

## Living with an Internal Cardiac Defibrillator

I first discovered that I had a heart condition in 1984 and after many years of managing my cardiomyopathy and associated arrhythmias with drugs, in 2002 I developed a side effect (Hyperthyroidism) from the anti-arrhythmia drug Amiodarone. I had been taking this drug since the discovery of my condition. Because of this my Consultant decided that I required an Implantable Cardiac Defibrillator (ICD) with Biventricular pacing in an attempt to stabilise my worsening Dilated Cardiomyopathy (DCM). This would also enable them to find suitable alternative drug to Amiodarone. Unfortunately at the time, it was too difficult to install the third ICD lead. It is this lead which basically transforms an arrhythmia controlling device into a device that is also capable of pacing the heart. The aim is to better synchronize the heart pump as it enlarges and struggles to pump effectively.



Even though the third lead had not been placed, I still had the life saving shock and associated treatment elements of the ICD, which over the ensuing years I would need several times. Unfortunately for me my first ever experience of a full shock was an episode of eight shocks with just a few minutes or less in-between.

I had been admitted to my local General Hospital with flu and a severe chest infection. The following morning at about 6.30am I was lying flat on the hospital bed just dozing, when WHACK, I think I had woken from my sleep by this mighty jolt, a jolt that had moved me about 12" further down my bed. I bleeped the nurse and as she arrived I was just trying to explain that my device had shocked me when WHACK, I didn't need to explain anymore. She went running off trying to grab the attention of a rather dismissive doctor. Anyway, there were shortly two doctors at the side of my bed staring at my heart monitors screen, casually trying to decide if I were in VT or Sinus Rhythm, then WHACK, I now had their full attention. I was quickly wheeled into Coronary Care where I received a further five shocks until they were able to stabilise my condition with IV drugs. So although my first experience of the capability of my ICD was not a good one, it possibly saved my life.

Since stopping Amiodarone, it was proving difficult to control my arrhythmias and over the next few years I continued to have the occasional single shock. Unfortunately this was taking its toll on my heart and it became weaker. My consultant decided that as ICD implant procedure and lead technology had improved since my last attempted Biventricular ICD installation, the next step was to upgrade my ICD and to install the third pacing lead. In 2007 I underwent successful implantation of a Biventricular ICD. They now seem basically able to pace my Heart at the flick of a switch.

It seemed however, that luck was not on my side. In January 2009 I was again ill in bed with flu and at home alone, it was the middle of the afternoon. I thought I had nodded off when WHACK my reaction was to jump out of bed like a boxer who had slipped on the canvass and was ready to defend himself. I felt another VT coming on (after a while you get to notice any irregularity with your ticker) and so I sat

on the edge of the bed when WHACK I received a second shock. It was time to dial 999. Whilst sitting on the bed making the phone call I lost consciousness fell and smacked my head on a cupboard. I lost consciousness three times in all and I went on to have a further four shocks. The last one was with the paramedics and fortunately the VT's/ shocks stopped spontaneously following a request from the paramedic to take my top off, cooling my body temperature down.

I have had several single shocks with my new device, some sitting quietly doing nothing then suddenly a VT will come on and WHACK. I have had shocks while shopping, whilst coaching rugby and whilst exercising at the gym. There has always been a reason for a shock in my case, more often than not a drop in my blood potassium, calcium or magnesium – I get them checked regularly now. The single shocks are manageable and I prefer to have them whilst awake; at least then you know that if you're in the middle of a crowded area you don't have to lay flat on your back to prevent harming yourself with a fall, which can be embarrassing, especially if it's just a case of being a little over sensitive or the VT is stopped though ATP (fast pacing of the heart without the need to shock). My VT Storms (series of shocks together) are RARE! And have always occurred whilst suffering a fever. Never again will I take to my bed if I have a fever, I have the flu jab every year, but this year I managed to contract Swine Flu (confirmed through blood test). I sat upright in a chair for 48hrs with ice packs on my head back and chest – no shocks – no lasting effects.

I have had 28 shocks in all, including the eight shock VT storm and nine shock VT storm.

**Does it hurt?** No, how can something that seems to occur in a millisecond be considered painful.

**What does it feel like?** If you're awake, it feels a huge thump in the chest. If you lose consciousness, in my experience if I awake on my back it seems tranquil as though you were asleep but then you recall what happened. If you're caught out and fall forward awaking is rather more disturbing.

**Are there any lasting effects?** – With me yes, a shock is exactly what it is, nobody likes to be shocked. It takes me about 24hrs to relax after a single shock. It took me six months+ to relax after each of my storms.

**Do I regret having an ICD fitted?** No, how can I, I may be afraid of what it does to me and I really look forward to a day when I am no longer dependant on it. But without it, I simply would not be here.