

# Defibber News

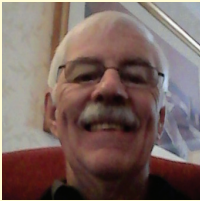
MARCH 2017

## UHSM Patient ICD Support Group



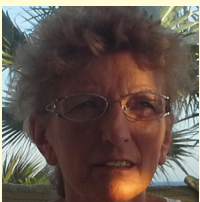
**Gordon Liversage**

'Feeling great and more active.'



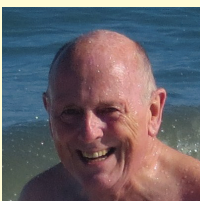
**James Jones**

'Things are settling down'



**Jackie Brooks**

'Her holiday to remember'



**Eamonn Munelly**

'As he walked into the Church Hall'

## Our next Meeting is on Wednesday March 15th Education & Research Centre

### Ask the Consultants?

This is your opportunity to ask general cardiology questions to our top consultants here at UHSM. Ask about New drugs?, New devices?, 'What the media says'! Device Follow-up?, Community clinics? Or any cardiology topic and they will know the answer!!

You can ask the question yourself or if you wish Susan and Adrienne can ask the question for you. It is an open forum.

**Tea and coffee will be served at 1pm for an informal meet and greet with the consultants meeting starting at 2pm.**



**IF IT IS YOUR FIRST TIME AT OUR MEETING PLEASE ASK TO MEET ONE OF THE COMMITTEE MEMBERS.**

**The Consultants at your disposal for this meeting will be Dr Ben Brown, Dr Dave Fox and Dr Niall Campbell**

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

# Gordon Liversage

This is the third issue of my recovery after the ICD shocks. In April, emotionally, I wasn't feeling good but family, friends and the professionals have been a great help. The five-hour ablation in April did the job by stopping fast VT but didn't stop VT all together.

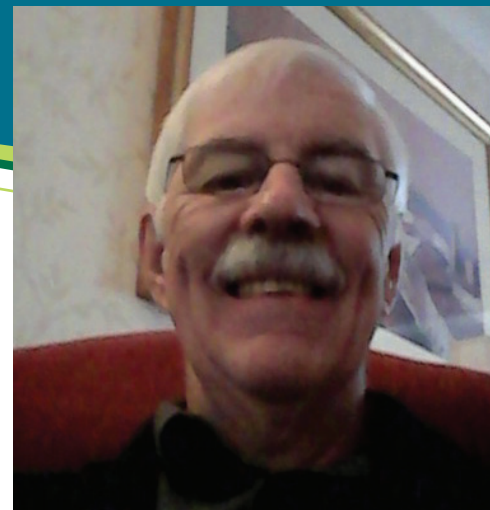
Doctor Brown decided to give me a different medication. This was called Ivabradine. It was taken alongside the medication I was already taking. It does have side effects, like most drugs, but they were bearable. For a while everything seemed fine. Then one night I woke up and could feel my heart racing. Here we go again, I thought. I sat up and tried to relax, which can be hard when you start to become concerned. Eventually the fast pace went back to normal. Several days later it happened again.



This time it was more persistent. Coming and going throughout the next few days and nights. It was arranged for me to see Doctor Brown at his clinic He decided that he would try another drug that would help my condition. I would need to go in hospital for a few days to sort out the dosage and to see if I was able to cope with the side effects. The drug was Mexiletine. Over the following weeks it certainly sorted out the rhythm, but gradually the side effects became quite debilitating. Again I went to see Doctor Brown. It was now agreed that I would need further surgery. I went into Wythenshawe in late September and had more ablations, which lasted about three hours.

Since this final procedure I feel great. I have become more active and no longer have the side effects, plus I no longer need to be on Mexiletine. 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 can definitely accept and cope with it and 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 I most needed them.

