Defibber News

November – December 2019

Wednesday November 6th

All Saints Church, Hale Road,
Hale Barns WA15 8SP

Tea, Coffee, Biscuits, Cakes &

Raffle 1.00pm

Meeting Starts at 2.00pm

NONYA POWELL…
"I'm Not That Clever"

ERIC MARSH…
" It could be said my story starts in 1950, my 21st birthday arrived……"

MICHAEL POWELL…
" In 2016 whilst on holiday in Devon, I suffered a series of heart failures…."

ASK THE CARDIAC NURSE….
"How do I get the best out of my Clinic appointment?"

CAROLE BARLOW…
"Living well, living life"

Our Next Meeting

GUEST SPEAKER
Lindsay Ford – Representative from Medtronic

Meet the Medtronic Representatives at the next meeting!

Lindsay works for Medtronic and can answer questions about your ICD or CRT-D. If you are too shy to ask, Adrienne will ask for you, just speak to her before or during the meeting.

Ode to an I.C.D

The relationship with ‘our ICD’ Began twelve short months ago My husband carries it in his chest To pace his heart, fast or slow.

It’s neat and fits quite snugly Just below the collar bone It’s both brake and accelerator And doesn’t beep, click or drone.

A welcome guest in our family We are still learning why and how, This addition affects our lives In our here and now.

In comparison to a bodily frame It’s size is really very neat Just lately it had to do its job, As his heart began a faster beat.

As ‘newbies’ to, this regime, The incident came and passed. So quickly, we just thought, What the ‘heck’was that.

The ICD knew, what we did not And instructed rectification Returning his heart back on track We carried on, in oblivion.

The ICD remembered well And the ‘download’ told us all. The teams at Wythenshawe hospital Then made their telephone call.

It was a shock and will admit to, Some panic and confusion. Lack of knowledge, our downfall, Soon corrected by discussion.

The ICD was tweeked a touch And the medication adjusted. All co-ordinated to perfection By people who we trusted

We really should and must Pay tribute to all the staff, Who play their part so well With cheery smiles and laughs.

From the ladies at the café, with the welcome cup of tea, Their service, really excellent and felt like ‘just for me’.

To the lady at reception, attentive, spotting my confusion. She proffers help, no need to ask, she’s gifted with, intuition.

The ladies at the ‘book-in-desk’ no down turned heads, in rejection, with smiles and friendly chatter, It really is a ‘warm reception’.

The technical staff with expertise still display the human face, whilst processing all the data in their wires and monitors place.

The nurses with a ‘special’ role with data and experience to hand, explained all our ‘hows’ and ‘whys’ in language we, could understand.

So to ‘ALL’, who gave ‘of themselves’, my sincere thanks and gratitude. We may all train to do a ‘job’ But the extra, is the attitude.

Noyna Powell

It could be said my story starts in 1950, my 21st birthday arrived, this marked the end of my sevenyear indentured apprenticeship, lots of cards and presents and the arrival of my call up papers; National Service beckoned.

After training I was despatched to Celle in Germany as a driver/gunner in the RAF Regiment. I eventually returned home and returned to my trade as an electrical engineer but after a couple of years decided on a change and joined the Lancashire Constabulary which required medicals and suchlike. As was the practice, in those days I had to leave my home town of Lancaster and it found me in the greater Manchester area where I still am. Fast forward to the 1970's when my young Son wanted a 'grown up' watch, the Timex Snoopy had to go and, like many other little boys, it was to be one of the new digitals Casio had launched. He loved it and mastered all the button pressing and excitedly asked me to listen to all the pips it made. I couldn't hear them, my Wife announced I was deaf, but I was having none of it.

I retired from the Police Force and took another job until I was sixty-five, only my Wife complained about my lack of hearing and it was getting worse. We continued like this for some time and I was able to explain the fact I couldn't hear her when I accompanied her on her speaking engagements down to her mumbling, she wasn't impressed!

