

# Defibber News

November 2018

**Welcome to the latest edition of Defibber News which we hope you will all enjoy reading.**

This edition has a theme – SHOCKING though it maybe!

A patient reveals what it is like to experience his ICD delivering therapy in the form of shocks.

An Arrhythmia Nurse advises us what to do if we are to be shocked by our ICDs.

Rosie Stone will be telling us about how our ICD's work and what is in the pipeline for their evolution.

**THIS IS YOUR NEWSLETTER!**



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](mailto:georgedavies48@sky.com)

- *What can your ICD interrogation tell us? What does your ICD download tell us? When and why does your home monitor send us information?*

- *What new technology has been incorporated into ICDs? What's new? What's the future?*

- *Thought of asking any of these questions? Then we have an expert with all the answers*

- *Rosie Stone has worked for an ICD company for many years, she is very knowledgeable in all aspects of ICD function with an insight into future developments.*



**‘New Technology – The Future for ICDs’**

**Rosie Stone**

**WEDNESDAY Nov 7<sup>th</sup> 2018**

**All Saints Church Hall,**

**Hale Road, Hale Barns,**

**Altrincham WA15 8SP**

**Tea, Coffee & Small Refreshments served at 1.00pm + Raffle**

**Meeting starts at 2.00pm**

## SHOCKING- WHAT TO DO?



**ICD patients are a mixed bunch. All have heart conditions of an ischemic or cardiomyopathy variety. Each of us takes daily medications in differing amounts. Depending on our health at any one time, we see our doctors regularly and sometimes very frequently. What we all have in common is the implantation of an ICD programmed by our doctors to suit each one of us and to allow us to lead as normal a life as possible.**

In my case I was a healthy and very fit 55yr old at the time of diagnosis with ARVC (Arrhythmogenic Right ventricular Cardiomyopathy). After finishing up in hospital for two weeks following a life-threatening bout of VT during a twelve-mile threshold training run, I was taken to Wythenshawe Hospital for Dr Neil Davidson to have a look at me. Following a failed attempt at ventricular ablation – going into VF twice on the table – Dr Davidson came up with the answer I was seeking, which would explain what had happened to me.

So far so good. Diagnosis. Medication. ICD. Doctors and nurses on hand to take all the necessary measures when I needed it. Sounds straightforward but in reality, it often isn't so, especially when it comes to being shocked by your ICD.

Thankfully, many patients haven't and hopefully won't have experienced their ICD shocking them out of VT and/or VF, their device being implanted prophylactically. However, many patients have had this experience and some of us, more than once. I have been shocked on countless occasions – walking, jogging, sitting in the chair, working at my desk, whilst asleep, having sex with my 'lucky' wife, walking across the road, in the park, in the town centre, at athletic matches, even coming out of hospital whilst being discharged after another ablation and on some occasions being rushed into A&E and Resus by ambulance.

Patients will be told – correctly – that with the implantation of the ICD they are protected from a 'sudden death episode' and should wherever possible, carry on living their life as

normal. Many patients carry on working, go on holiday and even exercise – (which is extremely important if you can) – and have a long prognosis of life.

And Then!! The first shock!! My first shock took place in the gym as a result of going into VT while jogging (literally) on the treadmill. The Gym staff panicked and called an ambulance and I was taken into A&E and moved into Resus. Later that day I was released to go home and after a night in bed carried on as normal the following day which meant going to work as a Health & Safety Officer in a care home.

This first incident of the ICD firing taught me to understand that once the trauma of the actual shock was over, I was back in sinus rhythm and safe. That's a big deal. To know that you will survive an otherwise life-threatening arrhythmia is more than just a 'comfort blanket'.

Under no circumstances do I try to make light of this. Each shock for me was very traumatic, physically and emotionally. I was fearful of them, not in expectation, but in the actuality. They never got any easier and most definitely, I never got used to them! No amount of being told that you were alive and should be thankful in some way helped either!.

No doubt everyone who has ever experienced a shock can testify to their own trauma's in dealing with them. So, when you are lying there on the ground, feeling shook up, probably with a sore and heavy chest, your head spinning a bit whilst you get your bearings, What Do You Do? My experiences have taught me to understand that once you have come around from the shock and are back in sinus rhythm – you are safe. You don't have to call an ambulance. I have been shocked on a number of occasions in the street and at various locations when members of the public have showed their concern by trying to ring for an ambulance. On some of these occasions I have been able to stop them as I knew that I had recovered sufficiently to get home safely. Sometimes I haven't been able to prevent the ambulance being called and have been taken in, only to be discharged later that same day.

