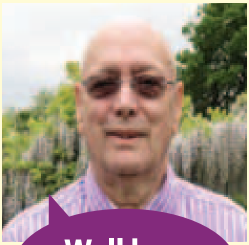
Defibber News

JUNE 2017

UHSM Patient ICD Support Group



Our next Meeting is on Wednesday July 5th

All Saints Church Hall,
Hale Road, Altrincham WA15 8ST

'Living and coping with an ICD'

We are proud to present by popular demand the return of Mr Mike Connolly Consultant Nurse

2.00pm

Mike Connolly has been an expert for many years in the psychological aspects of having an ICD implanted, the impact of having a shock or the potential of having a shock on patients' as well as the psychological impact for carers.

Peoples mental health and wellbeing has been increasingly highlighted by amongst others - the 'Royals' as well as in the media with people being encouraged to speak about their experiences, thoughts and concerns.
This presentation will be interactive – and - if you would like to ask any questions or speak about any concerns or thoughts you may have please feel free to do so - or if you prefer - just come to listen

Tea, Coffee & Cake will be served at 1.30pm

Well Here Goes!

My name is Nigel Worthington and Adrienne has asked me if I would share with you my medical adventures and as we all know you don't say no when Adrienne asks!!

I had a heart attack in March 1994, when I was forty-nine, and was one of the lucky ones who made it to hospital. I seemed to recover from this OK but in February 1995 I had a quadruple bypass, which was a bit of a shock. Obviously quite frightened at the time but there didn't appear to be any alternative so that made the choice a lot easier.

Everything went alright from then on for quite a number of years and I returned to work and all the sports I had previously played. In 2013 I was diagnosed with aortic valve stenosis and various tests were carried out on me. I then started with heart rhythm problems and in December 2014 had to go into A&E in Chester and cardioversion was performed on me.

I was then transferred to Wythenshawe and a pacemaker was fitted. Unfortunately, or possibly very lucky for me, the pacemaker became infected and had to be removed in July 2015. This was replaced with an ICD with the flashy box at home by the bed for downloading info if required.

In September 2015 I had the aortic valve replaced by the TAVI method, which was done under local anaesthetic. Since then I have had a couple of VT incidents and the ICD has fired appropriately each time.

However in December 2016 I had what I believe is called a VT storm and the ICD fired eleven times in three hours – very frightening indeed. This was apparently caused by my low potassium levels and my drug regime was changed considerably. Since then I have had only one VT incident, which may well have been caused, by my stupidly missing one of my drugs. Shows that you should always take as and when advised!!

I am sure that you will all agree that we are so lucky to have such wonderful care and facilities in our area. The support I receive from the arrhythmia team is fantastic.

Am now scheduled for 'ablation' in June so hopefully this will finally solve the VT problems. Will let you all know how things go.

Nigel Worthington

Andy Sarno

I've never really been one to think about the rest of my life, I wake in the morning and take each day as it comes. I'd always been fit and healthy, into sport and never had any symptoms attributed to heart disease. Until an emergency visit to A & E with heart palpitations resulted in months of tests being carried out, and ultimately me being more appreciative of how precious life is.

When it came, my diagnosis of hypertrophic cardiomyopathy, at the age of 30 came out of the blue and was an incredible shock. I thought heart disease only affected older people. Even with the support of my wife and family, mentally at times I felt lonely - why me?

An incurable disease that will be with me for life, I needed to know more. The cardiologist, nurses, GPs have been brilliant in answering my questions. I've discovered charities that I didn't know existed, who offer unimaginable support. They've allowed me to talk to people with my condition and help me realise that I'm not the only one, and you can still lead a normal life.

Talking about and understanding the disease has definitely helped me and my family relax more.

I've had an ICD implanted and will have to go back to hospital every year, but there is that peace of mind that if something does go wrong, I'll have a fighting chance. It means I'll be here to help and support others going through what I've been through.

I'll continue to take each day as it comes, and even though it has taken a while to adjust mentally and to some degree I still am adjusting - I now see myself as the lucky one who was caught - gets to spend his life with his wife - family - and new born baby daughter.

Question from the relative of a patient: -

‘My husband had a cardiac arrest and needed to have a defibrillator put in. I was there when it happened and had to give him CPR till the ambulance came. We are adjusting to normal life again but I find it very hard not to wrap him up in cotton wool. I’m scared to leave him on his own and worry he is going to have another cardiac arrest again. He’s getting short tempered with me and says I am being over protective. Is it normal for me to feel like this and am I being over protective?’

Arrhythmia Nurses say: -

Thank you for contacting us to ask your question. It’s no wonder you feel like you need to wrap him up in cotton wool! Out of the blue, he collapsed, without any warning. You gave CPR while you waited for the ambulance to arrive. It often takes only minutes for an ambulance to arrive on the scene but can feel like hours to you! It sounds like you all had quite a traumatic time!

So firstly, well done you. You acted quickly and effectively in getting the right help for your husband. Carrying out CPR is the most effective way of “buying time” till the ambulance crew arrives to deliver a shock to the heart during a cardiac arrest. Cardiac arrest is different to a heart attack. Cardiac arrest is when the electricity which makes the heart beat suddenly becomes chaotic, fast and ineffective in pumping the blood round the body. Treatment is the delivery of a shock.

