

What is wrong with me?

Liz recalls a ten year struggle.

I was diagnosed with permanent Atrial Fibrillation in November 2005. As I lay in the ward near the nurses' station so they could monitor me I felt an overwhelming sense of relief. The nightmare for me had ended.

The story really started when I fell off my horse and injured my knees. After an initial delay in appropriate treatment and conflicting advice, I was left in pain and not eager to face medical professionals again.

“terrified I would just be dismissed”

Throughout the struggle for treatment on my knee, my breathing had been deteriorating and during a trip to Wales, I had severe breathing problems which resulted in a hospital visit and a diagnosis of asthma. My work continued, but I began to blackout. Back to the GP, and a referral to a heart Consultant. I was uneasy, fearing I was seen as an overweight, whinny middle aged woman, and terrified I would just be dismissed. I had an ECG, which the Practice Nurse said showed a slight abnormality. Further tests and a heart monitor followed, but when I saw the Consultant I was told nothing was found and it was probably the asthma.

By July 2005 I couldn't really walk across the yard without gasping for breath, and I struggled to get upstairs! I had a permanent pain in my back and couldn't stand for long. I was also 'swelling' (with fluid as I realised later) which really didn't do a lot for my view of myself. I was so scared they would tell me I was overweight and unfit and it was my fault that I didn't make a fuss and just carried on. Riding was hardly an option any longer, I somehow managed one last ride in September 2005 although nearly passed out at the start. In fact, that was to

be the last time I would ride for several years. The breathing got worse. My life alternated between trying to work, to lying still in bed throughout the day trying to stop the pain. Thinking it was yet another chest cold, I took whisky and lemsip at night but simply woke more tired than the day before, and that's if I managed to sleep. The pain in my diaphragm was nearly always present and I had pain in my neck and chest. I really needed someone

to go to the doctors to tell them how bad I was, I was just too scared to make a fuss.

Finally with another chest cold, I returned to the GP – but this time, I saw someone new to the practice. He asked me how far I could walk. I said about to the wall opposite the surgery because I wasn't very fit. To my total relief he said that it wasn't a question of being fit, I was ill. He ordered an ECG, a chest X-ray and a consultation with a specialist. He said to go to a certain hospital as the waiting list was

“I would just have to manage, I didn't argue”

less for the consultation. The ECG was done immediately, as too the blood tests. That evening he telephoned, making sure I would return to the surgery the next morning and only rest before then. The next day was when I first heard the words, 'Atrial Fibrillation'.

Suddenly no waiting list, straight to the local Medical Assessment Unit. The staff were so kind and I felt so relieved I wasn't just an unfit middle aged woman. That was just before the anger bubbled up, anger I still feel now because no one had taken any notice of

me being so ill and that I had allowed myself to be intimidated by people who were supposed to be looking after my health.

I was in hospital for two weeks, and that year I underwent several cardioversions. In the autumn of 2006, one was at last successful. However, by 2007, I was feeling very ill again. When I went to have an angiogram I was told I was in AF again, and the Consultant said I would just have to manage, I didn't argue. Thank goodness my GP didn't agree! He arranged a thyroid test which showed the Amiodarone had upset my thyroid and this had pushed me back into AF.

My new GP, who has been fantastic throughout, simply believed in me as a person. He was quick to remind me that late 40s, early 50s, is not old. Without him, I believe I may have died. So now we were off on the cardioversion trail again but this time I was admitted to an Arrhythmia Clinic, where I finally got a dedicated consultant plus specialist nurses who have all

been so very helpful. Although an unsuccessful ablation followed, and then a couple of partially successful cardioversions, I have been given enough encouragement to try another ablation some time soon.

Now, I am 51, I think I have had AF for ten years. I work full time, have travelled, written two books, Chaired the local Parish Council and sat on a number of committees. I am resigned to my body, to the Warfarin - which I hate and to the foul taste I have for hours after taking some of the

many tablets. I find I am still angry - to those who did not see beyond the 'middle aged lady', and with those who still don't recognise my health problems and think I am simply lazy when I have to sleep. If I don't sleep, I begin to feel

I wake more tired than when I went to bed. It is both frightening and frustrating.

The future? I haven't a clue. Will any one ever answer all of my questions? Should I change my life style? I

distance very tiring and bending almost impossible as I can't breath. I have learned from my young ponies, that taming a wild animal relies on getting their confidence, not on strength - perhaps another lesson learned? However, I too feel that AF has brought with it a form of 'premature ageing', without even meaning to you find yourself taking things more slowly, and thinking out how far you have to walk in order to pace yourself, I resent this, and I realise, I am still very angry.

“sleep it is like falling down a pit”

really tearful, and my brain goes to mush; I can't think and my words are slurred. When I sleep it is like falling down a pit. Sometimes

choose to carry on, and I do have more confidence in myself - and in dealing with medical professionals. However, I find walking any

2009 will see AFA working towards raising greater awareness of Atrial Fibrillation through a 'Know Your Pulse' campaign. As part of this work we hope to have posters displayed in shops, clubs, libraries colleges... everywhere! Not forgetting hospitals (but not just the cardiology departments) and local medical centres. So if you know 'just the spot' please contact AFA and we'll be delighted to send you a poster or pack of AF materials to hand out.

News from India

AFA receives enquiries from patients, carers and clinicians from around the world.

John, a member in India, shares his story:

Co-existing Uneasily with AF

In June 2006 I noticed I was breathing with irregularity, so went to a local cardiologist for a check-up. I already had hypertension and was borderline diabetes, now, after tests were carried out, I was diagnosed with Atrial Fibrillation. Current drugs continued with Warfarin being added to my daily cocktail. Fear of stroke was uppermost in my mind, and constant exhaustion plagued me.

I looked into other options, but in India there is no National Health Service, and private services are prohibitive due to high costs. So, the position for me, and for that matter, anybody in my country, is precarious so far as advanced medical treatment is concerned.

I am 70 years of age, a retired teacher, but as inflation goes up, I hope that some new medical gadget or invasive method cures me of this ailment with the cost being very, very low. Perhaps

that can only be a distant dream. My physical mobility is slightly compromised now, and each night I sleep with prayers on my lips that there will not be an emergency – this type of care is practically non-existent or extremely expensive.

I look forward to learning more about Atrial Fibrillation and hope one day to meet a kindred soul with whom I can exchange insights and ideas about this ailment.

John

The AFA moderated Forum offers individuals the opportunity to share experiences with fellow AF patients and carers. It is a friendly and supportive forum which protects the individual's contact details while enabling contact. Follow the links from the AFA website: www.atrialfibrillation.org.uk . 'to join'

Alternatively, join AFA at the 2009 AFA Patient Day, Sunday 18th October, further details on page 2.

www.HeartLibrary.com

Heart Library is a collection of educational, patient-focused videos about the human heart. The videos illustrate the causes of and treatments for many heart diseases and arrhythmia, including Atrial Fibrillation and Atrial Flutter. Each video is narrated by a physician in everyday language. New videos are added to the site regularly.



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