

Living with Atrial Fibrillation, an ICD and the aftershock of a Cardiac Arrest (Part One)

Hello, my name is Andy and I am one of the lucky recipients of an Implanted Cardioverter Defibrillator (ICD).

Before all this kicked off, I was no stranger to the inner workings of a hospital or indeed the cardiac ward, but what happened in July 2004 was to make all my other illnesses and ailments pale into insignificance and to change my life radically.

I had a previous long-term history of high blood pressure (hypertension) - this was being controlled by medication and also on my "portfolio" was noted thickening of the walls of the heart around the left ventricular area.

I have not worked since Christmas Eve, 2002 when I collapsed at work. I had felt unwell, tired and out of breath for some months prior to that event, but put this down to being unfit or overweight. I did not know then if there was anything medically wrong with me.

I don't know whether it was the anticipation of my Christmas Dinner the following day or the fact that I was going to have a few days leave from "stalag luft", but I sat at my computer waiting for the boss to give us the "green light for go" and felt strange.

I remarked to a colleague that I felt as though I was keeling over and daren't move from my seat lest I should collapse in a big heap on the floor.

An ambulance was summoned and after a few preliminary checks I was taken to A&E. I was admitted to hospital and checked out. It was diagnosed that I had an irregular heartbeat (Atrial Fibrillation).

I was kept in hospital overnight while I was started on a "loading dose" of warfarin anti-coagulation therapy to reduce the risk of heart attack, stroke or thrombosis which can be caused by this ailment.

I was allowed home around mid-day on Christmas day, just in time for my Christmas Dinner, but as I remember I had to return several times to the ward over the Christmas period to have bloods taken and warfarin levels determined.

Quite a sober Christmas that year!

During the following months I underwent several consultations and had various tests carried out on me. It was decided that I needed to undergo corrective therapy to attempt to jolt the heart back into a regular sinus rhythm again, this is called a cardioversion.

I waited for approximately 18 months for the operation to be done under the NHS.

During that time period I was very depressed, nervous and to put it bluntly, felt absolutely knackered most of the time.

Possibly another contributory factor to throw in the equation was the fact that I had also been diagnosed as having Lupus antibodies in my bloodstream but nobody had to date bitten the bullet and said that I have got full blown Lupus.

Lupus is a disease that affects the auto-immune system of the body.

"A little knowledge is a dangerous thing", I should have known better but being the inquisitive person that I am, I made extensive use of the internet to read up about AF and about the various tests that I was to have done.

Some of this information really put the "frighteners" on me and when I went for a particular test armed with my background knowledge (An internet "expert") I was in a heightened state of fear, blood pressure through the roof...you get the picture? In the event, the tests were a "walk in the park" and no need to have got wound up at all. So much for the internet, I now realise that often they quote worst case scenarios which does not allay the patient's fears.

It was decided that I needed to undergo corrective therapy to attempt to jolt the heart back into a regular sinus rhythm again, I was informed that there could be three potential outcomes to this operation:-

- The heartbeat would be corrected and would stay in regular rhythm for an indeterminate period
- The heartbeat would be corrected for a short while then revert back into A/F
- The heartbeat would remain in A/F

I received treatment in April 2004, a short operation when my heart was purposely stopped and given a quick blast with the "jump leads" or Cardioversion, for those of you who prefer "Medi-speak" terminology.

This treatment restarts the heart and hopefully brings the rhythm back into kilter, though there is no guarantee that the heart will remain in sinus rhythm.

After a couple of weeks or so of recuperation I began to feel good again, I could walk about without feeling exhausted and out of breath, gradients were no longer a problem.

To relieve the boredom and monotony at home, I began doing jobs around the house and playing catch-up with the endless list of DIY tasks on back order.

Next on my to-do-list was a programme of repainting the exterior of the house, this job had progressed quite well and as I remember even the weather was kind to me.

Work continued at a pace and the end of the job was hopefully in sight.....

So there I was, Saturday 16th July 2004 aged 48, I had been merrily painting the outside of the house from the highest limits of a scaffold tower erected by the front door.

I had decided to complete this phase of the job over a weekend to "minimise disruption".

Little did I know what was in store! I worked away happily until early evening.

