

Defibber News

October 2016



Paul Davis



Sue Grosvenor



Ian Woodward



Lawrence Smythe



Emma Boswell



Adrienne Worsworth



David Gallagher



Anne Davies



Pauline Smythe



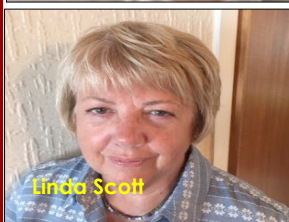
George Davies



Edwin Cash



Hazel Cash



Eirida Scott

**ICD
Committee
Members**

Our next Meeting is on Wednesday November 2nd Education & Research Centre

Following on from the extremely successful meeting in July, with guest speaker Mr Mike Connolly Consultant Nurse, who gave us a fascinating interactive in-site into the physiological aspects of living with an ICD, the committee has asked Cardiology Pharmacist Nizhat Iqbal to speak about current and new Medications.

Nizhat will discuss many of the heart drugs currently prescribed to patients as well as the new heart failure drug 'Entresto'. She will tell us about its function, criteria for use and patient suitability as this new drug will be offered to many patients at UHSM in the near future. Nizhat will also be able to answer any questions you may have on current cardiac drugs and their use.

Adrienne, Specialist Arrhythmia Nurse, and Sue Cardiac Physiologist will be available to answer any of your questions regarding ICD implant, follow-up and updates. Please free to ask any question yourself or if you prefer you can hand your question to any committee or staff member beforehand as your question can be asked anonymously or on your behalf. This will be an informative and interesting meeting and we look forward to welcoming you all.

Guest speaker Nizhat Iqbal Cardiology Pharmacist



Before Nizhat gives her 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 the opportunity to talk to other patients about your experiences of living with an ICD

You can also meet members of the Committee who will answer all your questions about our Support Group

WYTHENSHAW HOSPITAL ICD PATIENT SUPPORT GROUP

Round Two for Gordon Liversage



I thought I should continue my write up on my shocking reality, which was in the last issue of Defibber News.

Although being shocked by the ICD felt traumatic at the time, trying to sort out my life and accept what had happened has been a challenge in itself.

Coming back home was a hard task. I felt I was leaving the security of the hospital and there would be no cardiologist on hand if things were to go wrong. I know that this was complete negative thinking. Instead I should have been thinking how pleased the doctors were with my progress after the five-hour Ablation procedure and that I would be capable of becoming better at home.

When I arrived home, I couldn't talk about the experience without becoming emotional about it. Because of that I would not make the effort to see my friends, which was silly of me. Instead, they made the effort and came to see me, which was great. They only stayed a couple of hours but it made all the difference. That is why your friends

are just as important as your family and the support team at the hospital.

Another challenge has been the new medication. It's a matter of finding the correct one for me, as everyone is different. This is ongoing at the moment.

So it is a matter of persevering with the healing process. I have some help along the way and I would like to thank Adrienne, the Arrhythmia Nurse and George Davies – Editor of the Defibber News. Both were there for me when I needed support but most of all, my wife has been a rock. Without her physical and emotional help I am not sure if I could have managed without her. I know that my heart will never be at full strength again but I am optimistic for the future. The ICD is there to help my heart and there is support all around me willing to help.

So if you have had your own personal trauma, please feel positive and don't be afraid to ask for help.



When people go through traumatic events such as those that Gordon has written about, it is crucial that support is there for them at that particular time.

A patient recently asked, "What is the ICD support group all about?"

The ICD support group is exactly that – a support group for people with Implantable Cardioverter Defibrillators (ICD's) or Cardiac

Resynchronisation Therapy-Defibrillators (CRT-D's).

There is a Chairman, Secretary, Treasurer and members of a Committee. They produce this newsletter three times a year, which has stories from patients about their experiences of having an ICD or CRT-D and information on subjects that are relevant to you.

When you receive your Defibber News it will contain information on when and where the next support group meeting will be held. You don't need an invite, you just turn up!