Eventually she took up an offer of a free hearing test from one of the private deaf aid companies and it was easier to go. They did all the tests and then asked, "have you ever been involved with guns and shooting". My mind did go back to 1950 as there were no ear defenders then. I suggested they were just trying to sell their product and got a reprieve. Not long had elapsed when I was obliged to go elsewhere, the question was the same and we were told it only needs one shot to do the damage but as you age it gets worse. We had a bit of a false start with them before I was able to persuade my GP to refer me for an NHS test and hearing aid. With NHS changes I moved about but eventually settled down with the Audiology Dept at the local hospital. Late in 2018 I went to have the aid serviced and they found I needed my ears suctioning, this wasn't a new problem as they had been syringed or suctioned in the past. I got an appointment for early January.

We had Christmas, twelfth night came along and everything was taken down and I spent Monday putting everything back in the loft for another year. Tuesday morning came and off I went to the hospital, parked the car up the road, well the parking fees are exorbitant, aren't they? I arrived at the reception gave my name, nodded at the other chap waiting and sat down. That was the last thing I remember till coming to in a hospital bed in the resuscitation dept, my Wife and Sons arriving very soon after. I have subsequently discovered I was 'gone' for five minutes and consultants have made it clear to my Wife that had I not been on hospital premises there would have been no coming back.

After a wait on their wards I went on a day trip to Wythenshawe for an angiogram, the results were not good, so they kept me. I am rising ninety so not thought a candidate for surgery, after consideration I was considered appropriate for an ICD. For this I am very thankful as I had an active and full life before.

One of the biggest problems we have had is my ears, eventually my Wife set about trying to get them suctioned, in between complaining I should have, at least, waited till they were done. The Audiology Dept didn't want me back and referred me to the ENT dept where there is a qualified nurse and a doctor available. Deaf Aids and blocked ears don't go together, that is if I put them in as I am still not convinced but even I had to admit I couldn't hear well. Due to staff illness and other such problems it took us till the end of June.

Life is good I am back watching football regularly at our home town non-league club, being careful with electrical motors and suchlike means I can delegate jobs I don't like. My Wife now trusts me enough to take up again many of the things she was involved in and is busily planning a celebration for my 90th in September. I have even renewed my registration with the FA as a referee, sadly my whistle was confiscated some years ago, but I like to remain up to date. I feel so thankful for having the superb North West Heart Centre in the area.

Eric Marsh

In 2016 whilst on holiday in Devon, I suffered a series of heart failure. (I thought I had flatulence, due to burping all night). Maybe one too many 'roasties' or could have been the glass of 'red' the night before, usual thoughts. At Torbay Hospital two stents were inserted, and as a result, I was able to continue a normal life. What is 'normal' I can hear you say.

In July of last year, I suffered Atrial Fibrillation. I was taken to Tameside Hospital where I stayed overnight. Just prior to my release I suffered another similar attack. I was then transferred to Wythenshawe Hospital heart unit. During a camera investigation into the condition of my heart, I suffered another attack, and was given 'shock treatment'. Not an easy remedy to experience, but hey the alternative, won't go there. Physical adjustments now in the hands of experts, left one task, the emotional aspect.

Due to these factors I waa fitted with a dual chamber ICD. As per the norm, I surrendered my Driving Licence. Thoughts surrounding the driving ban, proved much worse than the reality. Offers of help from family, neighbours and friends raised our spirits and we fulfilled all of our commitments. We enjoyed the added dimension of extra company on our journeys. In January this year this was returned, as there had been no further problems.

In May we went on holiday to our caravan, purchased some years ago, after my retirement. I have always been fairly fit, having played most sports, and been a keen walker. As per normal, whilst on holiday, I went on an eight and half mile trek across a section of Dartmoor. Towards the end of the walk I felt ‘odd’. I stopped and took stock. I didn’t faint or pass out and didn’t lose vision. After a few minutes I walked to my car and drove the 40 miles back to the caravan. That weekend (Sun 26.5.2019) we returned home. I drove the 260 miles back home with no problems. Neither myself of my wife associated the ‘odd’ feeling, with heart issues. We ‘Newbies’ to this part of our lives, still have a lot to understand and learn.