I had packed up for the day, had my supper and was relaxing on the settee, watching TV and enjoying a beer and a scotch, as one does on a Saturday evening.

Suddenly, no pain and without prior warning, BUMP. I WAS DEAD...

I was spark out, in limbo, clinically dead, flat-lined and remembered nothing for the next ten days or so...

My wife, Jean, tells me that I went rigid and shaking as if in a fit and suddenly stopped breathing, my heartbeat ceasing too.

Jean is an experienced, qualified first aider and used to be a pool-lifeguard, she tried to move me and to perform CPR first aid on me. As easy as **ABC (Airway, Breathing, Circulation)**, the book of **St John the Ambulance Man** says.

Not so easy when the person is 18+ stone and rigid! (**I was that heavy!**).

A 999 call and help was on the way, but some 5-6 minutes had elapsed between raising the call and paramedics on site.

On site, clamber over the scaffold tower to gain access and in through the front door, piece of cake!

I am reliably informed that they managed to resuscitate me after several goes with their external defibrillator, or "jump leads" as they are jokingly known, and worked on me for quite some time to stabilise me and prepared to ship me out.

Next problem can't get the casualty out on a stretcher or a chair because of that blessed scaffold tower.

Fire Brigade in attendance to marvel at the size of my "erection" (4 metres and pointing skywards!!!) and dismantle aforementioned scaffold tower like a giant demented Meccano set.

In their haste, this was left strewn across the garden and on my return a few weeks later it was hidden by 6 weeks worth of grass that had grown around it in my absence.

Blue light ride in an ambulance to A&E, completely oblivious and non-compus-mentus, then began my long stay and transfer from ward to ward via North Staffordshire Royal Infirmary & City-General Hospital until a bed came available in ward 76, the Cardiology Ward.

The first ten days were apparently my most dark and gloomy; perhaps it is as well that I have no recollection.

Basically, what the nursing staff at A&E said to Jean, when they took her into a little ante-room, was that there was little or no hope of survival and that if I did pull through I may be a "cabbage" and physically or mentally impaired as a resultant.

"The golden 4 minutes" had long elapsed before I had been brought back and potentially the brain cells that had been deprived of oxygen were dying off.

Muster all the relatives to the bedside...

"Goodbye Andrew old chap".....In the event, I was to prove them all wrong!

I was told that I had many visitors while I was in a non-compass mentus state, but apart from the odd grunt, did not acknowledge or remember any of them.

Sister-in-law is a teacher by profession and she apparently virtually shouted at me to respond. I responded with a movement, but nobody has stated to this day if this was an arm, leg or indeed a bowel movement!

From that point onwards I improved physically each day, but was suffering with severe loss of short-term memory and not functioning correctly mentally.

After undergoing many tests and enduring having wires connected to me, things pumped into me, blood taken out of me, and in the early stages when I couldn't look after myself, a pipe connected to "*you know where*", the Cardiology team determined that I had indeed suffered Ventricular Fibrillation and Cardiac Arrest.

The prognosis in layman's terms was that although the plumbing and interconnecting pipework to the heart was basically ok, the "electronics" which control and regulate the heart were decidedly dodgy.

Cometh the great day and I was visited again by the consultant cardiologist and his team.

When a straight talking Scouser looks you in the eye and says "***make the wrong decision and you could end up dead as a result***" what do you do?

Give him the keys to the non-existent BMW, your wallet, or the wheel trims off the old Astra?

On this occasion, the scouser just happened to be my consultant cardiologist, discussing the forward plan for me and advising me that having had one "*arrest*"; I was at high risk of having another.

Doc: "We've done all our tests on you and determined you need to have an ICD fitted"

Me: "Uh, what is one of those?"

Doc: "An electronic device implanted in a pouch cut into your chest, it is there to resuscitate you in the event of another arrest"

Me: "But surely there must be an alternative?"

Doc: "Yes there is a choice, go to the desk sign yourself out of here and next time you arrest you may be out fishing or miles from anywhere, no help, no nothing...dead! My advice to you young man, is keep your arse close to that bedside and bear with us and we'll sort you out"

I needed to have an "*on board paramedic*", or Implanted Cardiac Defibrillator fitted, this device acts like a normal pacemaker in regulating the heart beat and rhythms, but in the event of a further occurrence of cardiac arrest I would receive a corrective jolt or shock to the heart to restart me.