You can come along to Wythenshawe hospital (usually the Education and Resource Centre (ERC) between 1 pm and 2 pm and have a cup of tea or coffee with a biscuit (it's all free!), meet members of the support group, other patients and their families or you can just sit and enjoy your cuppa!

We want you to feel comfortable about coming along to the meetings – it can be a bit nerve racking when you go somewhere you have never been before. We won't ask you to stand up and tell your story - we won't make you join in. We just want you to find the support group meetings interesting, enjoyable and informative. We do ask you to give us feedback (anonymously if you wish) on the meeting you attended and what you would like in the future. That's it!

We would love to see you at the meetings, so pluck up some courage and come along.

ASK THE ARRHYTHMIA NURSES

New Medications are coming out all the time and much is seen in the popular press. However, it's always best to get your information from your Consultants and Nurses at Wythenshawe Hospital.



(Adrienne Unsworth, Natasha Evenson (Arrhythmia Nurses), Carolyn Waywell and Julie Harris (Heart Failure Nurses))

There is a new Medication for dealing with Heart Failure called Entresto.

So. What is Entresto, who can have it and what is it for?

Many patients are asking us about a new medicine called Entresto (sacubitril/valsartan), which is now available for patients with heart failure. Not everyone will be able to have this medicine so your hospital Consultant will make the decision whether it is right for you.

It is a new medicine, which has been approved by the National Institute for Health and Care Excellence (NICE) and has been thoroughly researched in the PARADIGM-HF trial. It is called an angiotensin receptor neprilysin inhibitor (ARNI). You can find more on the research of the medicine on line at: <https://www.nice.org.uk/news/press-and-media/nice-gives-green-light-to-new-drug-set-to-benefit-100-000-people-with-common-heart-condition>

Entresto is a medicine, which is specifically for people with heart failure, with symptoms equivalent:

- (1) *Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea (shortness of breath).*
- (2) *Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnoea.*

It is a combination of two medicines- sacubitril, which helps to lower blood pressure and valsartan, which helps to

stop the blood vessels from narrowing and improve blood flow. The aim of taking this medicine is to help reduce the number of hospital admissions when heart failure symptoms become worse. It also aims to reduce the risk of death caused by heart failure.

It is usually given alongside other heart failure medicines and it means you will stop taking medicines like ramipril (an angiotensin converting enzyme inhibitor –ACE inhibitor) or medicines like candesartan (an angiotensin receptor blocker - ARB). Your Consultant Cardiologist and/or Heart Failure team will identify suitable patients to start the new medicine and supervise the transition from ACE Inhibitor or ARB to Entresto.

Are there any side effects?

As with all medicines, there may be some side effects when taking Entresto. You should not take Entresto if you are allergic to sacubitril or valsartan, or if you have ever had a severe allergic reaction to blood pressure medicines such as captopril, lisinopril, ramipril or ARB's. Not everyone will experience side effects but if you do, these will be monitored by the Heart Failure team while you are being started on Entresto. Serious side effects should be reported immediately. Most people can manage side effects and they reduce or stop once your body has adapted to the new medicine. Entresto should be stopped immediately if you develop an allergic reaction to it. It cannot be taken with aliskiren (a medicine for blood pressure). You cannot have Entresto if you are pregnant.

The most common side effects can include a cough, light-headedness, low blood pressure or increased fluid retention.

How is Entresto started?

Entresto is started in the Heart Failure clinic by the Heart Failure nurses under the supervision of your Consultant Cardiologist. It will take three visits to the Heart Failure clinic to introduce and increase the dose of the Entresto.

ACE inhibitors or ARB's are stopped two days before starting the Entresto. This is done at home. ARB medicines such as valsartan or candesartan should be stopped one day before. Entresto is taken twice a day, roughly 12 hours apart. Your Heart Failure nurses will monitor your blood levels closely. The dose may be increased if you are tolerating it well and should only be increased or decreased as advised by medical professionals. **More information will be given at the next ICD support group meeting.**

Contact Details for Patients

April Hopkins (0161 291 5998) -- Adrienne Unsworth (0161 291 5443) -- Natasha Evenson (0161 291 5076)

Email – arrhythmianurses@uhsm.nhs.uk

Cardiac Physiologists (0161 291 4615)

Just going on Holiday

On the 18 June 2016 Carol Barlow was looking forward to her holiday. It was the first morning of our 3-day holiday to Scarborough, followed by 3 days in the Lake District, so plenty of walking was on the agenda. However, just a few hundred metres down the road from our B&B I had to stop to catch my breath – this was the start of my breathlessness upon any exertion.

