

Atrial Fibrillation

My Journey

Lynda M

My journey began when I reached menopause. It started slowly with palpitations that lasted over a couple of days for a couple of hours at any one time. The pounding in my chest started to annoy me so I presented to the emergency department to find out what it was. The diagnosis was atrial fibrillation (AF) and I was informed that I needed a cardiologist to investigate the cause. Well I found my cardiologist who organised a stress test and my blood pressure to be monitored for 24 hours. During the stress test I went into atrial bigeminy and it took about a couple of minutes to recover at the end. The cardiologist was not worried about the atrial bigeminy and therefore I passed the stress test. I commenced taking sotalol for the arrhythmia and things seem to settle down for a couple of years. During that time I would see the cardiologist on an annual basis. Now sotalol is an interesting drug to take it slows down your heart rate and you feel as if you have a slow working pump in your chest. It feels like your heart does not have enough petrol to run and you want to get a hand pump to give it a kick start. It took a little time to get used to this feeling. During this period I tried to live a normal life but the AF kept encroaching into my life. I remember one winter when I was very sick with the flu. My heart started to race and I became very breathless. During that night I woke up gasping for breath and my heart was so erratic I called triple 0 for help. The ambulance officers took me to the emergency department at the local hospital and would you believe I was in sinus rhythm on arrival at the hospital. This is what makes things hard for AF sufferers one minute you are in AF and the next minute you are out of AF. I cannot control this but people think you are just being hysterical and trying to get attention. This is the last thing you need to be told when you have runs of AF that are giving you physical symptoms and causing you a lot of distress.

All was quiet for a while after this episode of AF although I still continued to have short runs of the AF. I thought that I was able to cope with the situation. Coping is not easy there are days when all you want to do is sleep as you are just so tired. You are unable to walk short distances because you get so breathless and feel as if you are going to pass out. At night the AF would wake you up because you can feel the

pounding in your chest or because the naturetic hormone in your atrium has been stimulated and you need to pass urine. I later learnt that this is called the big" P". During those times I just started to cry for no reason. I would be sitting watching the television or doing some house work when I would just sit and cry. A feeling of sadness and aloneness would come over me. You feel as if no one really wanted to help you and did not understand what you were going through. I would later seek help with a Psychologist because of these feelings.

In January 2005 things seemed to get worse. I contacted my cardiologist after being in AF for three days. He admitted me to the coronary care unit to have some intravenous amiodarone. After being in the coronary care unit for about 4 hours I reverted back to sinus rhythm. The cardiologist spoke to me about the possibility of having a stroke because of the AF and would only allow me to go home if I was able to give myself clexane injections. Well I have been nursing for 40 years and did not think this would be a problem. I remember standing in my kitchen with the injection in my hand and grabbing a bit of fat in my abdomen in the other hand and just standing there not wanting to give myself the injection. It was surprising how easy it was to give the injection as the needle seemed to slide in through the skin and into the fat in my abdomen but did sting a little when I injected the clexane. I continued to give the clexane injections until my INR was in the therapeutic range. So began my life with warfarin. Taking warfarin requires blood to be taken frequently for INR levels. This is to determine what dose of warfarin you should be taking. At first this was twice a week and then once a week. Finally I was able to control the INR with monthly blood tests. You get very critical of people who take blood when you have it taken so often. I would determine who was on duty prior to going to the clinic. If I did not like who was on duty in the clinic I would not go. One person was so bad at taking blood I did complain to the pathology company. My GP was aware of my concerns and would organise other blood tests to be take at the same time as my INR's to reduce my stress.

So here I was again alone and at home trying to cope with this pounding in my chest and giving myself injections. I was constantly tired from the medications I was taking and was not sleeping well. At this point I went back to my cardiologist because I just wanted to talk to someone regarding what I was going through. I really wanted to talk

with someone who was going through the same issues as I was. However there was no one who I could relate to and my feelings of sadness continued. I was aware that there was a psychologist available who had a special interest in people with heart problems. However I still did not contact the psychologist because I felt that I understood what I was going through and thought that I could find a way out of my problem.