# James Story



*I was always fit and active when younger. Walked everywhere and played rugby until a shoulder injury put paid to that. I took up running for a while to compensate for the exercise rugby gave me. I like a drink but not to excess (I think so anyway) am not overweight and have never smoked. I retired from the Fire Service in 2001 after 29 years and looked forward to a happy retirement travelling with my wife and mountain walking. I was rarely ill never went to the doctor and any ailment was usually gone in a few days.*

About 3 years after I retired I did not feel too good and for a change could not shake it off. Finally I went to my GP who had very little information on me. He examined me and said he wanted to go to the local hospital for a chest X Ray. He managed to arrange this for the same day. Soon after I returned home from the hospital the doctor's surgery rang and asked me to go down to the evening surgery. I was told that I had an enlarged heart and a severe heart murmur. He was going to refer me to the Cardiology Department at Macclesfield Hospital. In a few hours I had gone from thinking that I had a bit of a bug to knowing I had a serious heart condition.

Macclesfield hospital gave me a full series of tests. I will not go into detail as most of you reading this have been there. I was then told I had a seriously regurgitating Mitral Valve and the Left Side of my heart was enlarged as a result of trying to compensate for this lack of efficiency.

They referred me on to Wythenshawe Hospital for further tests and subsequent corrective surgery. When you are young and daft you

think you are invincible but any remaining fragments of that belief were instantly dispelled at the thought of open-heart surgery. Obviously some discussion as to the cause of my condition took place but no positive conclusion was reached. It possibly goes back to my infancy in 1949 when I nearly died soon after I was born and before I had left the Maternity Hospital. There are no medical records but the family belief was that I had Rheumatic Fever and came through it OK. (Or perhaps not). The surgery was carried out in July 2005 and I was referred back to Macclesfield for follow ups. These were carried out on a regular basis and I got on with enjoying my retirement. Travelling, walking etc. I have recently been travelling in Japan, Spain and Mexico and walked Hadrian's Wall. This year however eleven years after the operation I was told there had been a change in my condition. During my check up in August I was shown the current ECG alongside the previous one and even I could see the difference. A new word now entered my life - Arrhythmia (try that one in scrabble). Something new to get my head around.

The enlarged Left Side of my heart was beating out of synch with the Right Side making it even less efficient. My already damaged heart was struggling ever harder to keep up and I had not noticed. What I now know were initial symptoms I was putting down to general wear and tear and beginning to show my age. I will not make that mistake again.

The solution was to have an ICD implanted. This occurred in November, delayed only by

the fact that I had a two week holiday planned in September. I was admitted to Wythenshawe Hospital very early on the morning of 14th November as a Day Patient. Everything went well and I was discharged in the early evening. I was even given a very welcome chicken casserole before I left. I took with me an envelope full of information and contacts; a head full of guidance and advice and a promise of lots of follow ups to look forward to both in Wythenshawe and Macclesfield. I also took a Monitoring Device, which works as a WI-FI modem and connects my ICD to a remote monitoring centre in Wythenshawe. This will keep an eye on me by giving a daily download to the Arrhythmia Team. Any problems will therefore be detected immediately. This with its little green eye now sits on my bedside cabinet. How clever is that, as my son would say. I had not noticed any deterioration in my condition but following the ICD implantation I already feel much better and fitter. My medication is next in line to be reviewed and further improvement is expected. Entresto has been mentioned. Sounds good. My thanks go to the Cardiology Teams at Macclesfield and Wythenshawe Hospitals, The Cath. Lab Staff and Wards F2 and F5. Far too many people to mention over the years. I will not even try to list them, as I do not want to miss anyone out. As far as I am concerned they are all excellent whatever their role. I know this is far from over but wherever it goes next I know I am in good hands.

**James Jones**

## *A holiday to remember*

It was April 2014 and as it was our RUBY Wedding Anniversary in January, Ken my husband and I decided we would celebrate it by spending a month on the island of Lanzarote in the Canaries, a holiday destination we both loved. We arrived on the 1st April ready for a nice long holiday as we had just finished doing a show the week before; we are both Gilbert and Sullivan fans. Everything was going fine the first week the weather was good, but the second week it got even hotter.