Once you are home, call the Arrhythmia Nurses and they will arrange for you to send a download from your home monitoring device, or if necessary, ask you to come into the hospital to have your ICD read and see a doctor. If you have more than one shock you should then call an ambulance or get someone to do that for you.

Your device firing and delivering a shock or even multiple shocks, is not, a very pleasant experience to say the least. However, take confidence from the fact of patient's experiences - recovering as they do, pretty quickly from the therapy delivered by the ICD. One final point, whether you haven't been shocked and are worried about having one, or you have experienced it

and are having difficulties living and rationalising the experience - Talk to someone. Talk to the Arrhythmia Nurses. Talk to another patient who has had the experience which can be arranged through your Arrhythmia Nurse. Do Not Bottle It Up. That is the worst thing you can do. A nurse once told me that I was fortunate in the sense that I was better protected from a heart trauma than most other people; And she was right. But that doesn't mean we are all titans of physical and emotional strength, in which, we can handle everything thrown at us. Sometimes we need to reach out and that's where our Support Group plays such a valuable role. Come and join us, it's an open invitation.

**George S Davies**

## Ask The Cardiac Nurse

I want to know what I should do if I get a shock from my ICD. Should I go to hospital?

Thanks for your question. First thing to do is try not to panic. Easier said than done, I know but firstly, sit down (somewhere safe obviously!) and focus on controlling your breathing. You will have a lot of adrenaline flowing through your blood vessels and this can make you feel anxious, frightened and shaky. This is the body's natural response to fear and it's ok to feel like this. It will settle down after a few minutes. You don't need to come to hospital after every shock.

Your remote monitor may look like one of these:-



When you feel better, go to your remote monitor and do a download. The instructions for your own remote monitor should be kept close to your monitor but make sure you know how to use it from the offset. You should have been shown how to use it when you had your device implanted. If you can't remember you can always call the Cardiac Physiology help desk on 0161 291 4615 or the Cardiac Rhythm Management team on 0161 291 5443 or 5076. The Cardiac Rhythm Management team phones always have the answer machine on as we all work Monday to Friday (except bank holidays). Please only call one of these numbers and someone will get back to you as soon as possible. There may be someone on the Cardiac Physiology help desk at the weekend during the day.

It is best to call the Cardiac Physiology help desk when you have done a download as the team will be able to look at your download and advise you on what to do next. If you have had 1 shock which was appropriate (i.e., you have had a dangerous heart rhythm and your device has correctly delivered a shock) there are 2 things which may happen:-

1. Do nothing. Keep taking your medications, don't forget to take them regularly and come back to clinic as previously planned. Inform the DVLA you have had a shock from your device and start your 6 month driving ban. Sorry, but this is the law and it is illegal to drive while banned. Start reapplying for your driver's license after 4 months.
2. We will arrange for you to come back to clinic to have a full device check and it may be necessary for you to see one of the medical team for review of your medications. Inform the DVLA you have had a shock from your device as stated above.

If you had a shock which was NOT appropriate (i.e., your device gave you a shock when it shouldn't have done) then you will be advised on what happens next. Although your device is normally very accurate in interpreting your heart rhythm it can get it wrong.

There is a computer within the device itself. This is the box you can feel under your collar bone. This computer can get confused about what it has seen and very occasionally it thinks you have a dangerous fast heart rhythm and delivers a shock.

This can be because you also have a non-dangerous heart rhythm called atrial fibrillation which has become very fast causing your heart to beat much quicker than normal. This may or may not be new. There may be a broken or fractured lead which needs to be fixed. There may be a fault within

your device which needs to be corrected by the Cardiac Physiologist. Therefore, it may be necessary for you to do one of the following:-

1. Come to clinic as arranged by us and have your device setting altered by the Cardiac Physiologist. Keep taking your medications and continue with your future clinic appointment as planned or perform a download a few months later to assess the effect of the device changes. You cannot drive for 1 month from when the problem has been corrected.
2. Have your device interrogated in clinic to find out in more detail what is wrong. If there is a broken or fractured lead you will need to see one of the medical team to discuss replacing the lead in hospital. You cannot drive for 1 month from when the problem has been corrected.
3. If your device shocked you because of a non-dangerous heart rhythm (atrial fibrillation) we may need to assess whether you need blood thinners (anticoagulants) to reduce your risk of stroke.