During the month of January and February 2005 no drugs could keep me in sinus rhythm and the AF continued on and off in an erratic manner. I felt so unwell when I was having runs of AF. I would sweat continually and felt like I was going to pass out. I just about saw my cardiologist daily and during this period. I began to respect and rely on him for helping me. I continued to work only because I felt so safe at work. I could get to a cardiologist if I wanted to and the emergency department was just a flight of stairs away. The cardiologist changed me to Flecainide and finally to oral amiodarone but nothing seemed to stop the AF. Finally he started me on atenolol. Getting use to atenolol is not easy. Your legs feel like jelly and I found it hard to breathe. I also found it difficult to walk up a small hill because I could not breathe and felt as if I was going to faint. It was at this time the heavy feeling in my chest and left arm began and I still have this feeling today when I have been in AF for extended periods of time. Another stress test was organised urgently but I failed this one because I felt as if I was going to faint and became very breathless after three minutes. Now the cardiologist admitted me to the coronary care unit again on a Friday. He suspected coronary artery disease and organised a coronary angiogram on the Monday. Sitting in coronary care for a week end makes you worry also. I had nursed people in a coronary care unit and now here I was requiring the same care.

Now in the midst of all this bad news something came out right. My coronary arteries were clear. I did not have any signs of coronary artery disease. However I was still in AF with a rapid ventricular response. For some reason I would not convert to normal sinus rhythm (NSR) and remained in hospital for a couple of more days. Finally I was discharged but still in AF. While I was in hospital the nurses suggested that I ask to see an electrophysiologist (EP) and have an ablation. Now I have never heard of such a procedure or such a cardiologist but quickly I learnt this is the person I needed to be referred to. My cardiologist made an appointment for me to see the EP but I had

to wait till early March because he was on leave. Well how I got through the next couple of weeks I will never know. I started keeping a diary of when I went into and out of AF. I do not know if this made things worse but somehow I felt that I was in control of the AF episodes. AF is an interesting problem as you know the second you go into it and the second you come out of it. It is like a switch is turned on and off in your heart. You can be sitting quietly watching television or exercising and the switch will be turned on or off. I do not think I had any specific triggers as my pattern was so erratic but perhaps alcohol is a contributing factor. It is because of this my consumption of alcohol has been reduced from a bottle of wine a week to about 2 glasses of wine a fortnight. It was around about this time that I brought a statue of an angel. I put the angel on my bedside table as I wanted someone to look over me when I was asleep.

Once you have dealt with a difficult health problem you tend to trust the doctor who got you through it completely. I trusted my cardiologist completely and now I was to be treated by someone I did not know. The EP appeared to be very nice and was willing to answer any questions I had. He looked at the treatment options available for me and decided that my best option was to have an ablate and pace procedure where a pacemaker was inserted and at a later date the atrioventricular (AV) node is ablated. This sounded crazy to me. I already had one arrhythmia and now he wanted to give me another. I found it hard to accept the treatment and for the next couple of months asked both cardiologists a lot of questions and searched the internet for answers. Finally I agreed to have the pacemaker inserted but did not want my AV node ablated. I did not realise that my decision was right until about 3 years later.

My feelings of aloneness began to appear again. I do not know if this was because I was living alone or because I was so independent. So I began to search the internet for more information regarding atrial fibrillation and its management. While searching the net for answers I stumbled on a web based support group for people with AF. Well I think I found gold or won lotto. This was a World Wide Web group based in the USA for people going through the issues and problems I was going through. There is no support group in Australia for people with AF. I tried to form one but found the cardiologist and cardiac nurses did not think that forming a group was necessary. Now believe me the thing you need the most when you have AF is

support. The best support comes from people going through the same problems and issues as you. AF controls and changes your quality of life. You are ruled by AF and anything you want to do is determined by you being in or out of AF. I now have friends all over the world who have given me advice and support with my journey. Information is another important thing you need when you have AF. Treatment options give you hope and all need to be discussed with you I think when you are first diagnosed. You need to make your own decisions regarding management as any decision can determine what will happen to you in the future. AF changes everything regarding your quality of life and what plans you have for the future. Some people on the web refer to AF as monster that is controlling your life. Sometimes I think they are right. The other issue that is important is you look well despite what is happening inside you. People have nothing to see and therefore think that the issue could not be that bad.