On the Wednesday of the second week we needed some water so off I trot with my bag on wheels, thinking I was being clever I decided to get 2, 5 litre bottles, which I can tell you, were quiet heavy. I dragged them back to the apartment thinking I'll not do that again. On the Thursday I had some pain in my chest but because I suffer from an inflammatory problem call Ankylosing Spondylitis I didn't pay much attention to it and just took some anti-inflammatory tablets, after a while the pain seemed to have disappeared. I started to feel unwell later on the Friday but still put it down



to dragging the water and setting off my Ankylosing Spondylitis, so I increased the anti-inflammatory medication and it eased a little and then I thought perhaps I had pulled something in my chest, which would take time to heal. Saturday I felt a little better and everything seemed to be OK. On the Sunday I felt even better when I got up but as the day wore on I started to feel ill again but this time I thought I had indigestion because the pain seemed to have gone from my chest to my diaphragm, so off I trot to the chemist with just my purse with no form of identity not even my mobile phone, it was about a 15mins walk there and 15mins back. I bought some tablets as I thought I had indigestion. On the way back I had to sit down, as I couldn't get my breath, but put this down to the hot weather. When I got back I realised that I had no key to get in as Ken had gone out, so I sat on the kerb waiting to see if anyone would let me in the private complex we were staying in, as luck



had it someone did. I was feeling ok just a bit breathless but didn't think that anything was wrong, it was hot but it had also got very humid. As the day wore on I did start to become unwell again, but as usual putting it down to my inflammatory problem.

Late on Sunday night the pain started to get worse but I still had no idea what it was, I tried to sleep but couldn't, all I kept saying to myself was I wanted the pain to go away, Ken would ask me if I was ok and I would say yes go back to sleep. Around 5 o'clock in the morning I started to be sick and this kept up until around 8.30, in the end Ken said he was going to get a Doctor as he had been wanting to do this since Saturday and I kept saying no it was only the Ankylosing Spondylitis. He went to a lady that lived on the complex to see if she could help with a doctor, Julie said it would be quicker for her to take us. When Ken came back all I could

think about was that I needed a shower before we go. I can't go like this (typical woman). We arrived at the doctors and thought we would have a long wait. As we entered the doctors I could see the waiting room was full but a nurse came walking towards us asking what was wrong when Ken said I was having chest pains she straight away took me in to a treatment room and put me on the bed, another nurse came in and connected me to an ECG machine while the other nurse was preparing my other arm obviously to take any needles I may need, they worked very quick - no one asked us if we had any medical insurance - all we took was my EU card and my passport] a doctor arrive and ask me 2 questions if the pain was between 1 & 10 what was it, I said 10. Was it compressed? I said it was as if someone was sat on my chest, and by then another doctor had come in and was looking at the ECG, the next thing I remember there where

2 paramedics strapping me on to a bed plus 2 more to help carry me down the stairs to an ambulance and take me to Arrecife General Hospitals, intensive care unit. In the ICU I remember coming round to see Ken by the side of the bed but them drifting back to sleep, I kept thinking to myself that I would be OK once I had a good night sleep (little did I know I wouldn't) I was in this unit over night, as they had to stabilise me as I was told later. I remember coming round occasionally and every time there was always someone with me either a nurse or a doctor sat by my bed. As there was no heart surgeon at this hospital on Tuesday 15th April I had to be transferred by helicopter to Las Palmas, Gran Canaria where there is a very large teaching hospital. I was again put in to an intensive care unit. I was still unaware of what was wrong with me. On the Wednesday I was taken into theatre and had 3 stents put in.

I was back in the intensive care unit for another 5 days; during this time I was given an ultrasound to see if there was any damage to the heart. During this the doctor who spoke good English became very chatty asking questions about the holiday and what had happened in Lanzarote. I told him

what I could remember, he then said oh you must be the lady that we thought wouldn't last the night, which was a bit of a shock, but then didn't give it another thought.

They then transferred me to the wards, which were actually a corridor like a hotel with rooms off with two beds and a shower room. The room they took me to already had one bed occupied by another British lady, they thought it would be better for both of us to be able to talk to each other; they really went out of their way to make me feel safe and cared for.

I remember one day being in the day room and the doctor in charge of the intensive care unit I had been in met Ken and asked him how I was doing, when Ken told him I was in the dayroom he said he had a patient to see but would come and see me, when Ken told me I said he's far too busy but he came out of his way to see me and check on my progress, that's what I call CARE. The care I received was of a very, very high standard from going into the doctors in Lanzarote to being discharged from the hospital in Gran Canaria. You hear stories of people having heart attacks, accident or other illness while on holiday and having a terrible experience.

Well I can say that my experience was quite the opposite, and of the highest standard.

