Defibber News

JULY 2016

Our next Meeting is on Wednesday July 13th Education & Research Centre

We extend our thanks to Dr Ben Brown and Dr Mohamed Boatiwirat who kindly accepted our offer to be the guest speakers at the last ICD patient support group meeting in March. The informal nature of the meeting allowed patients and relatives to ask a full range of questions to the experts ranging from the new technology, new drugs available, to general advice or comment on the latest newspaper articles concerning devices! Following the feed back from the meeting a number of patients suggested a talk on the psychological aspects of having an ICD and the impact of having shocks on patient's well being, certainly as mental health and well being have been highlighted recently in the media.

Therefore we are delighted to announce that Mr. Mike Connolly Consultant Nurse who is an expert in this field has kindly agreed to take this interactive discussion at the next meeting.

Prior to Mike's talk we welcome everyone for a cup of tea or coffee – at 1.00pm - in an informal setting to meet other ICD patients, family and friends. This gives you an opportunity to talk to other patients directly about living with an ICD, as the best advice on that subject is from yourselves to others!
You can also meet members of the Committee who will answer all your questions about our Support Group

Meet the team

Wythenshawe ICD Support Group Committee

Help at Hand

After having a traumatic 2008, and with the constant return of AF & VT I was virtually housebound. Up to December of that year I felt useless and incapable of doing anything, but there were two forms of help I was receiving.

First there was Wythenshawe Hospital and the cardiac team who looked after my physical wellbeing, but just as important was my wife who looked after my welfare and emotional needs and believe me all you hardnosed males out there your emotions do need looking after. Physical and emotional repair go hand in hand. Those people who have to find a way to manage on their own I can only admire you, well done.

In January 2009 it was decided that I was a good candidate for having an ICD fitted and could not believe that I would be awake for the procedure, but I did not need to worry. It was quite painless. It's hard to describe how immediate the effect of having the ICD fitted was but just to say that I had entered the hospital in a wheel chair and left on my own two feet. Everyone kept saying how different I looked and most of all I looked happy.

For several years everything was ok. There were a few glitches during those years but nothing that stopped me getting on with my retirement. In 2015 Wythenshawe replaced the ICD due to the battery running low, again all very painless. On the 12th April 2016 things began to happen which were out of my control. I was constantly feeling like I was going to pass out and my head would become quite warm. I went to my GP. He suggested I contact my Cardiologist. I immediately contacted Adrienne, one of the ICD specialist nurses. She organised everything. She asked me to conduct a remote scan at home. Thank goodness for technology. After one hour Adrienne contacted me and asked me to go to A&E at Wythenshawe where a Cardiologist was expecting me, after being seen there I was given a bed in CCU.

The day after, Adrienne came to the CCU to see me. When she arrived it was if she had flicked on a light switch. Everything seems to happen almost immediately. First I kept going very dizzy, about every half hour, then every ten minutes, and then it was continual. The ICD was working hard to try and pace my heart, but eventually it had to do what it was there for. I wasn't prepared for what it did next. There was a loud bang and a bright white light came in my head. I can only describe the feeling I got by saying that it felt like someone had punched me with great force in the middle of my chest and it hurt, really hurt. This all happened whilst I was sat on the bed. If I had been standing I'm sure it would have put me

flat on my back. The shock took me out of VT and gave the heart a steady rhythm. Adrianne was great; she took over and made me relax by breathing slowly and deeply, which helped a great deal. Half an hour later it happened again. I shouted and swore some unprintable words. Sorry nurses, please forgive me. Again you hardnosed males, it is ok to cry and cry I did. Bucket loads. I was now very scared. I started thinking negative thoughts and what would be the worst thing that could happen, after all the ICD was doing its job even though it was uncomfortable. Then low and behold it happened again. So sorry to all the nurse's for even worse profanities. Surprisingly, after the shocks, there was no pain in my chest at all.

By now the cardiologist had arrived and immediately gave me high strength drugs and a sedative, which slowed my heart down and helped, keep me calm. This seemed to sort things out. Surgery that was booked for two days later was brought forward to the next day. The procedure took over four hours. I will be eternally grateful to Dr Brown and Dr Skein. Everything now seems to be ok. There have been no instances of VT. Yippee!

My next challenge is to start getting on with my life. It's hard not to worry about what happened. I am still quite emotional about it all. All you people who have had an ICD fitted, may never have to experience what I went through. It will happily work in the background letting you carry on with your life as normal.

If, like me, you experience the shocking reality, then so be it. It will certainly be tougher to get back to everyday living, but remember you will still be living, and I'm almost certain that if I didn't have the ICD I wouldn't be.