I had the pacemaker inserted in April 2005. I fought so hard not to have the pacemaker but finally I realised that this was a good option for me at that time. Having a pacemaker inserted is scary. You are only sedated during the procedure and can hear everything that the EP is doing. I could hear the tinkering of tools and it sounded as if the EP was building a tinker toy to put into my chest. It is painful after the procedure especially for the first week post implantation. You have a piece of metal inside you and believe me you can feel it sitting there. To me pacemakers were for old people and I did not consider myself to be old (I was 56). After about a month I could not feel the pacemaker but could feel its presence when it would do a self check. It is like a twitching inside you. At first I did not understand what was happening but now I am use to it. There has been times when I was glad to have my pacemaker.

At this time two things happened that caused my thyroid function tests to become abnormal. The company that was making my thyroid replacement medication (I had a total thyroidectomy 10years prior) changed the formula of the medication and I started taking amiodarone. A routine check of my thyroid function tests revealed that I was taking too much thyroxine and my dosage had to be reduced. Now everyone knows that thyroid toxicosis is a cause of AF and now my thyroxine medication was contributing to my problems. It is also well known that amiodarone can alter thyroid

function. I was sent to see an endocrinologist who agreed that both issues could be a contributing to my AF. The thyroxine was reduced and my thyroid function tests are now being checked every three months. The amiodarone was ceased and I was recommenced on sotalol. The endocrinologist also advised me never to increase my dose of thyroxine by more than 50 micrograms per week. Well even with the pacemaker the sotalol did not control the AF so the EP increased the dosage of atenolol. I have never liked taking atenolol but I must admit each time the drug was increased I did feel better. I later learned that this was because the atenolol was controlling my ventricular rate. Taking beta blockers makes you dream. At this stage I was taking both sotalol and atenolol. I started having these amazing dreams in vivid colour. I would dream about anyone I met but mainly about the people I worked with and the doctors that were looking after me. Mostly they were good dreams with no drama or danger. Twice I had a nightmare. I can still remember the dreams today.

During my moments alone my episodes of crying continued. I blamed the doctors for not stopping the AF. I blamed the doctors for my thyroxine levels being out of control. I was angry with them because I thought the pacemaker would bring things back to normal but it did not. The doctors seemed to understand what I was going through and tried to offer help but this was something I had to work through myself. I often feel guilty for how I treated the doctors but like before they always treated me with respect and tried to help me work through my feelings.

Now I met a group of people who gave me some support. I was walking down the stairs at work one day when a young man approached and asked me if I intended going to the cardiac rehabilitation gym. Well that was interesting because I did not know that this should be considered as an option in my treatment and rehabilitation. He was so nice and persistent that I agreed to go. This was probably one of my best decisions in my recovery. At the gym we mainly exercised under supervision. All the people there were recovering from some type of cardiac condition. My strength returned and finally I had some people to support me. No one there was suffering with AF therefore they did not fully understand what I was going through but they did give me support. The staff tried hard to get me away from thinking about the AF but believe me this is impossible. At times I would go to the gym and could not exercise other times I felt so well that exercise was not a problem. It has been do what you can

at the gym and at times things were hard for me. I am still going to the gym four years later.

My friend (a Nephrologist) in Sydney was very concerned regarding what was happening to me. She approached a cardiologist in Sydney and asked him to review my case. An appointment was made with the doctor and off I went to Sydney for a second opinion. I cannot emphasise enough the importance of having a second or even third opinion especially when you have a chronic illness. It opens you up to different ideas and gives new treatment options. The cardiologist in Sydney discussed the possibility of having a pulmonary vein isolation ablation (PVIA) with me. Now this is a very complex procedure with a number of very serious complications. Agreeing to have such a procedure should be considered carefully. All aspects regarding the procedure worried me and I discussed this with my EP when I returned to Brisbane. Overall the PVIA was the right treatment option for me but it would be four years before I finally agreed to have this procedure. I was surprised regarding the reaction of my EP to me going to Sydney. He made me feel as if I was being disloyal to him and really did not understand my need for knowledge. I have nothing but praise regarding the two cardiologists that look after me in Brisbane. Being a nurse has made it difficult for me and both cardiologists. I would not accept any treatment option they wanted to do without questions and I constantly challenged their opinions. I researched AF and often asked questions regarding why they had chosen a particular treatment option. Through it all both of them have always treated me with respect and were so patient when I was trying to make a decision. I respect both of them. I later learnt that my EP had reservations regarding the PVIA procedure because of the number of deaths that had occurred on the table during the procedure. Waiting four years was the right decision but I did not know this at the time.