On my return to England my Doctor came to see me and said I would have to see a heart specialist here so I asked him to send me to Wythenshawe Hospital, as it is the best one around. After my first appointment I was referred to Dr B Brown to see about having an ICD fitted. I was very apprehensive about this but after talking to Dr Brown and having him explain it to me in great detail and in a way I could understand I was happy to have one fitted.

My ICD was fitted on 9th December 2014 by Doctor Brown and I have to admit I went into the theatre very nervous and frightened but Dr Brown and his team are great at putting you at ease and again explained everything that was about to happen, which made me very relaxed and so drifted off to sleep a happy patient. I have to say I never think or worry about my ICD, in fact I always tell people that I have my very own defibrillator; I think Ken worries more about it than me.

When people ask me where are you going on holiday and I tell them back to Lanzarote they always say oh are you sure you want to go back there after what happened, but I have to say I feel very safe in the knowledge that should anything happen and should I

need hospital treatment I know where to go and I also know that I will receive the very best of care there is, and don't forget I have my ICD fitted and working, so Lanzarote here I come again.

I couldn't finish this article without thanking the ICD Support Group for their meetings at Wythenshawe Hospital, because I have found these meetings invaluable with all the different Subjects they cover, from the medication, how your ICD works, to psychological aspects. One of the meetings that stand out for me is the one about Mobile Defibrillators and the important of having them in as many public places as possible. Our local community centre came to mind as it is a very busy centre we definitely needed one there, but that's another story.

*Jackie Brook*



# My Story

**My name is Eamonn Munnely and I was 67 when my events took place. The first was on the 3rd April this year when, while walking into a church hall, I collapsed as quickly as if someone had turned off a light. I came around a few moments later, as my wife tried to straighten me out in order to carry out CPR, to find my very concerned wife and two or three friends peering down at me. Paramedics had been called and a short time later I was admitted to Stepping Hill hospital A & E unit.**

I had felt faint for a couple of moments earlier that morning and once, too, earlier in the week, but had had no pain or other warnings so thought nothing of it. I considered myself to be reasonably fit, have never smoked, and take regular exercise.

It was decided that I had had a heart attack, and after some hours a bed was found for me on the Cardiac Care Unit, where I was wired up to a monitor and a defibrillator and then assessed. I spent the next week sitting in bed, feeling like a fraud, being observed, monitored and tested, the last of which was an angiogram. For this I was taken to Wythenshawe Hospital by ambulance and then returned to Stepping Hill. Less than two hours later I had a cardiac arrest.

I had eaten some sandwiches and had drunk a cup of tea and needed the toilet. I stood up next to my bed, realised that I was going to faint and made sure that I fell back on to the sheets. This time there were about a dozen faces looking at me when I regained consciousness.



The nurses had been alerted by the monitor that I had collapsed, had re-aligned me on the bed, started CPR and defibrillated me. The "crash squad" had also arrived, so my return to this world had a lot of witnesses. After being checked over it was decided that I was in reasonable condition and that in the short term I needed oxygen and in the long term an ICD implant.

Four days later I was again transferred to Wythenshawe Hospital, this time to be admitted for the insertion of my ICD, something that was beyond the scope of Stepping Hill. I was admitted into a four bed unit on ward F5, with fellow patients and for the next six days we settled into the routine of ward life, the high-light of which was the doctors' rounds at about 9.00am, when we each tried to glean what was to happen to us, and when. Various further tests and assessments were carried out while we waited as patiently as possible for our allotted treatment, all the time wired up to our monitors.

Eventually my turn arrived and on the morning of Wednesday April 20th I was taken to the Catheter Laboratory to have my ICD unit implanted, a procedure that took a couple of hours, followed by some further hours of rest and close monitoring. Then my monitor was removed and I was told that I would be discharged on the morrow, after the doctors' rounds and after pharmacy had prepared my medication. I was released from the hospital at 4.00pm.

After nineteen days it was nice to be outside in fresh air, even though I had been well looked after at both hospitals and, for the most part, well fed! The staff, from consultants to cleaners, were very professional and caring. The people of Greater Manchester are very lucky to have these people and facilities. The cardiac facilities at Wythenshawe are amazing, and you could feel a sense of pride from all those who worked in them.