On Tuesday 28.5.19 Sarah from the Remote Download monitor section, phoned me and explained that whilst on holiday the ICD had recorded an incident of Ventricular Tachycardia, which the ICD had corrected. In view of this I would again have to surrender my Driving Licence. (Oh! well it’s happened before). This means my wife takes over control of the car again and I am in charge of the shopping list and trolley, hmmm, no licence needed for that.

I telephoned Adrienne (one of the Arrhythmia Nurses) and left a message on her answer phone to ring me. This was to ask had I done too much exercise. Adrienne phoned back and assured me that this was not a problem. It was then established that a probable cause, was a reduction in Bisoprolol. Adrienne suggested I contact my GP and change the Bisoprolol back to the original dosage. It was completed the same day. Thankfully not another tablet to take, small blessings do add up in the long run.

The next day, 30.05.19 Adrienne phoned again, asking me to ‘hold myself available’ at the request of Dr Campbell. On Friday at 9.30am 31.5.19 I received a call asking me to be at the Heart Unit at 11.00am that day. I duly attended (as one does) willingly. It was Dr Campbell’s suggestion that my ICD’s base rate be increased from 40 beats per minute to 50 beats of accommodate my lifestyle. This was done, that day.

May I express my heart felt gratitude (excuse the pun), to all the people connected to this event, for their advice, professionalism and swift action.

Mike Powell

ASK THE CARDIAC NURSE

Question from a patient in clinic:

How can I get the best out of my clinic appointment?

Adrienne replied:

A great question that! It is really important that you are prepared for your clinic appointment. You need to bring an up to date list of your medicines, even if these haven't changed since you were last in clinic. If you have any questions to ask, write them down and bring that too! This helps to keep you focused on what is important to you.

Try not to make your list too long, we do not have a lot of time to spend with you. One of the main reasons why clinics run late is because it takes longer to see some patients than was planned. We try really hard to keep to a tight schedule but unfortunately this doesn't always happen.

If you have an ICD and nothing has happened to make your ICD treat a dangerous heart rhythm, you no longer need to see the Doctor or Nurse. This should be seen as good news! We have a lot of people with an ICD or CRT-D and resources are tight. If you do have concerns, please tell the Cardiac Physiologist who checked your device. They may well be able to answer your question without you being put through to the medical team. We do tend to see people who have a CRT-D. This is not because they are getting special treatment. It is usually because their heart condition is more complicated and is more likely to change rapidly.

If the Cardiac Physiologist needs to check the leads of your device, they will tell you. This is an important part of your device check, but some people can feel the effects of checking the leads which can feel a little unpleasant. Remember, the Cardiac Physiologist is in complete control of what they are doing to your device. They check the leads as quickly as possible to get the information they need while limiting the amount of unpleasantness to you. A lot of people do not feel anything when their leads are checked.

You usually get your next appointment for a device check before you leave the hospital. This can sometimes be up to a year in advance if you just have an ICD. We keep an eye on your device through your Remote Monitor, so always keep it plugged in, in the room where you sleep. Remember to make a note of your next device check (many people make a note in the diary of their mobile phones and set up a reminder). It's really important that you let us know if you can't make your next appointment. About 10% of clinic appointments are not attended by patients, with no explanation.

We could use these slots for people who really need to be seen in clinic, so it is really wasteful of our resources if you do not attend. We won't shout at you if you tell us you can't come for a device check, I promise! Just let us know! The number to call is the Cardiac Appointment Team on 0161 291 4640.

Stay regular everyone!

Adrienne

Living well, living life.

In September 2016 just after my cardiac arrest, and being fitted with an ICD, due to heart failure, I was persuaded by Adrienne to write about my experience for the Defibber News. I hope you don't mind me doing a follow up, 3 years later!

At first, I was very wary about what I should and shouldn't be doing. My mind was full of questions that I didn't really want to know the answers to, such as 'Is my life expectancy drastically reduced, will I be limited to a very sedate life-style, will I have to give up work, will I be able to lift up and cuddle my grandchildren, can I go abroad on holiday?

