

# Defibber News

OCT/NOV 2017

**Barry Edwards**  
'Around 1957...'

**Andrew  
Shorrock**  
'I thought  
I had it all...'

**Gordon  
Liversage**  
'Trying to feel  
positive...!'

Remembering  
Edwin Cash

Cardiac  
Rehabilitation



**WEDNESDAY NOVEMBER 1st 2017**

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

## **Fiona Green – 'Cardiac Rehabilitation'**

**(Clinical Specialist Physiotherapist Team Leader)**  
**(1.00pm for Tea & Coffee – Meeting starts at 2.00pm)**

Fiona is our expert here at UHSM - she is the specialist team leader responsible for looking after cardiac patients including all ICD patients. Fiona will be talking about the benefits of taking regular physical activity and how exercise plays a substantial role in enabling individuals with heart conditions to take control of their lives, giving advice, practical solutions and reassurance with regard to cardiac rehabilitation. This will be an interactive as well as very informative presentation so please come along and ask your question.



Hi all, around 1957 aged 9 I had an injury in my testes!! So what you ask?. Fast forward to 1975 I went for a vasectomy - led on the table the surgeon said "have you had a problem here?" I affirmed this and he replied "well the tubes are embedded I need to get them out" and he proceeded to tug and pull and I nearly jumped off the bed. I went home and went to bed and awoke that evening with chest pains and called the Doctor. Bronchitis was diagnosed and off she went.

The next morning at 8am my own GP called (this was in the good old days). At 10.30am I was in ICU at Crumpsall hospital with an MI. After 10 days I was discharged and 2 weeks later I attended Dr.Brays clinic at Wythenshawe for investigations. No reason could be found for the incident and I put it down to stress from the vasectomy but this could not be proved. I was discharged with no further treatment necessary.

In 2006 one morning after an early gym session I was getting ready for work and suddenly felt ill with a vague pain in my chest, I called an ambulance and was taken to Tameside hospital A&E and admitted. I was told that whilst being checked over I passed out and the defibber was used on me. At the time I was lucky enough to be in BUPA and a week later I was transferred to the Alexandra hospital and Dr. Bennett fitted my ICD.

I always remember my first clinic consultation with Jeanette Hornsby (retd) when she asked if I had experienced my device activating, (an incident), I said innocently "I get the odd flutter like a palpitation" and she said that was ok.

My first incident was about 12 months after my ICD was fitted, again I was in the gym after work and sat on a machine resting, and felt clammy and sickly, suddenly I jumped and let out a yelp! as something gave me an mighty thump in my chest. I realised my ICD had gone off. I sat there petrified at first, waiting to see what would happen next. Nothing happened, I realised that the clammy feeling and sickness had gone and I felt fine. I rushed home to tell my wife and rang the hospital and left a message on the answer phone.

Next day Jeanette rang me and said "come in on Thursday and we'll check you out". The laid back manner really reassured me that it was all routine. In 2013 following a mixup in drug regime between me, my GP and the hospital I experienced a "storm" where at 3am one morning my device went off and after the 3rd go in just over an hour I called an ambulance and was admitted to the MRI where it continued and I had about 8 shocks up to around 8am when it was brought under control.

My last incident was in February 2016, again in the early hours of the morning. I turned over and went back to sleep and did not bother ringing in as I have a Medtronic monitor at the side of the bed and thought well, if I need to go in, the hospital will ring me. When I attended the next clinic in May and happened to mention it they checked and confirmed it had activated appropriately. I was duly told off for not ringing in and will do so in the future.

The reason I have written this is because in the latest De-fibber News I read that people and their families worry about their ICD. My wife was very protective and still is to some degree but I have a life to lead and want to do as much as I can obviously being sensible.