The strange thing about walking out of the hospital and travelling home was that for the first time in a long time I was not connected to a monitor, even if I had now become the proud owner of a small computer with "magical" properties. My wife, who had been a nurse all her working life, must have felt a little like a new mother when she takes her first-born home from the maternity hospital, wondering "what do I do with him now", whilst knowing that I do not take kindly to swaddling.

Getting back to my own bed was great and I caught up with some sleep. I found that I could not sleep comfortably on my left side because I was conscious of the pacing of my unit when my heart slowed, but other than that I slept well. I went out for walks and built up the lengths of these, as I felt stronger, my appetite returning as my body needed more energy. Being able to use the bathroom and shower when I wanted was luxurious, keeping my wound soap-free was not a problem and this soon healed well. After a few weeks I started swimming again at a pace that suited. I am not now allowed to swim crawl, but I couldn't before my events either!

I do get more tired, more easily; I do not have my former stamina. Whether this is as a result of my events or because of my medication I am not sure, possibly both. I am also aware of being more breathless at times; this could be me listening for it or, again, as a result of my events or because of my medication. To be investigated. That said, I have managed walks of ten miles or so, up-hill and down-dale, in the Peak District without mishap. I feel well,

and forget most of the time that I have an ICD. My biggest problem is, say, exploding out of a chair to answer the door or the phone without giving my blood pressure a chance to build up and then feeling faint as a result, but I am learning.

I contacted the DVLA on my return home and surrendered my driving licence. Until I got used to living with my ICD I could not have considered driving but after having had a license for fifty years it did take some getting used to. My wife has been very good at delivering me to places and says that for the most part I have not been too bad a passenger! My bus pass has been well used also. I am now looking forward to sending off for the return of my license this week after six months, and soon returning to the roads.

Sorting out holidays and holiday insurance has been something of a toil. I had to cancel one trip because it involved flying too soon after my event and a second that involved walking in the Dolomites because of the altitude and the strenuousness of the walk. In hindsight I recognise that neither holiday would have been possible because of my new situation. A third trip, with friends, had to be cancelled when my wife slipped a disc. Finding holiday insurance quotations with an ICD and previous cancellations is both time consuming and frustrating but we persevered and are now due to take our daughter and two

of our grandchildren away this October half term, so I will be having some more lessons on how to live with an ICD then.

For others who face similar travel problems, both the Arrhythmia Alliance and British Heart Foundation offer suggestions as to where to get travel insurance.

My wife has looked after me very well and has been very patient with her new charge. My son, daughter and daughter-in-law have been very supportive. Our four young grandsons have followed my progress, even if number two felt moved to utter the opinion after a while that "I think Granddad Eamy is just attention seeking." This humbling concern by our children was illustrated when I accidentally activated a panic button on house-alarm fob attached to my key-ring when I knocked it on a chair arm. I then had to spend the next twenty minutes fielding telephone calls from concerned family members that the alarm had automatically contacted.

When I was discharged from UHSM at Wythenshawe I did not leave empty handed. Besides my discharge notes I was handed a very useful Information Booklet for patients with ICDs and had been previously comprehensively briefed on ICDs by Adrienne from the Arrhythmia Nurse Team. Having the booklet has provided answers to

a number of questions that have arisen and was useful to produce to my dentist when he was debating whether he could use his ultrasonic scaling tool. Before that I had been disappointed to note that it was safe for me to empty the dishwasher. I had also brought home a remote monitoring device that now sits beside my bed and fills the bedroom with a green glow at night. So far this has been only used to send a test transmission (that I know of) but it will be in use again at the end of this week when I try to regain my driving licence.



A page in the above booklet lists a number of Specialities and Departments at UHSM, together with names and telephone numbers. Inside the back covers are a number of suggestions for further reading and e-mail addresses for further references. I found these to be both informative and reassuring.

All-in-all my adventure above is not what I had planned for 2016 but for the most part it has kept me out of mischief and I look forward to the rest of my life thanks to the staff at the two hospitals that treated me, Stepping Hill and Wythenshawe. Thank you and God Bless to you all.

## Contact Details for Patients

April Hopkins

**0161 291 5998**

Adrienne Unsworth

**0161 291 5443**

Natasha Evenson

**0161 291 5076**

**Email – [arrhythmianurses@uhsm.nhs.uk](mailto:arrhythmianurses@uhsm.nhs.uk)**

Cardiac Physiologists

**0161 291 4615**