We just took things easy over the course of our holiday, but on our final evening in The Lakes my husband and I realised I needed medical attention, I couldn't breathe properly lying down in bed at night. I have had treatment for breast cancer (2005/2006 chemotherapy followed by mastectomy) and obviously our first worry was that the cancer had returned.

Following investigative tests over a 3-4 week period I was actually diagnosed with chemo-induced heart failure – both my husband and I were relieved it was not the cancer returning, just a damaged heart!!!

Towards the end of July I was prescribed a cocktail of medications, which would improve the pumping action of my heart, but advised that there would be lots of tweaking to get the necessary balance. My breathlessness started to improve quite quickly, and I carried on working full time even though I still felt quite tired by the end of the day, but I don't like to give in ...



I was due to see my consultant again on Friday 2nd Sept but unfortunately this had to be postponed. Not to worry, I enjoyed a quiet weekend, and then back to work on Monday.

My next memory was coming round in Intensive Care at Wythenshawe Hospital on Tues 6th Sept; completely unaware of everything that had taken place.

Apparently I had complained of feeling a bit unwell just before lunchtime at work, and then suffered a cardiac arrest at my desk. Amazingly for me we have a defibrillator on site, and 4 fully trained first aiders were able to perform CPR and shock my heart – they saved my life, and cared for me until the paramedics, (and firemen!!) arrived to take over.

I spent 2 days in Intensive Care, then 2 more days on CCU, before being transferred to Ward F5 where all the staff are fantastic. I was attached to a monitor for the next 7 days, checking out my blood pressure, heart rate and oxygen levels. Full blood counts were taken each day, and I was given an MRI scan too, I was certainly very well looked after. The decision was made that I would benefit from an ICD being inserted; this will take over (shock me) if my heart rate should race to dangerously high levels again, and avert another cardiac arrest.

The actual procedure took about an hour under sedation and was not as scary as I thought it would be. I spent some time in Recovery before going back up to my ward, I felt some discomfort but paracetamol soon eased the pain. The following morning I was given a chest x-ray to make sure everything was in the correct place! Joy of joys, I was allowed home that day (17th Sept) and given a remote monitoring device that enables the hospital to access my readings if necessary – such technology, I can't pretend to understand ... I will have follow up appointments, and all the support is on hand from the Arrhythmia Nurses and I am now much more confident in facing the future.

Dear Patients

We have had communication from the British Heart Rhythm Society (BHRS) informing us of a scam relating to a very small number of patients with remote monitors.

We understand that patients are being contacted and incorrectly told that their box/equipment is faulty in an attempt to sell a replacement and a warranty.

We wanted to bring this to your attention and confirm that you will **never** be asked to pay for anything to do with your ICD or CRT-D. If you have any concerns, please contact the Cardiac Physiologists on 0161 291 4615 or the Arrhythmia Nurse team on 0161 291 5998, 5443 or 5076. If we aren't able to take your call, leave a message for us with your name and phone number and we will call you back at the earliest opportunity in working hours.

In no circumstances should you give your payment details over the phone, and if you have any concerns please do not hesitate to get in touch.

Arrhythmia Nurse Team



Welcome to this edition of your Defibber news, I do hope you enjoy reading it, as always there are some great stories in this edition.

It is coming up for 2 years since I was elected to the role of chairman of the ICD Patient Support Group here at UHSM. I thought it was about time I gave you an overview of the support groups' role.

The ICD Patient Support Group was formed in 2001, by ICD patients with the sole purpose of helping, supporting, educating and informing other ICD patients who have been through sometimes traumatic but definitely life changing experience, I am proud to say that some of the founding members are still on the committee giving their support.

