Defibber News

Wythenshawe Hospital ICD PATIENT Support Group
March 2019

ASK THE DOCTOR

Dr David Fox and Dr Ben Brown

Have you heard something, read a research paper, or an article in the newspaper of future development's and want to ask an expert for clarification? Are you looking for explanation on anything within general cardiology? Now is your chance to do just that.

Come and ask! You can ask your own question for the benefit of yourself and the others listening, or, if you prefer, your question can be asked by Susan, Adrienne or chairman Paul, please note that individual cases cannot be answered on the day.

WEDNESDAY March 20th 2019
Education & Research Centre
Wythenshawe Hospital

Tea, Coffee & Biscuits served at 1.00pm
Meeting starts at 2.00pm

Welcome to the latest edition of Defibber News in 2019.
In this issue:

Chorley Athletic Club member – Martin Harrington - shares his story and what led to him having an ICD

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Martin Dawson ‘feeling weird’ after a ‘beer and a Chinese’

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Adrienne explains what to do if you cannot make your appointment

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Wythenshawe Contact details for all Patients + Support Group Website Link

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Car Parking difficulties at the Hospital? Why not try the NCP Car Park: -

Floats Road M23 9NJ
£2 for 4 hours
£3 for all day

‘On Friday 7th December after advice and persistent nagging from Tessa’

I considered myself to be a very fit 65-year-old man whose sports background included running 49 marathons. As a member of Chorley Harriers for 30 years, I was out running most days and racing at weekends.

In 2011 at the age of 59 I lost my job. It was a stressful time. I found that when I was out running, I became short of breath. I put this down to my recent circumstances. A visit to the doctor suggested I had become asthmatic. Now I never thought this was the case, but I went along with it. On reaching 60 years of age, I booked myself into the local Wellman Clinic. Within a few minutes of the nurse taking my pulse she said there was something else going on and sent my ECG report to Wythenshawe. A doctor came into the room and said that Chorley MAU was expecting me and then gave me an envelope to take with me. “Don’t read your notes”.

Five days in Chorley MAU and further tests I was diagnosed with Atrial Flutter. It was this that was causing my breathlessness and not asthma. One Cardioversion then an ablation later, I was able to start running again but told to keep an eye on my pulse. I also had had a loop recorder inserted that I was to use should I have “an episode”. All had been well for five years and I never had cause to use it.

All was fine until about six weeks before Christmas 2018 when I started feeling unwell. I became lethargic, short of breath and palpitations. My stomach ballooned, my weight increased from 80 kgs to 85 kgs and I was feeling tired throughout the day. I visited my doctor and to cut a long story short it was suggested I need more fibre in my diet! In the meantime, I had sent several loop recordings down the line to Wythenshawe.

On Friday 7th December after advice from Wythenshawe and persistent nagging from Tessa, my wife, I finally went along to Chorley A&E. I was seen straight away and wired up for an ECG. Then everything kicked off. Alarms started ringing and I was taken off to the resus bay. My heart rate at this stage was 160+ beats per minute. Despite being given amiodarone, it only dropped a few beats then went back up. Then suddenly my blood pressure dropped, and I started to become unconscious. I actually thought I was going to die. I then had a cardiac arrest. Unbeknown to me, the hospital doctors and staff reacted so well and after a Cardioversion I came round with my heart running at 44 bpm.

I was kept in Chorley CCU for a few weeks until a bed was available in Wythenshawe. It was suggested that fitting an ICD would be the answer. I had a visit from the ICD cardiac nurse who explained everything and answered all my concerns. I had the operation on Christmas Eve under local anesthetic and all went well. After four hours bed rest, I was able to return home the same day. I must add that the staff at Chorley and Wythenshawe could not have done more. They were fantastic and we had a lovely Christmas.

Since having the ICD fitted, I have felt quite well and thanks to support from Tessa, I have restricted my activities. I have since had several emotional moments when I thought about what happened prior to Christmas.

However, I am now on the mend and able to start Cardiac Rehabilitation to help build up my heart muscle. I’ve done several walks without any issues and now looking forward to leading a normal life.

P.S. Health professionals talk about things to improve lifestyle; eating healthily, taking exercise and limiting alcohol intake. Considering my background, I did ask the doctor what else I could have done. I was told that it is what it is. Without doing what I had done over the years, my cardiac arrest could have occurred ten years earlier. Food for thought.