Finally, I think that once the team at Wythenshawe get a grip of you, you are more likely to be run over by a bus than have your heart clap out. My heartfelt thanks to all the team for all they do. Must dash, late June and off to Italy in 2 days

Regards to you all

Barry Edwards

# *...I thought I had it all*

Since I was 17 I worked in the Building Trade, working my way up the ladder and becoming a Company Director. Aged 46 in October 2008 just as the recession began, I took over the running of a Building Contractor doing 11 million a year, good job, good salary, good house, good family, holidays, dog, rabbit – the usual. Then came the stress, the depression the sheer weight of employing 80 odd people paying wages, paying the taxman, paying the mortgage doing jobs for nothing

Then came sleepless nights, sweats, drinking, even the odd cig! – it was in 2009-2010 that if I was to 'have one' it would be now but it took another two years of worry and stress for me to develop firstly – high blood pressure then high cholesterol and then a prostate problem and two 'probes' (that was interesting) and 12 months later it was benign but the rot had set in and the depression was taking over my life – dark thoughts bad ones, I had had enough, I was ill

Things worsened, I was turning into 'a rabbit in the headlights' I was stumbling from day to day week to week, my life was falling apart. I had to pack it all in in 2013 – now surely if I was to 'have one' it would be now wouldn't it ?



What to do? where's the money coming from? – my wife supported me with tremendous effort and commitment – she was and still is, a 'star' - For twelve months, I tried to decide what to do

In 2014 I started my own e-bay business working from home and all was going tickety-boo so why oh why did I suddenly have a heart attack in Feb 2016 – the danger time had passed I thought but I had been stuffing indigestion tablets in my gob for years, turns out it was angina - having processed it I think the inevitable was merely delayed, put on hold.....23 Feb 2016 I felt like my whole body was coming apart, cold, hot, sweating, pains, I thought that was it, over, kaput, end of the road but why at 53 was it happening now? I went to Wigan Infirmary and they rushed me to Wythenshawe, boy did I hit that Morphine drip...two hours later with Stent fitted, I was on ICU with all these wires on me and three days later I was home – safe.

## *I consider myself extremely lucky*

The staff at UHSM put me together again, they saved my life – I survived, I beat the dreaded stigma of 'having one' and now eight months later I have had an ICD fitted (bloody hell the good news just keeps on coming) but I have come to terms with it and it's there to help me – that's what Adrienne keeps telling me and I know it's my friend (I call it My 'Iron Man') So, apart from the stress, the depression the prostate, the heart attack, the high blood pressure, high cholesterol, atrial fibrillation – oh by the way I just got an earing aid my my 'willy doesn't work properly - but hey – I am here for gods sake I still live in the same house, were still married, we still love each other – what a roller-coaster ride and my daughters are still beautiful - and you know what

*...I do have it all*

I am grateful for the chance to start again  
Andrew Shorrock

# Trying to feel positive...

Since the last procedure in September, I have felt great. I am more active and no longer needed to be on Mexiletine, which meant I no longer had the debilitating side effects. Now I feel more confident about going out without worrying about how I am going to feel. Now and again my heart rhythm misbehaves itself and I feel unwell, but I have accepted and coped with it.

In February 2017 things started to go wrong again. I was asked to do a home ICD scan. This showed that I was going into VT and on several occasions nearly reached the threshold of being shocked again. I went to Dr Brown's clinic the same month and it was decided that I should go back onto a lower dose of Mexciletine plus further surgery. This meant I would have more VT ablations and a different procedure called Epicardial Access. I would have to have a general Anaesthetic, plus it was higher risk. On the 16 March 2017, I was asked to conduct a further home scan. The results showed that the procedure would need to be done. This was done in April 2017 and lasted about three and a half hours. I was in hospital for two days. Again, I feel great after the procedure but time will tell as previously seen. The rhythm seems to be good and I am sleeping much better but still become breathless quite easily and my heart rate seems to take a long time to get down to normality, but crucially, I have not had any episodes of VT. So, it looks like the previous ablations have done the job.



At the last clinic in June, it was found that I was regularly going into AF, which I had not been in since 2008. It has been arranged for me to have a Cardio Version, which will temporarily help the AF. Then later, have an AF Ablation.

As I said previously, it seems that recovery cannot be rushed. You have to be patient and positive about the whole process and of course put your trust in the hands of the experts. So once again, thanks to all of the doctors, staff, family and friends who have always been patient and understanding and were there when.