As we know, as patients we are aware of the medical, nursing and allied professional staff at UHSM are experts in their field, but we can be that extra support from talking to another person who has been through a similar experience as yourself, and can fully appreciate the value of close family, friends and carers around us.

As I said in my opening sentence I hope you all enjoy reading the newsletter and find it informative and helpful, especially patients' own experiences, I would just like to take this opportunity to thank all the

patients over the years who have taken the time to write about their own experiences in order to help others with theirs. We are always looking for patient stories and experiences to print in the newsletter it can be long or short, long hand or rhyme! It doesn't even have to be grammatically correct because it's your story!

Just send them to the editor e-mail or post

The newsletter is sent out 3 times a year to all ICD patients' at UHSM that's around 1200.

The ICD Patient Support Group newsletter has always been and still is entirely self funded with donations from patients and I would like to thank those patients for their generosity it is hugely appreciated.

Three times a year we hold a meeting at UHSM for all ICD patients this is mainly for patients to come for an informal chat over a cup of tea. A guest speaker is invited to present on subjects requested by ICD patients, so if you have any ideas for future speakers please feel free to suggest them.

Myself and the other members of the ICD committee are all volunteers working to help you, so we are always interested to hear your views in ways UHSM can improve patient experience and care now and in the future. If you have never been to a meeting please come along you have nothing to lose but a lot to gain.

I hope to see you at the next Meeting.

Kind regards

Paul Davis – Chairman

Leap year 2016

February 29th should have been a normal day at work for me but it was anything but. The next few paragraphs are from what people have told me, as I have no recollection of any of what's to follow.

I went into work as normal and was having a meeting with my boss in his office. I started to complain of indigestion then soon after I collapsed on the office floor. My breathing had stopped so a colleague was summoned and promptly gave me CPR for 9 minutes until an ambulance arrived. I was shocked 5 times by the paramedic and was taken to Macclesfield hospital's intensive care unit where I was sedated and covered in ice to cool me down and later put in an induced coma.

My wife and family were in bits and have told me since how worrying and frightening it was for them. I was moved to Stoke hospital as there was no room at Wythenshawe and an angiogram confirmed a heart attack and a cardiac arrest. During those first few days I was really sore with damaged ribs. I remained in Stoke hospital for another 3 weeks then discharged with lots of meds and advice to rest and take things very easy. I was told I had blocked arteries and mild damage to part of my heart. I was given advice on healthy eating and referred for cardiac rehab at Wythenshawe, which I attended for 10 weeks. I enjoyed the rehab and felt so much better. I had lost over a stone in weight and was keeping it off, exercising regularly and following a healthy diet.

Everything was fine and I had been recovering well until one day in August when I was driving back from Yorkshire. I felt really unwell and had a very fast heart rate whilst driving on the motorway. I pulled onto the hard shoulder and asked my wife to call an ambulance.

Whilst waiting for it to arrive I had the feeling I was about to pass out several times and was extremely nauseous. When it arrived I had an ECG and blood pressure taken which showed my heart rate and blood pressure were through the roof. I was then blue lighted to the nearest hospital, which was

Blackburn.

At Blackburn hospital I was admitted to A&E where I was given some strong meds, which stabilised me, that was the first time I heard the term Ventricular Tachycardia (VT). I was admitted on to a ward and the next day I was told I needed an ICD fitted, the operation was arranged for 2 weeks later and was carried out successfully at Wythenshawe.

During the wait for the operation lots of thoughts were in my mind like "I am only 52 is this it? "Am I not the man I was?" "What if it goes off randomly?" "How bad is my heart?" By the time I was on my way home I had the answers to these questions, I feel the ICD is a little insurance policy that I may need one day and if I need it I need it!! I still have anxious moments but feel reassured knowing I have my arrhythmia nurse (Adrienne) who I have rang several times since my return home.

I have now been re referred to cardiac rehab which I am looking forward to and will attend every session as I feel it's important to get all the help I can.