Gordon Liversage

My name is Emma Armstrong and here is my story....

I'm 26 and never ever thought anything bad would ever happen to me I couldn't of been more wrong..... it was the 18th of December my last day at work before we broke up for Christmas, I don't remember anything of this event or a few weeks after I suffered memory loss so the gaps have been filled in by my family and friends.

I went shopping after work with my friend.

On the way home I told my friend i wasn't feeling right. Next minute I'd passed out making a funny breathing noise. My friend, who i scared to death, rang 999 and my mum immediately.

A couple going past stopped as they saw my friend was distressed. They pulled me out the car and this is when they realised I didn't have a heartbeat. The couple preformed CPR on me till the ambulance turned up.

My mum had just turned up in shock and scared. I'm very close to my mum but not only that, no one wants to see there daughter like that...well my friend and mum watched helpless as I was lay in the middle of the road.

The paramedics had to shock me twice to bring a slight heart beat back, I was then rushed to Tameside hospital where I found out I had suffered a cardiac arrest.

At Tameside hospital I was put in an induced coma for the next 24 hours, my mum and dad were told I was critical. They didn't know if I'd make it or not, they can't even tell me the story yet without getting upset. It was the worst time of mine and their lives, not what any parent wants to hear. I was woken up the next day and I've been told I was a bit of a nightmare, to put it nicely. I don't like hospitals and I'd made that clear, I wasn't myself, I was acting and talking very out of character, no one new if I'd ever be the same again...I spent 3 days in intensive care and then moved on to a special ward in my own room.

The staff were lovely, but I begged to go home a lot, it was all far too much for me. I had to have my bloods taken a lot (one of my biggest fears) it was horrible. I also had to have a blood thinning injection in to my stomach every night that I ended up doing myself. I felt better doing it and it didn't hurt as much,

I was told I had a suspected broken rib in between my chest from the CPR they gave me, the pain was unbearable. I don't remember much but I do remember the pain. I couldn't breathe or talk without feeling like a 100 stone person was sat on it. I was given painkillers, morphine, diazepam, and sleeping tablets. My wonderful family and friends spent most of their time taking turns in visiting me so I wasn't on my own for long, I honestly don't know what I would have done without each and every one of them.

I spent the next 3 weeks in pain and worrying what was going to happen to me...I then got sent to Wythenshawe hospital. This is where I had to confront my biggest fear. I don't think I've ever been as scared in my life...I was here for 2 weeks. I was told I needed to go to theatre for something called an EP study, basically tubes inside me to look directly at my heart...I think my family and friends have seen me cry more times then anything. Without their support I couldn't have got through this nightmare...I went to have this done after crying and almost losing control and feeling like I couldn't cope. I went to theatre and had the EP study done.

After this i was then told I needed a defibrillator device fitted. I took the news really badly and my fear hit a point I didn't know I had. I was over scared and didn't think I could cope.

Adrienne, my Arrhythmia Nurse was like my guardian angel, she really helped me cope with everything and that's hard to do, as I'm the kind of girl who's scared of a paper cut! I was worried, would I feel the operation?

How big would the scar be? Would it stick out? Will anyone see it? Will I look stupid? Not only my age just nobody wants this stuck out their body. I thought if I closed my eyes tight at night this would all have been a bad nightmare and I'd wake up at home, but I didn't. I woke up still in hospital, it wasn't a dream. It was my life and I was living it...

My mum, dad, auntie, uncles, cousins and great, great friends really helped me deal with it all, after lots of text messages and phone calls I knew I had to man up...the night before my op I was on all sorts of tablets and I did surprisingly sleep.

But the morning of my op was the worst. It was too early for any of my family to be there so I was on my own and sooooooooo scared is not the word, I cried and was shaking walking down to surgery. I cried until they put me under.

Adrienne took me to theatre and waited with me.... before I knew It I was lay down on the bed in surgery praying I'd wake up as I didn't think I would. Two seconds later, before I realised I'd been put to sleep I was being woken up.