Martin Harrington

ICD SUPPORT GROUP WEBSITE:

http://wythenshaweicd.wixsite.com/icdsupp ort

HAVE A LOOK -Details of the Group’sMeetings, Specialist Medical Information andPast Newsletters are all there for you to see.

Ask the Cardiac Nurse

Patient: Adrienne, I can’t make my appointment for my ICD check. What should I do?

Adrienne: Thanks for your question. Your ICD check is really important for many reasons.

1. We can check it is working well.
2. We can check the leads are all ok.
3. We can check the battery levels are ok and not coming close to end of “battery juice”.
4. We can check how you are in yourself.
5. We can check if any therapies have been delivered since your device was last interrogated.
6. We can check you are on the right mix of tablets.
7. We can check if there are any issues with your skin or wound over your device.
8. We can check if you have had any other heart rhythms which could affect how your device functions.
9. We can make any necessary changes to the functioning of your device.
10. You have the opportunity to ask questions face to face.

When you leave clinic, you get another

appointment for your next check. This can vary, but is usually either in a years' time, 6 months' time or 3 months' time. Sometimes the Cardiac Physiologist or Nurse may want to see you within a particular time frame. If this is the case, we will tell you, explaining the reason why and write on your outcome form which you hand in at the front desk, so they know when to book your next appointment. Sometimes, if all is well, you can go as soon as your device has been checked. Not everyone will need to be put through to the Nurse.

If you cannot make an appointment, for whatever reason, you must call the Pacing helpdesk on0161 291 4640 and let them know. Put this number in your mobile phone. If you do need to cancel your appointment, you won't be in trouble! We just need to know you cannot come. Your existing appointment will be cancelled and you will be given another one. If you do not do this, you have technically failed to attend for your appointment. This appointment could have been used for someone else, who really needs to be seen in clinic. It is a really bad use of our resources. Imagine if it was you who needed to be seen and you were told there were no appointments for 2 months! If your battery is running low on power (battery juice!) it is vital that we monitor the rate of drainage so your battery does not run out. We can do a lot of the checks through your Remote Monitor, but not everything. And we cannot make any changes to your device through your Remote Monitor. We can only do that in clinic. This is one of the many reasons why it is important to keep your Remote Monitor plugged in and kept near the place where you sleep.

If we see that your battery has drained more than we had anticipated, a clinic appointment is a good opportunity for us to go through a "box change" procedure, give you some information to read and list you for the procedure. You may be surprised to know that quite a lot of work goes into organising your appointment. If you don't turn up, this is again a big waste of our resources. So always do your best to come to clinic.
If your level of mobility has changed dramatically and you can no longer walk long distances, you can discuss this with your GP who can then organise hospital transport. I must warn you though, the criteria for who is eligible for hospital transport is very strict! We only get 20 minutes to see each patient, which goes fast if you have questions to ask us about your device. So be prepared before you come to clinic. Write your questions down beforehand!
So we look forward to seeing you in clinic guys! See you soon

Adrienne

We would love to hear from you all. Share your story and your experiences with the rest of the Support Group. Just send it along with a personal photograph to: georgedavies48@sky.com

All went relatively smoothly until about 8yrs ago........'

30 + years ago I had a heart attack, out of the blue no warning signs. I believe I arrived in Macc hospital in VT but responded and came out with I think aspirin. Had another, approximately 10 years later followed 6 months later by a full-blown stroke paralysis down left side and no speech. Fought a bit and got most of it back apart from my memory problem. I was going to have a bypass until the stroke was found to be a thrombosis on the back of my heart. I decided to live with it and warfarin for the rest of my life. I think we all know without me mentioning the ongoing problem with side effects and heart meds.

All went relatively smoothly till about 8years ago. I came back from Silverstone, my wife had gone down south visiting my two boys. I was having a beer and a Chinese, I started to feel weird, unlike anything I'd felt before, I did my blood pressure and temperature, checked pulse, which was a bit quick, phoned 999 quickly gave brief description and history. Let's say 5 hours later having to have heart redone forgotten what it's called but that fixed me. I had a two week stay in Cardiology and then two weeks with Wythenshawe. and came out with an ICD and suffered a 5-hour stent operation that hadn't gone so well.

Anyway, i'll skip a few years before you fall asleep. two years ago, I started thinking about when my next episode might be going to happen (my wife calls them episodes). I'd had a TIA, was diabetic type 2 insulin dependent, so nothing bad.

