able to do anything and not thinking much about my health are more than the weeks of sickness, weakness and anxiety the hormones in my body seem to have an effect on everything. Is it my hormones affecting my heart? Who knows, I don't.

Iron had the effect I knew it would; making me sick and nauseous and sent trickles of Fibrillation that scares me

Protocol means that I am only "allowed" to go up a milligram a time on the warfarin. My Dr put me up a bit, but whether that will make any difference I don't know.

I was in a bogged down, drugged state. Couldn't wait to get out of it. It was different again a week later eating, sleeping, off the iron and living on a positive mental attitude, better period, warfarin in the zone, and all together doing well. Just a lady in waiting.

The lady has waited and now the lady has had the pulmonary vein isolation. Papworth is the most wonderful place and specialist in so many ways skill, compassion, dignity and ducks. The grounds are wonderful and have a duck pond. Although you may be scared and poorly the grounds help to build a holistic approach to the well being of patients, staff and relatives, bird food on the NHS is a bonus!!

The recovery is going as I thought; slow but sure. The next song that comes to mind is the Power of Love by Jennifer Rush. I was the basis of an article about my condition in the Daily Mail and the Atrial Fibrillation Association got many hundreds of comments and I thought I was just going to be the next day's chip wrapper.

"Each one, teach one." If I can pass my knowledge on to one person who does the same then soon the ripples on the pond go far and the information is shared and that is what love does to make the world go round.

So now the next step towards the rest of my life three months to recover and then maybe tablet free.....

Well six months down the line I have been back to the Dr's many times feeling exhausted and dizzy, loads of ectopic beats and a mixture of good and bad health. I had my follow up at Papworth and was doing well. Then I was diagnosed about being anaemic with a HB count of about 8.6. the fibrillations and funny beats got worse and at the end of October I was back in hospital with a slow but irregular heart beat so again I was observed and taken to the acute assessment unit where they thought I may need a blood transfusion, but with the care of a wonderful Dr I was informed that of course one of the side effects of severe anaemia is an irregular heartbeat. He asked the haematologist to put me on an IV transfusion of iron. It looked like black treacle. I was transfused

and as it takes several weeks to work I am resting at home awaiting further blood tests to see if it has worked, still putting up with ectopic beats and palpitations and busy knitting, doing patchwork and writing articles on Atrial Fibrillation, so every cloud has a silver lining.

I have to go back to Papworth soon and at last after many years of saying I have abnormal periods I have been referred to the gynaecologist at the local hospital to see why the bleeding is happening and maybe the anaemia will improve the sickness. Palpitations around my periods may be sorted a bit too... who knows.

All I can say is thank you to the Atrial Fibrillation Association for the friendship and love and information they have given and continue to give me. I send a bouquet of pink carnations to each of you