

Defibber News

March 2016



WYTHENSHAW HOSPITAL ICD SUPPORT GROUP

‘ASK THE CONSULTANT’

with Doctors Ben Brown
and Niall Campbell

Wednesday 16th March

1.00pm – 2.00pm for Tea,
Coffee and Biscuits

Meeting starts at 2.00pm

Venue

Education & Research
Building
Wythenshawe Hospital
Southmoor Road, Manchester

INSIDE THIS EDITION

**‘My story starts
way back – August 201’**

- by Andrew Brown

‘Ok, so let’s start at the beginning’

- by Lindsey Power (Nee Tyson)

‘It’s a fine day in early March’

- by Joe Murphy

Arrhythmia’s Nurses Team

Consultant Cardiologists Dr Niall Campbell
and Dr Ben Brown will be answering general
questions in Cardiology about new technology
and procedures, the new heart failure
drugs that are now available to NHS
patients and new Leadless ICD’s.

Will ICD’s become MRI safe?

*Here are some of the questions
they can answer, so come and
ask the experts.*

Andrew survives a real horror story

My story starts way back August 2014, I'd been away on holiday with my family and some special friends, and really hadn't been to well but as normal you just struggle through and hope for the best, upon our return home my wife insisted that I went to my doctors for a check up, well after much persuasion I went, on arrival I was told as that it had been SO long since I'd been that they had actually removed me from their books several years earlier, so after much debate I managed to reregister and see my old doctor ,(I've only had two doctors in my whole life time Dr Burke that delivered me and Dr McCarthy) both great doctors.

Anyway The docs says we need to run some test lets do bloods and come back in a couple of weeks or so and we shall take it from there! No problem I think

Well the following Friday comes and I'm in a bit of a rough way, the beloved missus has had enough and literally takes me there and then to the doctors Then everything happens the nurse at the doctors says you need to go to hospital and calls for an ambulance, that promptly arrives and takes me to Blackburn Royal (blue lights going etc etc) I loved it never been in an ambulance and one with sirens and lights going WOW like being a kid again.



Now this is the 12th September 2014, I was taken into A and E and was promptly taken through the proverbial check in procedures, I couldn't believe what was happening to me, all nurses and doctors fussing over me and one in particular my old pals daughter Lauren (it was great to see a friendly face amongst the chaos)

Well that's the last thing I properly remember until around the 8th October and sort of coming too, in Wythenshawe hospital, having suffered between 35 and 37 heart arrests several strokes and approximately 121 defibrillations (lol rough figures as they did lose count) I'd been placed in an induced coma for a few weeks as i had contracted heart sepsis, pneumonia and attained the doctors nightmare of quadruple organ failure, a trachotomy was carried out as, my body was

failing, nerve damage was occurring along with a vocal palsy issue from all the pipe work that was keeping me alive, i.e. kidney dialysis, heart pump, lung suction, full life support ,breathing apparatus etc - (not really in a good shape eh)

Again I was thankful for being out of it during all this upset, at which point I really have to thank my wife, parents, sisters, friends and family for all watching over me, along with the seriously long suffering doctors and nurses and all the staff and helpers at Royal Blackburn ICU and then CCCU and ICU at Wythenshawe,

As you can tell from reading this I survived, okay my life style has had to change, my body has been badly battered and I have stents fitted along with an ICD and take enough tablets to sink a battle ship (as they say) but I'm still here, I think the fact of the attention to detail that's given from people like Dr Williams, the ICU and CCCU staff, the unbelievable super nurse Adrienne, the physios and salt teams are second to none, that's why I'm still here

After months of hard work sorting me out Wythenshawe peeps had gone as far as they could in aiding my recovery and I was then sent to Rakehead rehabilitation centre (a very special place with what I can only say as superb exceptional doctors, nurses and helper

staff) at Burnley general for further help and retraining of my body to get me eating and talking again (Mandy and Rihannon), (as all vocal cords, voice box and epiglottis had taken a beating and didn't work) I was being kept nutritionally alive by a PEG feeding tube inserted into my tummy

It's now over twelve months on from that terrible day and I'm now getting stronger and fitter with each passing day, I know I will never be properly right (but hey what's really properly right) but I'm learning to cope with what I've been left.

A big thing I've found is mentally trying to accept what has happened and where can I go from here, One thing I will say to others is that try to never get upset with people that don't understand what you've been through and many will scorn you for surviving, they may have lost others or loved ones in similar circumstances. I know some will be reading this and I am truly sorry if I haven't mentioned you but take it from me, I will personally always be in your debt and will never forget all the love and attention I received then as in now.