One thing that should be made clear to a patient is which cardiologist is in charge of your care. I now had two cardiologists looking after me and I really did not know who I should be seeing. So I started see both. This started to get confusing for me and for them. One cardiologist would make a decision and then I would go to the other to make sure it was the decision they would also make. I must say both worked out of the same practice so both had access to my notes but I really did not know who I should see. It was a difficult situation but both cardiologists treated me with respect.

For the next three years I was in and out of AF all of the time. Sometimes I would get very sick and other times I could cope with the situation. If the episodes lasted longer than a day or I would start to get symptomatic I would always seek medical help. I did not like disturbing the cardiologists so I would often present to the emergency department where I worked. I came so often the nurse in charge of the area was thinking of naming a room after me. You only go to the emergency department when you are frightened. Having a rapid pulse rate for extended periods of time makes you very tired, breathless and you become frightened especially when you do not know when it is going to stop. One of the most important things to me was to stop the pounding in my chest. I would do anything or go anywhere if this pounding would stop. You cannot walk a short distance without this constant pounding you cannot do anything without this constant pounding. I tried so hard not to disturb the doctors or burden any one with my problems but at times I got so frightened I felt as if I was developing heart failure and needed to be reassessed by a doctor. Some doctors were marvellous and understood what I was going through. One doctor in the emergency department treated me as if I was just annoying him and what he was doing was more important than seeing me for something I was being treated for. I wonder if that person should continue to work in medicine. I was very ill one day with the AF and had to go to the emergency department. All I could do was cry when the triage nurse was assessing me. I explained to the nurse that I was frightened to come because the doctor told me never to come again to the emergency department unless I had chest pain. Stress can be a trigger for AF and now I was in AF with physical symptoms and because of the stress things were getting worse. The triage nurse must have spoken to the doctor who looked after me on that day because I was treated with kindness and respect by him.

Now I began to realise that when I had a fib/flutter pattern I felt worse than if I only had AF. I could not exercise in fib/flutter and my symptoms were worse. Now when I went to the gym and I felt unwell a rhythm strip was always taken and sure enough the fib/flutter was present. Now the staff began to recognise what was happening to me and started determining what exercises I could do at that time. They also encouraged me to go back to the EP because of the severity of my symptoms when I was in the fib/flutter pattern. I would not do this because I did not like to disturb the doctors especially when I was coping. However the cardiac rehab staff kept asking

me to tell him how unwell I was. It is difficult because you generally see the EP when you are well and you see the cardiac rehab staff when you are unwell. This is again the nature of AF when you are in NSR you are well because you do not have the symptoms. My problems did not change and after a year I started to get tired of the situation I was in. One nurse decided to be my case manager and every time I was unwell she would discuss it with the EP. I do not know if it was my case manager or me who convinced the EP that I need a flutter ablation. One day I felt so unwell at work I attached myself to a cardiac monitor and took a rhythm strip. Sure enough I was in a fib/flutter pattern with all the associated symptoms. I took the strip up to the doctor's rooms and waited while he reviewed the strip. Now the EP came out and advised me he could stop the flutter waves and this should relieve my symptoms. So I agreed to have the procedure. Now I had been to the cardiac catheter theatre before so this was familiar. However something was different as a part of my heart was to be burnt. Scar tissue would form and I did not know if it would be painful. I also was fearful that my AV node that I had fought so hard to protect may be damaged. I must say the staff in the cardiac catheter theatre was very supportive and they seem to know what you are going through. It was an uncomplicated procedure and successful. I do not think I have any runs of flutter since the ablation was performed.

Now I was happy my symptoms had been reduced and I felt much better. However I was still getting very breathless especially when walking only a short distance. I also noted that my feet were becoming swollen. This was so bad at the week end I would spend most of the time sitting with my feet up. I went back to my original cardiologist and demanded something had to be done as I was getting fed up with the situation and I thought I was developing heart failure. He gave me two choices for treatment I could be referred to another cardiologist for a PVIA or I could start taking Lasix for the oedema. Being a renal nurse the option of taking Lasix did not suit me so I agree for the referral to another cardiologist.