I am due to return to work next week which I am a little apprehensive about but I know I have to get back to a routine and get on with the rest of my life.

Sean Graye

In January/February 2014 I had been suffering from pains in my chest on and off and I put it down to indigestion and just kept taking painkillers. On Tuesday February 18th whilst alone in our flat the pain seemed to be a lot worse than it had even been before and after 3 lots of pain killers it wasn't getting any better.

I eventually collapsed. It was impossible for me to get up and my arms and legs just would not work. It seemed like all my body functions had shut down. After some time I managed to get cleaned up and changed. I then collapsed again, the pain was getting more intense at which point I rang an ambulance. I get a bit confused, there seemed to be lots of people in green in my front room and after I was connected up to various bits of kit one of the paramedics informed me I was having a heart attack and they would need to take me to Blackpool Hospital. At this point my wife Gillian returned home from work and contacted a friend of ours to tell him what was happening and he said he would make his way to Blackpool to bring Gillian home. We then left in the ambulance with the full blues and twos and after a couple of stops on the way for more pain killing, we arrived at Blackpool Hospital.

I went straight into Theatre and that's the last I remember till I woke up in the Recovery Ward. At this point I was told that they had fitted a Stent and ballooned some arteries. After attending Cardio Rehab and after various tests, I went to Blackburn Royal on July 22nd for an Angiogram during which, two more Stents were fitted and more ballooning. Back to Cardio Rehab on 26th September at Blackburn Royal Cardiology Dept. for an ECG and a Dobutamine stress echo test. After all this I seemed to be out of breath all the time and had chest pains from time to time.

While away visiting family in Jersey I could not walk as far as I could before and was also unable to sleep due to constant coughing. On our return my wife Gillian insisted I went to the doctors – it was April 6th (Easter Sunday) when we went to Accrington Victoria Minor Injuries Unit. I was prescribed antibiotics, steroids and ventolin. On our return to the flat I passed out and Gillian rang 111 and they said they would send an ambulance but she said she would drive me to the hospital. We arrived at Blackburn Royal A&E where I was admitted and after three days

diagnosed with COPD. Over the next few months, after attending COPD Rehab once a week for 6 weeks and feeling a bit better but still short of breath and suffering the occasional chest pains, I was never sure whether the pains were the COPD or my heart, but with use of both GTN spray and Ventolin, it seemed to calm down.

On September 18th whilst having a social drink with the lads in my local – The Griffin Inn – at one point I was aware of someone stood over me saying are you all right. It wasn't till afterwards I told the lads I had no recollection of the event. Then on November 13th a very similar event happened when I was at home in our flat with Gillian. Apparently, I was sitting in my chair when I suddenly flopped back and threw my arms out again. I don't remember any of this; just her standing over me saying 'are you alright'. As a result of this Gillian insisted I go to the doctors because I couldn't describe these events. I made an appointment for us both to go to the doctors. My GP gave me a thorough examination. He decided the problem must be with my heart and made an appointment for me to see Dr R Singh, my Cardiologist at Blackburn Royal.

On January 7th I attended the Cardiology Clinic and was admitted right away and it was arranged that I should have an Angiogram that evening, but this wasn't possible so I had it the next morning: I also had an Echo sound test. On my return to the Ward I was put on a telemetry heart monitor. During the night of 9th January the alarm of the telemetry went off. I had gone into VT. After this, Dr Singh decided after consulting with Dr D Fox at Wythenshawe Hospital that I needed an ICD fitted. On January 20th I was taken by ambulance to Wythenshawe Hospital and my ICD was fitted by Dr A Di Marco; that evening I was returned by ambulance to Blackburn Royal followed by more tests on January 21st. I have attended my first ICD Clinic on 17th February and everything is fine. After being home a couple of months I am slowly getting to terms with not being able to drive, so thank goodness Gillian can drive. But it's really a good feeling to know I am now safe. I would like to thank all the brilliant staff at Blackburn Royal and Wythenshawe Hospitals for their care and treatment during my stay.

Ken Robertson

All contributions to Defibber News go to:

Georgedavies48@sky.com