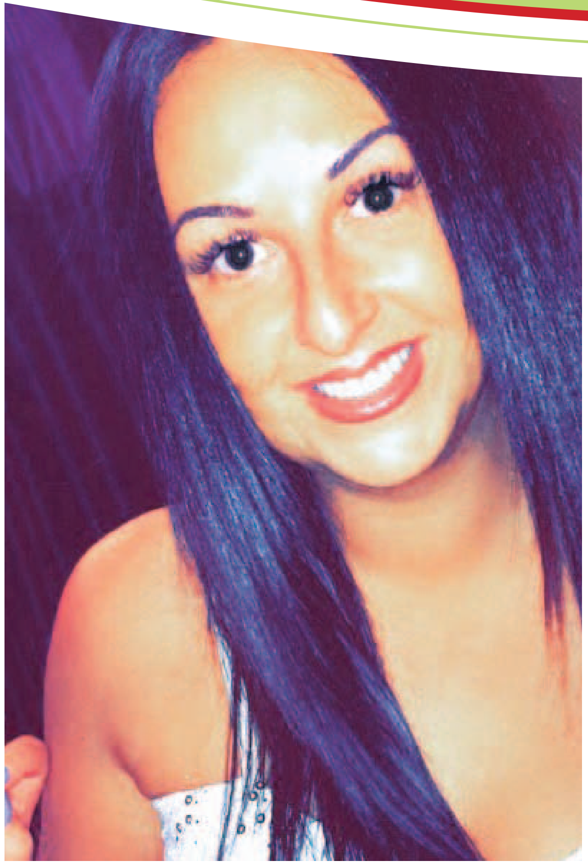
YES!!! And the nightmare was over. I'd done it. Three hours had passed. I was very emotional and thankful, I couldn't believe how easy it had all seemed, to do this all this panicking and worrying was for nothing.

I got taken back to the ward where my mum was waiting. I was very sleepy and emotional, I was so happy to see my mum and she was even more happy. This nightmare she was also living was over. 5 hours later we all had the best news we had all been waiting for.

After 5 awful weeks and 2 trips to surgery I could go home. The doctors were happy with how I'd come round from the op. I couldn't believe it! I was very, very sore, I couldn't move my left arm for 2 weeks and was so scared of knocking my device or pulling a wire out. I still am a bit now....my mum was my nurse at home and my family and friends ran around after me a lot and I loved this :)

It's been 11 weeks since I had my operation, my scars healed and is only small under my collar bone, it's a small lump under my arm pit where the device does stick out. I'd be lying if I said it didn't bother me but it's nothing like I thought. It's my battle scar :)) I'm back at work and I've bounced back fine, I'm still not 100% and can't do everything like I used to before but I'm getting there,

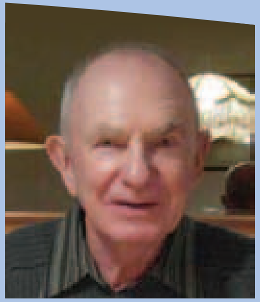
I have to have an operation every 5 years to have the battery changed and I could get a shock at any time. This scares me. I can not go near most electric things but that's a small price



to pay for having my life back. I don't think anyone should take their life for granted.

After reading this I see things very different as I've been given a second chance at life, I couldn't thank enough the paramedics, the staff at the hospitals, Adrienne my nurse, the couple who helped at the scene, my wonderful family and great friends and the top surgeon Dr Brown, I guess when it's just not your time it's just not your time xx

Triple Bypass



Whether my little story will assist anyone, I am unsure, because most readers of Defibber will have already been through the mill, at least you can spread the gospel to friends and colleagues who are considering an overseas holiday.

My son who is a resident of South Africa invited Janet and I to his wedding in October 2011, the wedding was a really romantic affair held in a Sun streamed forest glade.

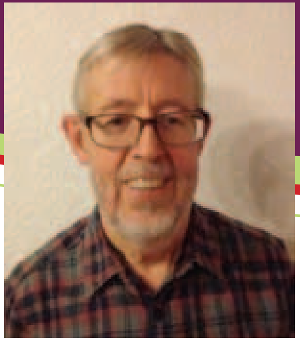
A few days afterwards I succumbed to a heart attack, and after many tests and examinations was informed a triple bypass was required, and because I wasn't fit enough to travel the procedure ought to be carried out there. This is where my Travel Insurance was kicked into gear, a phone call to Insure and Go helpline resulted in them contacting my UK GP for medical history etc. and three days later the go ahead was given. A point here is to always carry your GP's phone and fax numbers, and ensure your GP records don't carry any nasties not declared on the insurance application.

I won't give chapter and verse of the procedure and recovery, only to say it took from October to January before my return to UK, and because my South African medical team recommended I could require an ICD, my GP referred me to Wythenshawe.

Regarding insurance, I found Insure and Go really went the extra mile, and a year later for a follow up visit to South Africa was pleasantly surprised to discover the cost had not been escalated to ridiculous levels.