If you had 2 shocks or more, you should attend your nearest Emergency Department. If you feel ok, someone should drive you. If you feel very unwell then call 999.

Unfortunately, we do not operate a drop-in service to have your device interrogated. Clinic appointments are arranged by us as we see appropriate. You will not be seen in clinic if you turn up without an appointment. If you need advice on what to do call us on the numbers above.



## Hello, my name is Ashley Green



On the 18<sup>th</sup> of May 2013 I had a cardiac arrest in a cinema. What surprises people most about this though is I was only 23 at the time and film wasn't even scary!

During 'The Great Gatsby' on a Saturday evening unbeknownst to me I had suddenly suffered a cardiac arrest with no prior history of heart problems. I passed out immediately and my now husband next to me thought at first, I had fallen asleep. What he thought was snoring was my body fighting for air and trying to stay alive. He quickly realised something was wrong when I didn't respond to him and then immediately told someone to call an ambulance.

The cinema was evacuated, and a recently graduated doctor leapt up the seats to begin CPR upon realising something was seriously wrong. This doctor helped save my life and to this date I have no idea who he was or had the opportunity to thank him.

The paramedics arrived shortly after and shocked me to try and return me to a normal rhythm. Unfortunately, this proved to be difficult as my heart continued to struggle and over the next hour I was shocked several more times by the paramedics and the hospital team at MRI.

Two days later, I was transferred to Wythenshawe. I have absolutely no memory of any of this, or the next two weeks where I was asleep under heavy sedation, developed some slight brain swelling and suffered some kidney failure as a result of my long time without any cardiac output.

Thankfully the teams in both MRI and Wythenshawe hospital were amazing and supported me when I was woken up unable to walk, swallow or speak very well at all. My memory took a hit too but eventually just like everything else it got better with time.

4 Weeks after my initial cardiac arrest I had my defibrillator fitted. This was explained in full to both me and my family at Wythenshawe hospital and soon after with some new medication I was on my way back to a 'normal' life.

I have to admit this was all quite terrifying but the hospital staff were great with me and my follow up appointments helped me understand more about what had happened. It turns out I suffered from viral cardiomyopathy. Essentially a cold virus got to my heart, made the bottom of it swell and triggered all these problems that day in the cinema.

My life following all of this remained the same. I joined a gym, bought 2 dogs (one named Gatsby after the film we were watching), got married and there were only a few times the defibrillator reminded me it was there with a shock when something unusual happened with my heart. That was until the 4<sup>th</sup> of August this year at 3:30am.

Suddenly my defibrillator went off whilst I was sleeping. Four times. My husband phoned an ambulance and they arrived a few minutes later. With the paramedics there it went off 4 more times. They took me quickly to Tameside hospital where it continued to fire and in total administered almost 30 shocks.

The next day in Tameside hospital we used my defibrillator scanner which resulted in Wythenshawe hospital ringing me literally minutes later asking me to come to them asap. I was transferred, taken to ward F5 and ended up in a bed not 10 meters from where I was initially in 2013 with a lot of the same amazing nurses and doctors. This time, whilst my heart had shown an unusual cardiac event, it was the defibrillator that seemed to be the problem.

It is apparently the first time this has ever happened, but it somehow entered 'factory' mode settings and the parameters set for when it should/should not shock me went almost completely out the window.

A few weeks later and I was getting prepped for surgery to have it replaced and my medication adjusted. Whilst this might have been quite a scary and stressful sudden event, I'm still glad I have one fitted because without it I'm not sure I'd have the confidence to continue doing all the things I love. I'm defiantly putting the Lottery on each week now though as these 'one-in-a-million' events seem to be something of a trend with me.

**Ashley Green**

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

[pwdavisandsonltd@aol.com](mailto:pwdavisandsonltd@aol.com)

(07973-541382)



**Wythenshawe Hospital ICD Support Group has been set up to assist Patients and Carers alike in understanding what it is like to have to live with an ICD.**

<http://wythenshaweicd.wixsite.com/icd/support>

**HAVE A LOOK - Details of the Group's Meetings, Specialist Medical Information and Past Newsletters are all there for you to see.**

## **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**