Andrew Brown

Happy Living
Andrew Brown

Okay, so lets start at the beginning...

I was diagnosed with Hypertrophic Cardiomyopathy roughly 7 years ago. I purposely didn't 'google' or read up too much on the condition so as not to scare myself. I took one tablet everyday and lived my life pretty much exactly the same as always.

On 15th January 2015 I started to have palpitations at work - it wasn't out of the ordinary but this time it didn't ease off after a few minutes as normal. After 20 minutes I was also feeling light headed. I can't stress how lucky I was that my colleagues phoned me an ambulance. The ambulance hadn't even left the car park before at 29 years old I had a cardiac arrest. I was taken straight to hospital where 3 days later I had another cardiac arrest and was then transferred to Wythenshawe Hospital.

I was told I would need to have an ICD fitted which would make me a lot safer should this happen again to me. I would have my own defibrillator. I was worried about the operation hurting and the changes I was going to need to make like quitting smoking, cutting down on alcohol. I was also nervous about how it was going to look!! I didn't want a big box sticking out of my chest - I had a wedding dress to wear in August!!! The op was over and done with in what felt like minutes and



the following day I would be going home. I was terrified. I was too scared to move in case I pulled the wires out of place and I was so worried I would get a shock at any moment.

Four days later I was admitted back into hospital and being monitored for a build up of fluid around my heart. I was breathless and my heart rate was irregular and racing. I was so scared my device would go off..... and it did!! I got a shock from the ICD! It lasted a second but it was awful. I didn't feel any better though my heart was still racing. I spent the full night wide-awake; I wouldn't dare close my eyes in case I didn't open them again. This was the only time I honestly thought I wasn't going to make it. My mum spent the whole night by my side with no sleep either. I waited for what felt like a lifetime for a doctor in the morning to rush me to theatre to drain the fluid from my heart. I had the drain in for two days and was advised it was likely the fluid was a result of a slight puncture made during the ICD operation.

After a short while I was off home again. I was still getting out of breath a lot. I was struggling with the stairs at home and a shower would tire me out for the day, a supermarket trip took twice as long. When I was walking I would have to stop after a minute or so as I would feel light headed. I knew I needed to build my strength back up but I felt like I was getting worse. At my check up appointment I was admitted as a patient for a third time. This time I was in for around 2 months. My poor mother stayed in with me the whole time.

As a result of everything that had happened I ended up suffering with water retention and was put on medication and a limited fluid intake each day. I had big swollen legs and feet. I also had high levels of infection so I was taking strong antibiotics. My heart was also out of rhythm and I was given further medication to try to control this. I was practically rattling from all the medication, it was a big change. My body didn't like being out of rhythm and I was feeling really poorly this time.

“ I couldn't eat. I was vomiting. I was waking up each morning wishing it was time for bed so I didn't have to spend another day feeling rubbish. I felt like I was never going to get better or feel normal again. I was also an emotional wreck. I was convinced everything was going wrong. I was terrified of my medication being wrong I would double-check every tablet the nurses gave me. ”



Lindsey and her Mum

I didn't trust anyone. I would sometimes sleep with an oxygen mask as I thought my brain wasn't getting enough oxygen. I believed that my organs felt different although I couldn't even tell you which ones. I would only use a commode, as I couldn't bare the thought of any germs from the toilet. I was a nightmare. Eventually I was sent home, feeling somewhat better but considerably less sane! I needed to build myself back up - I had hardly walked for 2 months and I lost a lot of weight.

In May 2015 I had a controlled shock of the ICD, which put me back into rhythm. For the first time in 5 months I felt like myself. What a difference, I couldn't believe it. And on 1st August 2015 I walked down the aisle and wasn't breathless!

The whole day was perfect and we danced the night away. I didn't think I'd be feeling like this back in January. I have been in and out of rhythm since and it's not so straightforward to keep me how I should be, but I am feeling

so much more positive about it all.

I actually don't mind my ICD at all, it doesn't scare me anymore. I know if it's going to shock me it will be because I need it to and I feel so much safer knowing that. I have got a few more hurdles ahead but I am truly grateful for the massive amount of help and support I have had from Dr Ben Brown and so many members of the wonderful heart family at Wythenshawe hospital.



Lindsey on her Wedding Day

Andrew, Lindsey and Joe have opened up their hearts and shared their stories with all of us.

If you would like to share your story just e-mail it to me on georgedavies48@sky.com or post it to:

George S Davies
103 Redearth Road, Darwen Press
Lancashire, BB3 2AR

Cardiopulmonary Resuscitation

Learning how to administer CPR (Cardiopulmonary resuscitation) was the topic of one of our recent meetings. Joe Murphy's experience only goes to prove the importance of being able to do this.