## *Our Next Meeting*

Hello and welcome to this edition of your newsletter -- Our next meeting is to be held at 2 pm on the 1st of November at All Saints Parish Hall Hale Barns WA15 8SP. This Hall is next to Booths Supermarket, where you can park for free for 3 hours.

Our last meeting there was very successful. We had some great feedback about the venue and guest speaker on that occasion Mike Connolly. Mike dealt with the Psychological aspects of living with an ICD and recommended a book for all patients to read entitled 'Being mortal' (Atul Gawande)

Following on from this our next meeting will cover the Physical side of living with an ICD.

It was apparent at the last meeting that many people struggle with life changing aspects of having an ICD, especially regarding sports activities.

Our guest speaker at this next meeting will be Fiona Green who is the Cardiac Rehabili-

tation, Clinical Specialist Physiotherapist. Fiona will be able to help and explain in more details what you can and can't do. Our very experienced specialist nurses will also be on hand to offer advice.

I hope to see many of our regulars at this meeting, if you have not been before please come along and if it is your first time please make yourself known to myself or any one of the committee members, we are here to help you. Tea, Coffee and light refreshments will be available at 1.30pm and a small raffle will be held to help finance the venue.

Paul Davis - Chairman

**Share your story with  
other Patients and Carers.**

**Tell us how living with  
an ICD has affected your life.**

**Send your story to – [georgedavies48@sky.com](mailto:georgedavies48@sky.com)**

# The Cardiac Rehabilitation Service

This service is for patients diagnosed with heart disease. A team of healthcare professionals including physiotherapists, nurses, occupational therapists, dieticians, pharmacists, smoking cessation advisors and alcohol support advisers, delivers it. The aim of cardiac rehabilitation is to help you keep well by promoting your health and well-being and you will be supported in leading as full and active life as possible.

## This can be achieved by:

- Informing you about heart disease and its causes;
- Improving your awareness and understanding of the risk factors of cardiovascular disease;
- Developing a personal care plan to help you make positive lifestyle changes;
- Helping restore your confidence to exercise regularly and independently to improve physical fitness;
- Discussing your physical activity and exercise opportunities for the future, reducing the risk of further cardiac problems and improving your quality of life.

Attending the UHSM cardiac rehabilitation programmes are regarded by your cardiac consultant and GP, to be an essential part of your recovery following your cardiac event or diagnosis.

## Question from a patient regarding exercise:

“I am a keen sports player. I play football, rugby, tennis and swimming at a competitive level. I have just had an ICD put in at Wythenshawe hospital. What sports can I do now and when can I restart them?”

## Arrhythmia Nurses reply:

Hi, thank you for your question about exercise and ICD's. As a general rule of thumb, we encourage patients to return to their normal lifestyle after implant of any cardiac device.

You can have Cardiac Rehabilitation (CR) after implant of an ICD. You should have been offered this when you were admitted to have your ICD implanted. This involves being invited to a CR centre local to you about 6 weeks after implant to participate in a programme of exercise by the Physiotherapists over a number of weeks. You should build up exercise steadily over a number of weeks, warm up and cool down effectively before and after every exercise session and listen to your body. The next talk at the ICD support group meeting will be on exercise and ICD's. You and your family will be very welcome to attend. You don't need an invite, just look out for the next newsletter, which will contain information on where and when we are meeting.

**However, some lifestyle changes may need to be considered afterwards. For example, diet, alcohol and participating in contact sports.**



After your ICD has been implanted, you have a surgical wound, which needs time to heal. The skin has glue to seal the wound, which falls off naturally within 2-3 weeks after implant. The tissues underneath can take 4-6 weeks to heal. We advise that you avoid excessive movement of your arms (lifting heavy objects above your head, carrying heavy loads) for the first 4-6 weeks.

