

This is my experience of what it is like looking in from the outside of my wife's problems with Atrial Fibrillation and arrhythmias.

During the 15 years I have known my wife, Sarah, she has always had bouts of palpitations which came and went and were never explained despite numerous GP visits. The GPs never took it seriously as my wife was young; they just kept telling her it was indigestion. We both knew it was not as we could feel her pulse erratically jumping around during these episodes and as a nurse my wife would tell me she knew she had some sort of arrhythmia. Even when she had an emergency caesarean to deliver our son, the Doctors commented that her pulse was irregular but they put it down to giving her too much anti sickness medication. One night whilst Sarah was working a shift in a high dependency unit, she collapsed and they did an ECG which showed an erratic pulse rate of over 220!! She ended up in a bed next to her patients (which she found quite embarrassing seeing as she was supposed to be looking after them). She was immediately referred to a cardiologist, this was such a relief after 10 year of trying to get someone to take the situation seriously.

Sarah saw the consultant within a couple of weeks, but in the interim the GP put her on an anti arrhythmic drug which made her feel very ill and which the consultant immediately stopped as it could have proved fatal (since then we have followed only the cardiologist's advice). At the time the cardiologist was quite vague about the diagnosis but put her on Atenalol. He mentioned her having an ablation but felt that at that time the technology needed to be further developed.

A couple of years went by and we had moved to a different area which meant a change in cardiologist. The Atenalol was controlling things but only to a certain degree, so the new cardiologist suggested trying Flecainide instead, which helped but not enough so Bisoprolol was added into the mix. During this time Sarah was collapsing quite regularly and our son (then 7) found it very stressful watching mummy being taken off in the ambulance and often detached himself from her when she was having bad spells. He hated the hospital visits and wouldn't look at Sarah all wired up. For me, juggling work, childcare, housework and hospital visits was proving difficult.

In January 2006 Sarah was told she should go for an ablation to review her condition and potentially remove the irritant in the top chamber of her heart by burning away the affected area to stop all the extra beats being fired and causing some of her symptoms.

In February Sarah was taken for her operation, I was told she would be back in an hour or two. Well after 5 hours she returned, she seemed ok but she had chest and shoulder pains. Things had been more complicated than they thought. The consultant came round and briefed us on how the op had gone and basically announced that actually they could only do a little as the inside of Sarah's atrium was (in his words) a firework display, so the ablation they did was a small area to see what the effect would be, and whether further ablations would help. She was given a diagnosis of AF, Atrial flutter, SVT and ectopics (she never does anything by half).

Following the ablation Sarah had continual chest pain and bouts of arrhythmias and was often in and out of hospital. No one could get to the bottom of why she always

had pain and why she was collapsing. She hadn't worked since just before her ablation and was sadly notified that she would be made redundant from her job in the NHS on the grounds of ill health in the August with her last official day being Christmas eve. Her confidence disappeared and she became depressed at the loss of what she had once been able to do, she struggled with the guilt of not being able to do the things she used to do with myself and our son and I took on an increasing amount of things she used to do. The friends who had all been so amazing at the beginning were doing less and less as (understandably) there was no end date to what was going on and they had their own families and troubles to deal with. Admittedly, in these situations you very quickly learn who the real friends are. Financially there was very little help for us, which just made things harder. Thankfully my employer, unlike hers, was very supportive and enabled me to work from home for the most part.

As a husband I felt so helpless watching my bubbly, active, hardworking and caring wife go through all of this and not being able to do anything to help. I was watching her suffering in front of my eyes and watching while nothing seemed to be done to help her. Every time she went into hospital, she was resigned to being poked, prodded, bled, oxygenated, monitored and continually questioned. She dreaded the onslaught of junior Doctors who knew less about her condition than we did and would reduce her to tears with their flippant attitudes while she sat there in agony and on the verge of passing out.

2009 has been particularly bad and in July she had a nasty reaction to the Flecainide and ended up in hospital. She had a 'Reveal' monitor implanted to monitor what her heart is doing and has had a couple of changes of medication and fingers crossed things are a bit better.

We have found with Sarah that there are peaks and troughs; she can have horrendous flare ups which go on for months and then just niggling symptoms at other times. There has always been a fear that the Doctors were 'missing' something as her symptoms never quite fitted into normal patterns and in July it was suggested that she may now have developed something called 'postural orthostatic tachycardia syndrome'. Although not something anybody would want, it has been a huge comfort to Sarah as all those scary symptoms that were once the 'unknown' seem to finally make sense and although unpleasant have enabled her to get on with things with a bit more understanding of why her body does what it does. Further surgery is out of the question although we finally have a better balance of medication and are crossing our fingers that it lasts this time.

Over time we have learned to deal as a family with the limitations of her conditions, she has picked herself up as best she can and although she is unable to work, she busies her self with any household paperwork and organisation that needs doing, a distance learning course and being a member of a couple of forums which have proved a huge support to her as before she was told she was an unusual case and felt very alone. We realise now she is not so alone and there are other people who understand and this takes so much of the fear out of things for her. We try not to plan things in advance but will take the opportunity to do things on her better days. On these days she crams as much in as possible (despite my warnings that she will just make herself ill) and praises herself for the things she HAS been able to do (no matter how small). We used to walk for miles with the dogs and some days if she makes it to

the corner shop then that's a big deal. She has learned to forget the old her and learn to deal with the new her and I am so proud of her as I wonder if I could have done the same. Despite the difficulties we are a close and loving family, the three of us have been through so much together that I think it has made us closer. We will deal with things as and when we have to, as a husband, a friend and a confidant this is such a helpless position to be in, and I know many 'other halves' face a similar circumstance everyday all over the world and hopefully this is some comfort to those who find themselves feeling alone (family and friends often just don't get it or will deny it). We look forward to the good days, and help on the not so good days.