Then one night we were just about to watch "Shetland", heard a strange ring tone from somewhere, I put my wine down checked laptop phone and so did my wife. when "BANG "! felt like I'd just been smacked with a cricket bat across my chest, I fell back in the chair. A minute or so later bang again, I then thought! is this it! My wife phoned 999 and was quite calm but very concerned (she has in all fairness lived through all my problems as well as me) in the meantime I got another whacking. I'd lost count I got 5 I think before the battery needed a bit of a breather.

I think I was a bit of a wreck but felt ok health wise. Paramedic arrived, she did all the usual but hadn't seen an ICD devise and told my wife to keep clear. Boy would I have liked a warm embrace. Got taken in to A&E Macclesfield and then straight to Coronary Care. I slept till 7.00am leaned out of bed for a wee and bang again fortunately all wired this time. I did as someone had said and tried to relax and lay down. It was then I saw about 4 of the team watching over me. I thought I was on my own. Got 5 altogether, the nurses counted them. I had another rest then but the device chiming at me had me ringing the bell and bracing me for some more. Found out later it was the devise warning of low voltage.

The unit got switched off at 9.00 am. I won't bore you with all the in between bits but got transferred to Wythenshawe and as soon as staff came back after bank holiday the whole lot was changed. I was first on the list, and then out sometime later, Can't drive for a month. But I'm still here.

These last few years have been a bit bumpy. Macclesfield had started me on a drug called Entresto which ultimately didn't suit me and caused a lowering of my blood count. Macclesfield thought I'd had a blood loss from polyps which were operated on which caused a blood loss when warfarin was restarted, and I had to have warfarin reversed and a blood transfusion both big threats to a person with a dodgy heart.

Anyway, the trauma of inappropriate shocks had got to me and I kept away from ICD meetings after all no one wants to hear about faults with ICD's when you've just had one fitted.

Last week I went to the meeting and the first person I spoke to had also had inappropriate shocks. I then spoke with Adrienne which was another help to me. I then had a chat one to one with Rosie, the guest speaker and she told me all about the faults with the leads and the alarm. She asked me questions about what I had experienced and the effects on me when hearing the alarms. She seemed a little surprised after the unit had been switched off, it sounded an alarm again the night before my op to have the lead changed. I was once again a bit of a wreck. Rosie explained it was trying to reset itself, which it couldn't as it was safe.

I will finish by saying "I love Life " I think having a few health issues as made me appreciate what we all have! I have a three-year-old granddaughter and a grandson on the way and I've still a lot of living to do with my long-suffering wife Shirley. I have nothing but admiration for all the Cardiology staff of Wythenshawe and Macclesfield hospital.

One last thing when my lead failed I contacted Wythenshawe and my wife had an answer phone message left when she got back from the hospital. First thing I did was chase up all the contact numbers on my records. Be warned if you are not present in hospital when you do this, it's a lot harder than you can ever imagine, my two boys are on there as well now hopefully it won't be needed for a long time to come.

Best regards Martin

If anyone who attends our Meetings, wishes to make a donation to the ICD Support Group's running costs running costs, please speak to Paul and Ian at the Meeting.

Patients and Carers meeting at Wythenshawe Hospital. Convivial and a great opportunity foreveryone to meet and discuss with others in the same situation, all of the issues that we each have to deal with, as a result of our health. A very warm invite to everyone.

The ICD Patient Support Group was nominated recently in the 'Manchester University NHS Foundation Trust Excellence Awards'

We are very pleased to say the group are finalists in the 'Non-clinical team of the year' the winners will be announced on March 8th.

This is an amazing opportunity to recognise and show case the sterling work the group does on behalf of all the ICD patient's at Wythenshawe, as it continues to support, educate and inform ICD patients and their families.

As with any volunteer group, we are always looking to the future on how best the group can continue to provide the best support and care for ICD patients and their families.

So, if you are interested in offering your time and thoughts to the ICD group whether you are a patient or a carer, please feel free to come forward at one of the meetings and speak to one of the committee members, or you can contact us through the numbers and e-mail addresses in the newsletters' or on the Support Group Website.

ICD Support Group Committee

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!

If you require any further information about the
Support Group, please contact the Chairman at:
pwdavisandsonltd@aol.com
(07973-541382)

Contact details for all Patients:

If you have any concerns,
please contact the:

Cardiac Physiologists on:
0161 291 4615

Arrhythmia Nurse team on:
0161 291 5998 / 5443 / 5076