



My ICD and Me

By Rodney Ross, BDS

I am a 54-year-old dental surgeon, partially retired because of a chronic back condition, living in a rural area on the beautiful island of Tasmania, Australia. I was born and grew up in southern England, moving here in 1991.

Fifteen months ago I was suffering badly from LAF – experiencing 15/18-hour sessions every other day. I could not drink red wine, coffee or cold fizzy drinks. My diet was free of gluten, dairy products and artificial ingredients (as far as possible). I was reluctant to go out at all as I inevitably got an attack. I did not take any medication apart from aspirin - it either made the AF worse or made me feel ill. I had tried supplements of all types - some improved it for a while, but the effect always wore off. The AF had started when I was 48 years old and gradually got worse - several other members of my family, all male, have it. Tests had shown there was nothing wrong with my heart and there was no angina. I had a fairly slow HR, around 50 bpm, but this would very often sink to 40 at night. In bed I would be very aware of the heart thumping away slowly. I've always had postural hypotension, but that had got very much worse (it would take several minutes to clear after an afternoon rest). My BP was normal - 120/80. When in AF, my HR was 80/90 bpm, and felt like a washing machine in my chest. I could carry on with whatever I was doing, but I felt awful and just wanted to lie down.

Now, I'm a different person. I can eat and drink what I like. The postural hypotension has disappeared. I can no longer hear my heart thumping away at night. And, most important of all, I am no longer bothered by AF and I no longer take aspirin.

In October 2002, things had got so bad that I went to the cardiologist and asked about a pacemaker. In Australia, we do not have anyone doing pulmonary vein ablations with any success and my health insurance only covers treatment in Australia. The cardio thought that because my HR was slow and the rate in AF was also fairly slow, it would be worth trying a pacemaker. My first visit to the hospital was a disaster. First of all, I got gastroenteritis. Then a blood test revealed a high INR - had I been taking warfarin? No - I refused to touch the stuff after reading about it on this Bulletin Board! Aspirin does not affect the INR. More blood tests - my fibrinogen level was 25% of normal and I had bilirubin in the blood! "You should be bleeding like a pig", said my surgeon encouragingly! Had I had any bleeding problems? No - and I had a hernia repaired in '97 without any ill-effects. Off to a haematologist (by now I was convinced I had only months to live!). A liver CT scan and further extensive blood tests followed. The verdict - I had hypofibrinogenaemia and Gilbert's disease. Both genetic and neither serious. My bleeding time was raised, but it still clotted. Aspirin was no longer necessary and warfarin definitely contra-indicated. I was re-booked a week later.

On December 17th 2002 I was re-admitted and my pacemaker fitted under a local anaesthetic. I was aware of the whole procedure, which took about 90 minutes, but there was no pain. There was no abnormal bleeding. The pacemaker was set to 5 volts at 60 bpm. I was kept under observation overnight in an ICU. I slept well. Next morning the technician checked that the pacemaker was working properly and I was discharged. Apart from pain for a week when lifting my arm I had no problems. Unfortunately, the AF continued as before which was disappointing, but I wasn't too upset as I knew that the pacemaker had capabilities that had not been enabled yet. It is a Medtronic AT501 DDDRP with two leads, one to the atria and the other to the ventricles. It has dual pacing, a monitor function which can be downloaded onto a computer for analysis, and an ability to detect fibrillation starting and to take counter measures.

After a week I saw the cardio. He looked very disappointed that there hadn't been an improvement and muttered that it hadn't worked and that we would have to try something else. I said that there was some fine-tuning to be done with the pacemaker settings and that might produce an improvement. He did not look optimistic. I saw the technician a few minutes later and he downloaded the weeks AF sessions and printed them out. He said that he'd had some success out-pacing AF, so he turned up the pacemaker to 80 bpm. I had no AF for the next couple of days, but the combination of 5 volts and 80 bpm caused my diaphragm to spasm at night and it was very painful. It was the same pain that I got with long sessions of AF - a nasty ache under the breastbone - only worse. It was the technician who told me this was caused by spasm of the diaphragm. I went in to see the technician again.

I had not been aware of any AF during this time, but when the technician looked at my printout, he took it straight into the cardio. The cardio came straight back in and gave me the once over. He said that I may have had a couple of sessions of ventricular tachycardia - he wasn't certain, as the pacemaker monitor isn't as detailed as a Holter monitor. He arranged for me to have a Holter Monitor to check this out. Meanwhile he prescribed verapamil, a calcium channel blocker, slow-release once a day, to reduce the likelihood of VT. The technician reduced the rate to 70 bpm, atrial pacing only, and the voltage to 3 volts. It takes about 3 months for the pacing leads to become embedded so a relatively high voltage is needed at first. After this visit the AF stopped. I had the Holter two weeks later and there was no AF, no VT. Having hit upon a solution more by accident than design, things were kept as they were. At the 3-month visit the voltage was dropped from 3 to 1 volt - the usual is 2, but I felt I was still getting some irritation of the diaphragm and 1 volt worked. For several months I noticed my BP had gone up to 140/100, but it is now back to 120/80.

Since that time I've had a few attacks of AF, but it is all very different. The AF never happens during the day, always sitting down in the evening or in bed. It doesn't last. Usually I can stop it by just changing position. Although I'm aware that I have AF the ventricular beat remains steady. As time goes by I am getting less and less. I have re-introduced into my diet all the items I cut out with no ill effect. It doesn't affect my life anymore in any way.

So what is happening? In my humble opinion, I feel the verapamil has reduced the electrical activity in the heart and the pacemaker is pacing the atria at 70 bpm - much faster and with a far greater signal than my natural system, even without the verapamil. Perhaps new electrical pathways have been formed? The atria probably ignore any errant signals unless they get very strong. When the AF does start the atrial pacemaker will cut out as the rate goes above 70. But the pacemaker is programmed to pace the ventricles if the ventricular pace goes below 70, so it switches from atrial to ventricular pacing. The verapamil must stop the chaotic signals passing through the AV node at more than 70 bpm so the ventricles stay regular. It is interesting to note that just stopping my HR dropping too low did not work at all.

Now it is just 14 months since my implant so I'm not claiming a cure for good. It could come back. But the full capabilities of the pacemaker have never been enabled, so we still have a fall-back position. My technician says that he hasn't had much success with the fibrillation controls (termination therapies) on pacemakers, so mine has never been enabled - but I see from postings on the BB that they can help. And every year that goes by is a bonus - bringing a cure for this debilitating condition nearer. The pacemaker

implant is a relatively risk-free procedure, which is reversible - you can just switch it off. The verapamil does not have any side-effects for me. If I exercise and my HR goes above 70 my own system takes over. If the pacemaker malfunctions my heart will still beat. All in all, I feel lucky and if things continued as at present I would be more than happy.

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