It's a fine day for early March. Sunny, even warm. Looking through the window I can see a magpie building his nest in the tree opposite. The room is quite a nice one with a single bed, a nightstand and a comfortable chair. I haven't a clue where this place is, or why I am here. An airplane glides by in landing mode. Clearly we must be near an airport, but am I in England or somewhere abroad? There is a canula in each of my arms and I am wearing a new dressing gown and slippers. Obviously I am in a hospital but which one?

The door opens and a female voice asks 'how are you feeling' and 'would you like a cup of tea'. Drinking my tea I work out what to do next. 'I expect your wife will be here soon' the young lady says 'oh yes, I expect so' I reply. Of course. Margaret my wife will know what's going on. Margaret and I have been married fifty years and we have two daughters and two sons. We live in Stockport. I haven't long to wait before Margaret arrives bearing gifts, which she places at the foot of the bed.

A warm greeting and she gives me a searching look. 'Do you know where you are' she asks. 'Somewhere near an airport' I volunteer tentatively. 'You're in Wythenshawe Hospital Cardiology Department and you have had a cardiac arrest'. 'But that can't be, there's nothing wrong with my heart'. My chest hurts, have I been in an accident'.



'You've got some broken ribs but that's from the CPR'. She goes into more detail. How, one quiet Monday evening after taking a shower I sit down to watch University Challenge on TV and promptly stop breathing. We are alone in the house so Margaret calls an ambulance having started CPR. The ambulance arrives, twenty minutes later, during which time Margaret keeps me alive. It's my good fortune that Margaret is a life long member of Red Cross and once held an instructors certificate. But twenty minutes CPR single-handed is an almost superhuman effort.

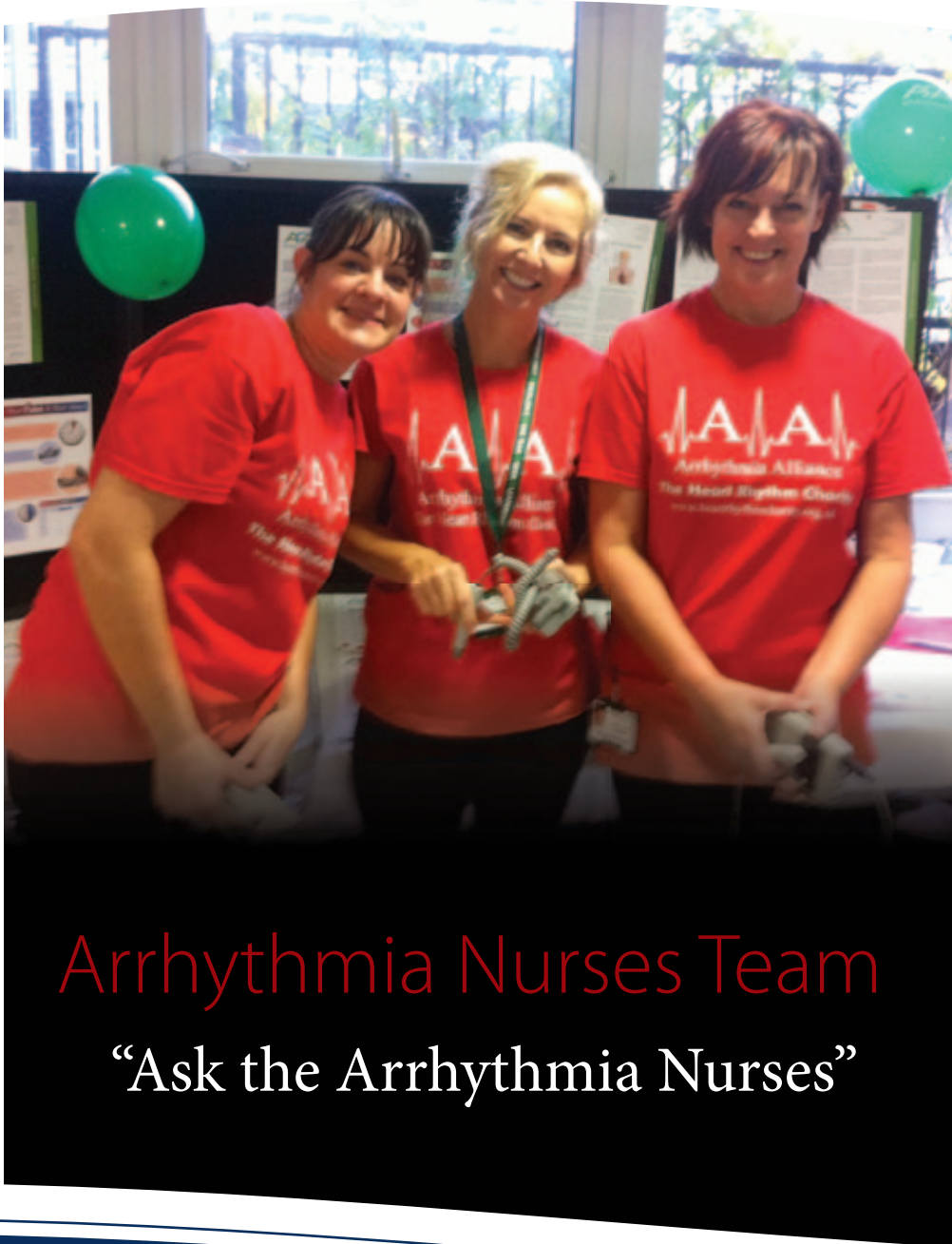
The paramedics shock me and stabilize me sufficient to transport me to Stepping Hill hospital near my home. There they commence treatment and tell Margaret that I am to be transferred to Wythenshawe Hospital. The next thing she knows, we are in an ambulance on the motorway, blues and two's in full cry and heading for Wythenshawe.