He strongly advised me to take this course of action and that it would be foolhardy not to have it done.

Indeed I could put myself in a dangerous situation or end up dead as a result of not heeding his advice!

I mulled things over in my mind and discussed this at length with my wife.

With all due respect to the nursing staff and cardiology team, they deal with the "nuts and bolts" of the situation but cannot be at home or with the patient or family all the time.

Imagine the pressure that Jean had been under, to hell and back is perhaps an inadequate or inappropriate description.

One of the Nursing Sisters from the Cardiac Ward asked if we would like to speak first hand to someone who already had such a device implanted.

A meeting was set up between the **Hospital Liaison Officer** of the "**ICD Patient and Family Heart Support Group of North Staffordshire**" and ourselves. This group, as we were to find out, is a voluntary organisation who give support to patients already fitted with "defibs", or who are awaiting implantation of such devices.

In my humble opinion and more importantly, they also give support to the patient's families and carers who are often suffering worse psychologically than the patient and who are completely in the dark.

We had our meeting with a gentleman from the support group, who himself is the wearer of an implanted "defib", and he did a marvellous job in answering our questions and allaying our fears and concerns.

By all accounts, I had been lucky to get this far and come through relatively unscathed.

Unfortunately, many people are not so lucky. I may not have been so lucky next time if, God forbid, I had another arrest and I did not have the device fitted.

I spent six long weeks in hospital while I was awaiting implantation of the "defib". Plenty of time to pause for thought, worry about what is going to happen next or what the final outcome might be.

Life is too precious to throw away now.

I had been resuscitated and pulled through ok, this was my second bite at the cherry and here was my chance to grasp my future, or at least hedge my bets as best I could towards longevity and to drawing my old age pension (If anything is left for me when I reach pensionable age, Mr Gordon Brown M.P., take heed!)

The staff from the cardiac ward prepared me for the operation and I was fasted from early evening.

At approximately 8.00am I was taken down to theatre and got ready for the implantation.

The cardiologist had told me previously of what he was going to do.

I was wired up to the heart monitor and various "bits and bobs" attached. I was given a local anaesthetic and an incision was made in my chest muscle/fat above my left nipple, this to create a pouch to accept the device.

Work proceeded and it was fascinating to watch the monitor above my head as two wires were seen passing along a blood vessel and into my heart.

The unit was wired up and initial testing commenced.

For the next stage I was completely under anaesthetic while my heart was purposely stopped and the devices tested to "fire up in anger" and bring me back.

The first thing I remember after the operation was of waking up in the recovery bay and being returned to the ward later, absolutely starving and pegging out for a cuppa.

Total time taken, approximately 2 hours.

Things were allowed to stabilise for a couple of days and then I was allowed home. Yippee.

I have to attend a clinic every twelve weeks during which time an interrogation is made via a scanning device rather like the barcode scanner at a supermarket. The device "talks" to a computer by telemetry to see what if anything has been happening during that 12 week period and data is downloaded.

As a belt and braces support, I continued to take warfarin anticoagulation therapy.

During a 6 month follow up appointment with the cardiologist post implantation, he commented on how well I looked and was pleased how I had progressed since coming out of hospital.

He then went on to tell me how lucky I had been to pull through all this relatively unscathed.

A long-standing appointment with another specialist from the Nephrology Department, who keep tabs on my hypertension, backed up that statement.

The renal specialist had read through my notes and without prompting stated that from the writings, noted that they had virtually given up hope with me in resus at the A&E department on that fateful night in July '04.

I have also spoken personally to one of the nurses who attended to me in the early stages prior to going to the cardiac ward.

He told me that their brief was to *"make me comfortable (T.L.C.) and to see how I progressed but not much hope I'm afraid!"*

Statistically many thousands of people in the UK die as a result of sudden cardiac arrest or Sudden Arrhythmia Death Syndrome (SADS) as it is known.

As many as 95% of people who arrest do not pull through, and of that other 5% many of those persons have either a heart attack (myocardial Infarction), stroke, mental impairment or other complications.