Any Defibber reader wanting more info: alec.hodgkinson@panurgic.co.uk

When The ICD Gives a Shock



(Colin Albin)

I haven't heard too many people talking about their experience of receiving a shock from their ICD, but I do get the impression that it is different for all of us. In fact, it is possible that people who have received a shock several times have found each experience has been different. To date I have only received one shock. Prior to that no one had told me what it would be like in any detail and with hindsight it would have been nice to have been forewarned. Maybe, because my ICD had been fitted in a different hospital, I slipped through the net and missed out on some of the post-operative information and support. In any event, what follows is a brief description of what happened to me. Hopefully, this might help prepare any ICD virgins for what is - sorry to say it - a pretty unpleasant experience.

On January 25th 2015 – after a wonderful Burns Weekend away in Scotland with our walking group my wife and I had gone to bed and at around 11.00pm I was drifting off to sleep. Suddenly I jumped up in the bed and rolled out of the bed onto the floor. Everything was black. I was completely blind. I didn't know where I was or what I was doing... it was as if I had been hit by Mike Tyson! I kept asking my wife what was going on and I was totally disorientated and confused. After a couple of minutes I could see again and as we chatted we gradually realised that I must have had a shock from my ICD. It was really horrible. However, apart from a slight nausea I felt generally okay so I didn't feel as if I needed to go into hospital.

The next morning I didn't feel too bad at all, just a slight sickly feeling. I uploaded the data from my ICD on the remote monitor and then I phoned the Pacemaker Clinic to explain what had happened. They said that I should come into hospital if I didn't feel right, but since I said I felt okay they said I should be able to carry on with my normal routine. They phoned me later on to say that I had indeed received a single shock from the ICD in response to an arrhythmia and that it had worked perfectly and restored the heart to its usual rhythm. Later that day I felt fine, so I went into Manchester. Two days later I went swimming and (since my wife said not to overdo it) I swam 50 lengths – I normally do 64 which is a mile! That weekend I did a 10 mile walk with my walking group. In summary what a lucky boy am I?!! I suppose the moral of the tale is that a shock from the ICD is not at all nice but it really does give us life-saving support. What an amazing gadget?!

Arrhythmia Nurses Team

Manchester Cardiac Update Meeting March 2016

I was fortunate to be asked to talk at the Manchester Cardiac Update this year on getting back to normal after a shock from an ICD. There were doctors, GP's, Arrhythmia Nurses and Cardiac Physiologists attending from both hospital and the community. The aim of the talk was to show staff what it feels like and the care patient's need after having a shock. As many of you know, it is not just a case of "Oh, I have just had a shock, carry on as normal"!

I spoke about the aftermath of having a shock, the emotional impact it can have and how to help patients "get back to normal". Feedback from the course director was very positive and many staff were not aware of the extent of the effect that having a shock can have on some patients. So thank you to the patients I approached to ask of their experiences of having a shock. You opened up a lot of eyes!

Ask the Arrhythmia Nurses

There have been a number of questions from patients recently about Wirex Cable such as

"I have had a Wirex cable delivered to my house. What is it and why have I been given it"

Arrhythmia Nurses reply:-

A lot of the remote monitors from one company have become obsolete. These are the monitors, which run on your telephone line. In order to update them and convert them to wireless technology you have been given the Wirex cable, which you plug into the side of your remote monitor. You should then do a download and call the Cardiac Physiologists on 0161 291 4615 to let them know. Once they have received your call and the download you are good to go! If you haven't heard anything from us your remote monitor has not been affected and you don't need to do anything.

Adrienne Unsworth

Another AED in the Community

I am pleased to say that a couple that attend our meetings, Jackie and Ken Brook approached me about getting an AED (Defibrillator) for Smallshaw Community Centre on Church Road, Flixton, Manchester.

Jackie and Ken are both very active at this Community Centre. After our meeting, when we had a paramedic as a guest speaker about AED's,

Jackie and Ken realized it would be beneficial to have one at their Community Centre. Jackie and Ken fund raised enough money to buy one, which I think is fantastic. They now have this AED in place.

My wife and I went a few weeks ago to demonstrate its use on our training AED, and CPR on a resuscitation mannequin. ThIs was attended by a nice group of people from the Centre. I hope they never have to use this AED, but if it's ever needed it could make a huge difference to the outcome of a very serious situation. Well done Ken and Jackie for your great effort.

Paul Davis

SHARE YOUR STORY

What's your experience of living with your ICD?
Do you get on with Life or do you let your
ICD get in the way of living?
WE WANT TO HEAR AND SHARE YOUR STORY
ALL CONTRIBUTIONS TO DEFIBBER NEWS PLEASE SEND TO
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