Now I had three cardiologists looking after me. My first meeting with the new EP was interesting. This was a lady working in a male dominated field. She was very petite and seemed to listen to what I was saying. I felt as if she understood the problems I was having and when I described my symptoms she took everything very seriously. I often felt that others did not take my problems seriously and thought that

I was not coping with my situation. I remember saying to my sister-in-law after the first consultation that this lady got me, she understood, she was aware of my situation and she offered to help me. Another thing that had never been said to me before was that she admired me for continuing to work full time. Now here was a doctor recognising that my situation was not good and praising me for my efforts to keep my life style as normal as possible. I did not know what to say to her. It would be three months before I would meet her again when I had the PVIA.

Now you would think it would be simple just wait three months for the PVIA. Not so. The swelling in my feet became worst so I made an appointment to see my original EP. As a temporary measure he commenced me on lasix and made a passing comment that maybe I had developed some renal failure because of the AF. Let me tell you never say that to a renal nurse. The next day I was immediately in the ear of the Nephrologist I work with and want him to investigate me for renal failure. He indicated to me that I have nothing wrong with my kidneys all my problems are cardiac related and this should be the focus of my management. So everything was the responsibility of the cardiologists.

I had my cardiac cat scan on the Thursday prior to the procedure. I knew this was an important test as the information collected during the CAT scan would be used during my procedure. On the Friday prior to the PVIA I had blood taken for a number of different tests and of course I collected the results of my CAT scan. I will never know why doctors seal reports and give them to nurses because the first thing you do is open the report and read it. I could not believe what the report said and contacted my EP immediately. It was noted that there was a possibility that a 2.5cm clot was in my left atrial appendage. This to me sounded dangerous and I thought this would mean that the procedure I had waited for so long could not go ahead. The EP was reassuring and indicated that I must have a transoesophageal echo (TOE) to determine if there was indeed a clot in my atrial appendage otherwise the PVIA procedure could not be done. The results of the TOE indicated that no clot was present so the PVIA procedure would proceed as planned on the following Monday. A layer of fat was on the outside of my heart and this is what the x-ray had picked up. I have never been so glad to have some fat in my body.

I came off flecainide three days prior to the PVIA and by the time I was admitted on the Monday for the procedure I was in AF with all the associated symptoms. It came on the Saturday night and never left till the end of the procedure. I was very nervous because this was a different hospital and I did not know any of the staff members there. However everyone at the hospital was excellent. They explained everything to me so I knew what was happening at any one time. The procedure took 5 hours and at the end I was still in AF so I was cardioverted. This was a surprise to me not that it happened but more the need for the cardioversion. They say nurses and doctors make the worst patients. I was only in hospital overnight and did not like it. Once I was given permission to be discharged I just wanted to go home. During my convalescence I did have some pain over the heart for about a week. I also was very aware of my heart beats and was always thinking that I was going back into AF. I have remained in sinus rhythm since the procedure. I have been back at work for over a month. The EP did indicate that during the next three months I could go back in AF and may need another cardioversion. I guess it is like living on a tight rope as I do not want to go back into the AF but if it happens it happens.

Since the PVIA procedure I can walk without feeling breathless or feeling as if I am going to faint. The pounding in my chest has gone although I am still very aware of my heart beating. Occasionally I feel something different with my heart beat but when I check my pulse I am still in normal sinus rhythm. During the last five years I did not sleep well because I was awakened two to three times during the night because of the AF or wanting to pass urine. Now I am sleeping better but I still dream because of the beta blockers. My colour is better, my lips are pink and do not have a blue colouration about them. I feel more relaxed, calm and do not sweat. The oedema in my feet is going although not completely gone as yet. I am thinking better and making clearer decisions. Having a normal heart beat brings you peace and I did not realise how AF altered all my normal body functions. The past four years have been very eventful for me but I am beginning to feel well. Being well is a precious feeling and having peace is powerful. I do not know where my journey is going now but I hope my heart rate remains normal. I am still an AF sufferer that cannot change. I have had a very good treatment to correct my problem. I must try and remember that I am not cured. I will need to be monitored for the rest of my life. I know that I am in good hands and now my journey should be less eventful.