Looking back with hindsight, I am left to wonder if it was the long term medication of the warfarin already in my system and slowing blood coagulation which helped towards damage limitation in my case.

I did not escape entirely without impairment. Although my long term memory is reasonably sharp, my short term memory is now poor to non-existent

I am very prone to doing stupid things like forgetting to take medication, leaving food unattended on a lit stove and not remembering what someone has told me a few moments previously, I also struggle with concentration and can no longer perform complex tasks without a struggle.

This is frustrating and there seems no logical end, but it is a small price to pay for still being here and leading as normal a life as possible.

To say that I have been very lucky is an understatement and the parting statement from my cardiologist on that occasion was most reassuring. I quote: *"You do realise that you are now amongst the elite? Not many people have got these devices fitted and you now stand a better chance of survival than the average bloke in the street should such an occurrence happen again."* (More words of wisdom from Dr J Nolan the Consultant Cardiologist, University Hospital North Staffordshire)

How does one come to terms with all this? Well it does help to have a good sense of humour and at times Jean and I have had a good laugh about the happenings but equally at times, particularly in an unguarded moment, we have both had reason to cry.

I admit that I did go through a bad patch during the first six months post implantation, feeling very depressed and upset. It seemed that the slightest thing would make me cry and disturb me. Watching "Casualty" on TV or seeing an ambulance screaming past on a "blue light" mercy dash would set me off.

My GP was consulted; he stated that as a last resort he could prescribe medication but that would be a long term commitment and one which would de-stabilise the "shopping list" of tablets that I am already taking for various ailments.

Counselling was suggested as a preferred option, but I have managed to "dig myself out of the hole" without treatment. If I am left to sit and ponder over the previous events then I get depressed but now I try to fill my day by keeping busy doing gardening, DIY, hobbies and interests etc to keep my mind occupied

I never used to like my birthday too much, another year older and all that. Now I can't wait for the next one and the one after that and so on. Similarly with Christmas which used to be a proverbial humbug.

Life will never be quite the same again. We joined the local ICD support group that helped us so much when we most needed it.

I was disqualified from driving for a mandatory six month period after having had the device fitted (DVLA Ruling), but having got my licence back we both enjoyed a 2 weeks holiday touring the Isle of Wight and Portsmouth areas in 2005.

Although persons with defibrillators can lead as normal a life as is practicably possible certain restrictions apply.

- Strong electro-magnetic fields such as electric arc welders, chain saws, and close proximity to car ignition systems are to be avoided. Climbing ladders and scaffold towers is a definite no as is too much stretching and heavy lifting.
- Vocational driving such as heavy goods or bus driving are prohibited by law under the ruling by DVLA
- Contact sports are to be avoided.
- The consultant or GP should be consulted before attempting certain activities.
- Mobile phones are permissible with care and are indeed another lifeline when one is out and about by oneself.

To summarise, having the defibrillator implanted gave me the confidence to get out and about again and it is a matter of common sense not to do anything stupid and to listen to what your body tells you.

Lest we should forget...!

Well actually, in my experience you never forget that you have got the device fitted, just to feel the lump on your chest is a constant reminder that the ICD is still there.

It is always at the back of your mind; will the device resuscitate me in the event of a further arrest? Will the device fire spuriously? Will I ever be able to drive again?

These and a million other questions are constantly nagging and churning over in the subconscious, many remain unanswered to this day.

For my input, I sold my scaffold tower on e-bay so I would not be tempted to use it and my ladders remain locked away in the garage. Should I ever be able to work again I am barred from certain occupations such as driving HGV lorries and other large vehicles

I also sold my electric welding equipment, no longer to be pestered by my neighbour's pleas "Can you just weld me this on my garden gates/car/security fence?" "No, I can no longer do welding due to medical condition..." Ah well, every cloud has its silver lining.

To date, I still attend the download clinic run by the cardiac technicians, downloads are carried out every 12 weeks.

Looking to the future, I am told that things are about to change and that downloads will be done by remote telemetry.

Patients will soon have their own "black box" at home, a gadget that temporarily plugs into a telephone socket and by prior arrangement the patient will position the scanning device over the ICD, press a few buttons on the box and the data will be sent via the telephone wires to the cardiac department.

We are now at a point in time approximately 2006, more to follow...