

My Experience of Cardiac Arrhythmia – David, 64

One evening in November 2009 I came away from a long, competitive game of tennis feeling I had overdone it. For a few minutes towards the end of the game I experienced discomfort in my chest like a kind of burning, but I played through it. I made light of my exhaustion at home and thought a night's sleep would bring me round. On the following day I felt worse, suffering periodic bouts of dizziness and breathlessness. It was not till I went to bed that night that I realised that my heart was racing. I was in palpitation, suffering my first paroxysmal tachycardia. I rang NHS Direct, and so began my engagement with the Health Service that has gone on ever since.

I am 64, and always led a very active life. I have loved walking, gardening, swimming, and playing tennis. I worked part-time, following my retirement from my profession as a social worker in 2007. As a schoolboy I discovered that I had a very low heart beat, around 50, and I became a long-distance runner. I always thought of myself as someone with exceptional stamina. It was not till the outcome of this game of tennis in November that I found out that my slow heart rate was an abnormal condition called bradycardia. And what was happening to me now, my racing heart, was called atrial flutter. My call to NHS Direct resulted in my admission to the Emergency Medical Unit overnight with a heart rate of about 125, which a few hours later, before I had received any treatment, went up to about 240. My case became an emergency. A medical team was around me, I was being given oxygen, I was having a heart-stopping drug called adenosine injected into my arm, and then, under sedation, I was subjected to electric shock, to return me to my normal heart rate.

On my discharge from the Cardiac Care Unit I was provided with medication and put on the day-case list for an ablation, which is a routine procedure to cauterise a rogue electric pathway on the muscle of the heart. This was carried out in January 2010, and I understood there was every chance of its being 100% successful. Over the weeks and months ahead I returned to a normally active life, even taking up competitive tennis again, as I was advised I could.

In August 2010 I found myself breathless during a game of tennis, and soon realised that my heart was racing uncontrollably again. Within a couple of hours I was in the Resuscitation Room of our local A&E Department, going through the process of having adenosine injections and electro-cardioversion to correct my heart rhythm. Over the next few weeks this happened to me on four more occasions. It didn't have to be tennis now. Following a hard day in the office, then just in the middle of the night while on holiday, randomly, without explanation, I would find my heart suddenly flipping into palpitation. I also found I was getting out of step with the NHS. A date to see the consultant was overtaken by events. Then a date for an exploratory procedure proved hopelessly too far ahead, and a second ablation procedure failed. One emergency admission resulted in my having a dual-chamber pacemaker inserted, which allowed me to be given effective anti-arrhythmic

medication. Till now my slow heartbeat had not allowed me to be given medication which would only make my heart beat even slower.

The accelerating deterioration of my condition was mystifying, frightening and frustrating. I found myself as if surrounded by an invisible trip wire which I could unknowingly set off at any time. I had to be off work. I felt worried about leaving the city and so going too far away from my local hospital. I could not judge what physical effort might tip me over into a palpitation. My wife and I had to cancel a planned holiday abroad. By the way, my condition was described in a variety of phrases, this adding to my overall sense of insecurity: 'atrial flutter', 'paroxysmal tachycardia', 'bradi-tachy syndrome', 'atrial fibrillation', 'atypical cardiac arrhythmia'. This shifting nomenclature left me feeling that no one was quite sure.

If, in November 2010, I thought that having a pacemaker inserted and being put on anti-arrhythmic medication was going to be the end of my problems I had another think coming. Nearly three weeks later I had yet another bout of palpitation in the night, was admitted to hospital once again, and my pacemaker was adjusted. And so it went on. In January another adjustment had to be made. And then I started experiencing further bouts of palpitation, more and more often. ECG readings brought furrows to doctors' brows. My medications were increased to the highest tolerable dosages. Etc..

This illness overturned my life. I felt that my understanding of my condition always lagged behind the latest manifestation of it. I did not have a satisfying explanation of what was happening to me, or of what I could expect to happen next. While I was very grateful for the technical skill which cardiologists in my local general hospital brought to their treatment of me, their communication with me tended to be brief, obscure, and sometimes impatient. Most other medical practitioners, in hospital or the community, were unable to help me much due to the unusual and atypical nature of my condition. Even my own GP, very supportive and generous of his time, admitted that he did not know enough about my condition to tell me what was going on or what to expect. I had to piece together for myself a way of understanding and a way of managing my condition by slow experience and endurance. Many people had something to say which gave me a little clue as to how to manage the next day or next week of my life. For example, a GP I sometimes met informally when swimming, a retired anaesthetist I bumped into with mutual friends, a counsellor at the British Heart Foundation I once rang. Others were positively unhelpful, only adding to my distress on occasions. No one was able to say much, but I was able to put the pieces together as in a jigsaw, however incomplete, to provide myself with a partial safety net. And there was my wife, whose total, unconditional, and loving support alone made my life possible.

In April 2011 I had an appointment with my cardiologist who acknowledged that things were not going well for me, and offered me three alternative treatments. One was to have my AV node ablated, two was to start taking a particularly powerful medication with unpleasant, and possibly lethal long-term side-effects, three was to go for a more complicated ablation procedure in London. He

recommended his first option, and suggested I went away to think about it. I did not rush into a decision. At first, I felt inclined to follow his recommendation, but I was not at all sure. I wonder now if my indecision contained some morbid resignation to my deterioration. I was becoming not just physically tired but quite disillusioned and depressed. Over a month later, with my mind still not made up, there happened something which turned my life around.

I had been in touch with the AFA over the previous few weeks and months, but only intermittently, and this seemed to be a distant organisation with nothing local to offer and I tended to dismiss it. In May, 2011, however, Trudie Lobban of the AFA e-mailed me. From this I learned that I could seek a referral to a 'heart rhythm specialist'. Having been signposted to a number of specialists, I immediately went into action on the internet, and found extensive information about the specialists. I selected one of them on a hunch that he was the consultant for me, and I telephoned his secretary. From that telephone conversation onwards, although I did not know it at the time, I was on the path to having the treatment I needed, at St Bartholomew's Hospital in London, under one of the best consultants I could have had in the world, I believe. My local consultant turned out to be fully in agreement with my choice, and generously agreed to refer me to the consultant of my choice at Barts Hospital. In describing this scenario to my family and friends, the responses have been similar. Wasn't I lucky, they said. Wasn't I plucky to hold out for the best. Doesn't it just show that there is an unevenness about the service provision by the NHS.

To cut a longer story short, in September 2011, nearly two years after the initial onset of my condition, I had an ablation procedure carried out in the left atrium of my heart by Professor Richard Schilling of Barts Hospital. I am writing about this over three months after the operation, as I would not wish to raise anyone's hopes unrealistically. Within one month of the operation I was allowing myself to carry out physical tasks which would have set off hours of palpitations before it. With my pacemaker still in place and on reduced medication, I have become increasingly able to lead a life which is as normal as I wish it to be. I am hugely grateful to the advice I was given by Trudie Lobban which, on reflection, feels as if someone touched my shoulder and set up a miracle for me. It worries me that it came down to a contingency that I might have missed, and that she was the only person I was in touch with during my illness who told me that an option of choice was available to me, and that I could take charge of my treatment pathway. It should be clear that this option is open to all. I feel eternally grateful to the AFA.

David