After a day and a half in Intensive Care I move to Coronary Care and thence to Ward 5 Cardiology. How long ago was this? I ask interrupting her story. 'Let me see'. She adds up the days. 'The best part of two weeks ago'

she says. 'Two weeks' I ask incredulously. 'What on earth have I been doing for two weeks?' 'You might well ask she replies'. 'You seem to have assumed some kind of Alter Ego' she grins. 'But I am glad to see today you seem much more like your old self'. Welcome back.

That's the gist of it really. I spend another couple of weeks in cardiology and leave for home with an ICD fitted in my left shoulder having lost a fortnight of my life, which I will probably not get back. To anyone who might find themselves in a similar position I would say 'hang on in there, you will eventually make sense of it all'. To my lovely wife Margaret without whose strength and bravery I wouldn't have had a chance and to the Ambulance Service, the staff at Stepping Hill and particularly the doctors and nurses, ancillary staff and volunteers at Wythenshawe who have handed me back my life when it appeared to have been lost, I can only offer my undying gratitude and the following quotation from the Talmud 'Whoever saves one life saves the world entirely'.

Joe Murphy



Arrhythmia Nurses Team

“Ask the Arrhythmia Nurses”

“Ask the Arrhythmia Nurses”

Question from patient in clinic: – “How do I go about getting holiday insurance now I have an ICD” Here is Adrienne’s reply – “That is a good question and one that we get asked a lot. Unfortunately, the Arrhythmia Nurses and Cardiac Physiologists cannot recommend a particular company to provide your travel insurance. The only advice we can give you is make sure you fully disclose all your medical conditions to the insurer. If you do not, your policy will be void and you will not be covered.

The Arrhythmia Alliance does offer advice on travel insurance. Go onto Google and search “travel insurance Arrhythmia Alliance”. You can also search the Arrhythmia Alliance web site directly, www.heartrhythmcharity.org.uk. You can also find information on car insurance.

We strongly advise that if you are coming in for an ICD implant or a box change, you try not to make any holiday plans until at least a month after you have had your procedure. We could call you in early due to cancellations so bear this in mind if you are booking a holiday before your procedure. We also prefer to see you at your first appointment after your procedure (this can be 3 to 5 weeks after implant) to make sure your new device is working properly and the wound is healing

well. It can take up to 6 weeks for the tissues under your skin to heal and carrying heavy luggage is not advised in the first few weeks.

If you are going on holiday, you do not need to take your remote monitor with you unless you are going away for a significant length of time. When you return home, your monitor will detect that you are home and perform any downloads it needs to do. If you get a shock while you are on holiday, you should attend the nearest hospital and seek medical attention. The Arrhythmia Alliance may be able to provide a list of centres, which deal with ICD’s in foreign countries. You should contact the Arrhythmia Alliance directly.

Ask the Consultant

The next meeting will be “Ask the Consultant”. So if you have any questions you wish to ask write them down and bring them along to the meeting. If you cannot make the meeting you can email us at arrhythmianurses@uhsm.nhs.uk or call us with your question and we will ask the Consultant on your behalf. If your question is asked, we will call you back with the reply. Please bear in mind; the Consultants will not be able to answer specific questions about your condition. If you are too shy to ask the question in public, we will ask it on your behalf.

Just because you have a Heart condition doesn't mean you cannot travel. Always consult your Doctor before you Fly and if you get the go ahead.....enjoy yourself!

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