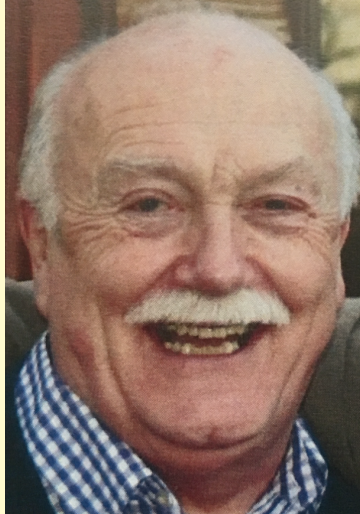
Providing the wound has healed well, after 6 weeks you can carry on with all your usual activities as normal. There are, however, some exceptions to this. Taking part in high impact contact sports such as rugby and football puts

you at slightly higher risk of damaging your ICD, especially if you fall onto the side of your ICD. The ICD and its' leads are designed to be robust, but are not completely damage proof. We advise you to think carefully about participating in high impact sporting activities. Once the wound has healed completely (2-3 weeks) you are fine to go swimming but stick to breaststroke if possible. Be mindful of being in swimming pools and the sea – we advise that you avoid these during the first 2-3 weeks of healing. Playing tennis and other sports such as golf is also fine but consider your arm swing during the first 4-6 weeks of tissue healing.

You can have Cardiac Rehabilitation (CR) after implant of an ICD. You should have been offered this when you were admitted to have your ICD implanted. This involves being invited to a CR centre local to you about 6 weeks after implant to participate in a programme of exercise by the Physiotherapists over a number of weeks. You should build up exercise steadily over a number of weeks, warm up and cool down effectively before and after every exercise session and listen to your body. The next talk at the ICD support group meeting will be on exercise and ICD's. You and your family will be very welcome to attend. You don't need an invite, just look out for the next newsletter, which will contain information on where and when we are meeting.

## *Remembering Edwin*

*'It is with regret I have to inform you of the sad passing of one of our founder members of this support group.'*



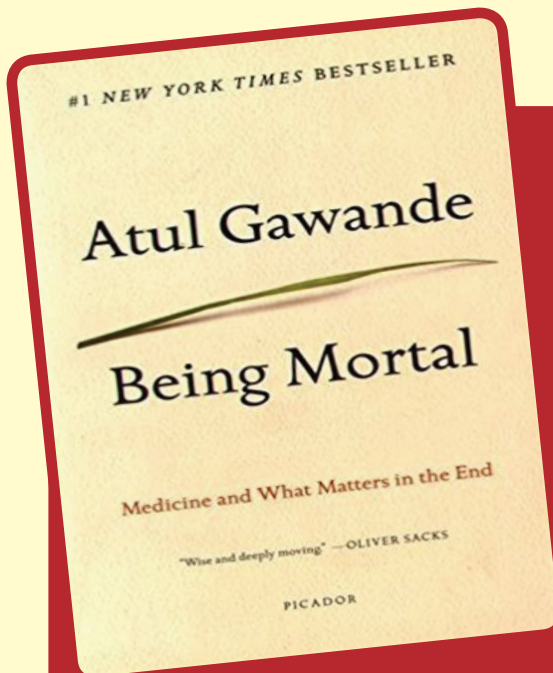
'Edwin Cash sadly passed away peacefully at Wythenshawe Hospital on the 21st of August 2017; Edwin has not had good health for many months. Edwin will be remembered for his huge contribution with the setting up of this support group 16 years ago, Edwin's wife Hazel is also a founder member but sadly Hazel's health has not been very kind to her lately either.

I would like to take this opportunity to thank both Hazel and Edwin for their huge amount of time, commitment and financial support. They have both given to this support group over the many years, purely for the benefit of others. Edwin was a true Gentleman and will be surely missed by many. I do hope Hazel's health improves and can try and take comfort from her lovely memories.

I do like Edwin's nickname that his grandson has for him "Grumps", I may adopt that name myself. Rest in peace Edwin.'

Paul Davis - Chairman

# Our Next Meeting



At the last meeting of our Support Group, the Speaker Mike Connolly recommended a book entitled '**Being Mortal**' written by Atul Gawande for all patients. This book can be purchased currently and is available on Amazon in Paperback, Hardback and Kindle versions.

For those who would like to delve a little more into the research relating to the experiences of patients living with an ICD, Mike Connolly recommended

**'Perceptions and experiences of patients living with implantable cardioverter defibrillators'**  
which can be located on-line at:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5114828/>

**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**