A heart attack is caused by a blockage in one or more of the special blood vessels (the coronary arteries), which delivers oxygen to the cells of the heart muscle. If the heart muscle loses its blood supply, the cells start to die.

It is very common to feel protective, frightened and vulnerable after this kind of life changing event. Your husband will have been completely unaware of anything that was going on during the time he was in cardiac arrest and having CPR. You were there all the way through this traumatic event. Wanting to wrap him up in cotton wool is understandable; it gives you a focus, it may help you feel you are needed and you have a purpose. However, in the long term it can be unhelpful. Resentment and frustration can develop if your partner feels you are being over protective. Talking to each other about your worries and emotions will really help both of you to understand what the other is feeling. It is ok to say, “I’m scared to leave you”. Your husband may not know that you feel like this. A lot of people go through these emotions at the beginning of life with a defibrillator, especially if it was implanted because of sudden cardiac arrest. If your husband does not want to be fussed over, you should try to understand this. He may be coping really well with the new ICD and this should be encouraged.

You should both make an effort to get back to doing the things you did before his cardiac arrest as soon as you feel comfortable. Once the defibrillator is in, it is constantly watching out for dangerous heart rhythms and will treat them very quickly if they occur.

Take comfort in this. You will begin to gain confidence to leave him on his own. Your husband’s recovery is both physical and emotional. He has a wound to look after and must be careful not to do strenuous upper body exercise until his wound has fully healed (if you have read our ICD booklet you will know this takes up to six weeks!). He also has an emotional recovery to make. He must now live his life with a defibrillator in his body. He has had a cardiac arrest. Let’s not forget the trauma and fear he went through too.

The team at UHSM is here to support you in getting back to normal. The Defibber newsletters are full of stories from patients who have experienced similar emotions. You are not alone. The ICD support group meetings are a great way to meet others who know exactly what you are going through and it can help to talk about it. Write your own story if you feel it may help you to put pen to paper.

Most importantly, trust the ICD to do its job.

Adrienne

From the Chairman

A very warm welcome to everyone and I hope you enjoy reading this edition of our newsletter. I would like to give you some updates on what's been happening within our group.

We held our committee meeting on the 24th of April; this is in effect our AGM. I have kept on my position as the Chairman, supported by Ian our Secretary and Emma our Treasurer, not forgetting the rest of our very supportive committee. We have been working on our Website, which I am pleased to say is now up and running. Our site can be accessed through UHSM website under the heading of Heart Rhythm then scroll down to devices or Log On direct via this Link:

http://wythenshaweicd.wixsite.com/icdsupport

This website is not a substitute for help and support, it is intended to provide information and additional support. Hopefully it can be used easily by all and there is a section Contact Us, which will allow you to send an email straight to the Chairman. There are links in there to other useful sites and there are also many copies of previous Newsletters, which should be very useful. There is also a link to a booklet for patients having an ICD fitted, this is a must read for new patients.

Hopefully this site will grow and develop as we go along. Currently it is my son and I running the site, mainly my son. However, if there are any of our patients with time and good knowledge of running and maintaining this site I would be very pleased to hear from you as my computer skills are not the best.

Our next meeting is being held away from the hospital site. As most of you will be aware, parking at the hospital is extremely difficult, with many turning away to go home. The parking problem at the last meeting was worse than ever with many vehicles being turned away by staff. This is the last thing we want. We cannot see this problem getting any better in the immediate future and therefore we have decided to trial having a meeting elsewhere. After careful consideration and planning, our next meeting will be held on:

Wednesday July 5th at All Saints Church Hall, Hale Road, Hale Barns, Altrincham, Cheshire WA15 8ST.

This hall is easily accessible and there is a small car park adjoining the Church Hall. There is additional car parking at the adjacent Supermarket 'Booths' over two levels, car parking there is free for three hours. There are also shops opposite the church hall with car parking spaces behind.

Refreshments will be served prior to the meeting at 1.30pm

As our support group is entirely funded from donations we intend to hold a small raffle at our next meeting; hopefully this will offset the cost of holding the meeting away from hospital. I would like also to take this opportunity to thank all the patients that have made contributions in the past, it is very much appreciated, without which we would not be able to produce our newsletter. We also rely on patients to submit their story, if you have not yet written your story please don't be shy. Whenever I talk to patients I am always amazed at what some people have been through prior to having an ICD fitted, please share you story either through myself or directly with George Davies. George's details can be found in this newsletter.

We always read the evaluation sheets to maintain and improve our meetings and subsequently we have invited Mike Connolly back after receiving great feedback. Mike deals with the psychological aspects of having an ICD and the impact of having shocks on patients well being. Mike is a consultant nurse who is an expert in this field. We hope you can come along to this meeting, especially if you have recently had an ICD fitted. If this is your first time at one our meetings please make yourself known to either myself or one of the other committee members, we are very friendly and here to help. Just before I finish as I am writing this article I just heard the President of Ireland, Enda Kenny is to step down. I thought to myself this is the Enda of an Eira

I'll get my coat. Hope to see you at our meeting

Paul Davis

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

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