I attended Cardiac Rehab which definitely sorted out a lot of the irrational fears that kept popping into my head and answered a lot of (what I thought) were silly questions. I really gained confidence from the Cardiac Rehab team in the gym and the talks afterwards. My husband John also attended the talks and I really think this put his mind at rest too, we both learnt a lot from these sessions.

I did take my time before returning to work. My employers were very understanding, in fact I think they were just as worried about me going back to work, as that is where I had my cardiac arrest. Our fabulous Health & Safety Officer had insisted the company bought a defibrillator for the Reception area and had trained up a team of first aiders, so my life was saved by them. (They have since added another defibrillator to the factory area as well).

I had to be seen by Occupational Health to discuss my return to work, and we agreed that reduced hours would be a good idea, I was hoping to reduce my hours anyway, winding down towards retirement. They also advised me to see a counsellor for my mental health and mindfulness, but after the initial introduction, and first session I decided I didn't need this as the Cardiac Rehab team had helped me so much previously.

My next hurdle was holidaying abroad, I felt I wasn't ready yet for flying, so we went on our first ever cruise sailing from Liverpool to the Norwegian fjords, which was amazing. This gave me the confidence to book a holiday to Corfu in September, (12 months after my event). I did have the collywobbles a few weeks before we were due to fly out, so I called Adrienne to check

I would be okay on the flight, needless to say she told me in no uncertain terms to pack my bags and have a great holiday! I have to report that I did feel somewhat breathless on the flight (I have medication for my heart failure), but this could have been caused by my anxiety, rather than cabin pressures, heart issues etc. I will have to let you know how I feel after my next flight ……. 🙂

I did retire from work at the end of August 2018 (almost 2 years after my event) as I now want to live life for me (not for work) with my husband, family and the grandchildren. In fact, at a recent 3rd birthday party for my grandson, I was dragged onto the giant slides by another 2 of my grandchildren, and I enjoyed it so much I had to do it again! I have joined my local gym and do 2 sessions a week there and swim once a week.

John, my husband has a new motorbike and I ride pillion, we are planning lots of rides out into the countryside. I really fancy learning how to play golf too, so life is for living each and every day, and for enjoying new experiences. It's not for worrying about what may or may not happen!

Carole Barlow

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

EVERYONE HAS A STORY TO TELL

One way of finding that support - either as a patient or carer - is to share your experiences with others who are going through the same kinds of things.

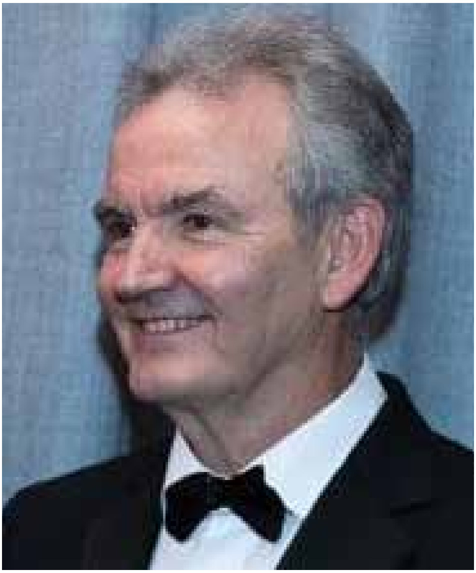
Why not write your story for the Newsletter and send it to

George S Davies

Georgedavies48@sky.com

If you require any further information about the Support Group, please contact the Chairman

at:
pwdavisandsonltd@aol.com
(07973-541382)



From time to time, members of our Support Group have asked if they could make a donation to help finance the Newsletter and assist in the cost of organizing our Groups Meetings.

Members, if they so wish, can now make a donation direct to the Support Groups Bank, the details of which are

If you would like to make a donation to the ICD support group, the bank account details are:

LLOYDS BANK

WYTHENSHAWE ICD PATIENT
SUPPORT GROUP

Sort Code: 30-91-91

Account Number: 30781868

Emma Maiden: Treasurer,
12 The Willows, Cranwell Village,
Lincolnshire, NG34 8XG

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!