Defibber News

October 2023

Our Next Meeting will be held on Wednesday October 11th 2023 at: All Saints Church Hall, Hale Rd, Hale Barns WA15 8SP

(Tea & coffee served from 1.15pm -- Meeting starts at 2.00pm)

Our Guest Speaker will be Dr Simon Williams who will be answering patients questions.

"Simon Williams has been a Consultant Cardiologist at Wythenshawe hospital for nearly 20 years (seems like 50 years….) and is an Honorary Professor at the University of Manchester. He has a specialist interest in Heart Failure and is the immediate past Chair of the British Society for Heart Failure, the national healthcare charity for heart failure. He has advised NHS England and NICE over the years and has written national guidelines and spearheaded national heart failure awareness campaigns. He has an active research interest and has published over 130 papers in major international journals. He likes running, skiing, boozing, the Arctic Monkeys and supports Altrincham FC and Man United"

Message from the Chairman

Welcome to the Autumn issue of Defibber News. including the announcement of our next Open Meeting in the All Saints Church Hall as usual. I am delighted that Prof. Simon Williams, a leading Consultant on Heart Failure, has agreed to speak to us and answer any questions that you may have. Please put the date in your diary and we will look forward to seeing you there. (I think you can tell from his introduction that he is a man with a good sense of humour.)

We are very grateful to Stephen Robertson for sharing his story with us, and I hope we can welcome him at the meeting on 11th October.

Also in this issue, there are two articles which tackle important aspects of ICD's. There are four different types of heart rhythms which can cause cardiac arrest, and the first article explains which will trigger the device to activate. Also details are given of situations where CPR is recommended. The second article concerns a new initiative by one of the leading manufacturers for recycling remote monitors when patients have no further need for them.

Finally, may I encourage you to send us your email addresses for inclusion in our data-base.

This is my Story

I was asked to send my story for the Defibber summer newsletter. My name is Stephen Robertson, from Heaton Mersey, Stockport. I have worked at Parrs Wood High School for over 20yrs.

It was a normal Monday morning (or so we thought), on 17th April 2023, returning to work after having 10 days off (Easter Break). I got up at 5am as usual, started work at 6:30am. After being in work for roughly 2hrs I was waiting on a colleague to have a routine coffee together. Unknown to me, the colleague I was waiting for had rung in sick. I have been the gardener since 2001 at Parrs Wood High School in Didsbury, Manchester.

I had run out of petrol before the Easter holidays for the industrial mower I use, so I made my way over to the main building. I said hello to another colleague who had just come back from long term sick and headed my way into the finance office. However, nobody was there, and as I made my way back into the main corridor, I felt like I was going to faint. This is when I began to collapse. *(Adrienne - this usually happens because you have suddenly gone into VF or VT. It can happen out of the blue, sometimes without any warning or symptoms).*

Thankfully, one of my colleagues saw me falling and alerted more staff members. Everyone's first thought was I was having a stroke because I had slid down the wall and my mouth dropped to one side, but once staff had realised I had stopped breathing and was a very blue colour they proceeded with CPR, and a defibrillator was used, which luckily was located just feet away from where I had collapsed. *(Adrienne - Other symptoms can include a pounding heartbeat, dizziness, chest discomfort, breathlessness, feeling your pulse in your neck and/or a sense of "impending doom").*

Various staff members continued CPR and relaying 999 messages, it was an amazing team effort. *(Adrienne - An AED (Automated External Defibrillator) was at the school. This talks a person through exactly what to do in the event of a cardiac arrest, even if they have no CPR training and is vitally important in*

increasing the chances of survival outside hospital). An air ambulance, a normal ambulance, a first response ambulance and the police arrived by the time the staff had restarted my heart and got me breathing again. It was approximately 4 minutes I had stopped breathing for. Once the paramedics had stabilised me further, they took me to Wythenshawe Hospital where they confirmed I had a cardiac arrest. *(Adrienne - Good communication is crucial during cardiac arrest. Everyone knows what their role is, and I have no doubt that this helped Stephen survive his cardiac arrest).*

I was taken for an angiogram which confirmed left ventricular failure. By 6pm (only 9hrs after the cardiac arrest) I was allowed to walk around the Acute Coronary Care Unit (ACCU) as my observations had stabilised. I spent two days on ACCU with a heart monitor attached at all times. Then I was transferred to F5 .Whilst on there, I had an MRI scan and a CT scan. The results confirmed I have dilated cardiomyopathy and would need a CRT-D device fitted. *(Adrienne - CRT-D is needed if your cardiac arrest was likely caused by poor heart pump function (dilated cardiomyopathy is one of those heart conditions). There are other heart conditions which need a CRT-D).*

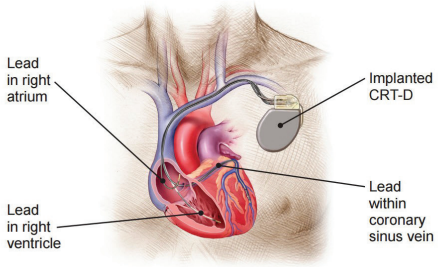
The device shocks the heart if it goes into cardiac arrest again and makes the irregular heart rhythm regular again. *(Adrienne - As well as delivering a shock to the heart, a CRT-D also co-ordinates the left and right pumping chambers of the heart (the ventricles). The aim of this is to improve the amount of blood pumped out of the heart, which increases the blood supply to the body and organs).*

Previous to this, I had no other health conditions other than asthma. After 15 days in hospital, I was finally allowed to go home with the CRT-D device and some medication to take to strengthen my heart. *(Adrienne - Medication is really important. Not only does it strengthen the heart muscles, it also tries to prevent further dangerous heart rhythms (VF and VT) from occurring. But if the dangerous heart rhythms do happen, the device will step up and treat them, all within around 10 seconds. Amazing!)*

The events that led up to my cardiac arrest, was as if someone guided me into the school that morning and to be near the defibrillator as I am usually always working outside and rarely enter the main building.

Stephen Robertson

What can a device (ICD or CRT-D) do (and importantly, not do)?



Hi everyone. I had a telephone conversation with the wife of a recently deceased patient the other day. She wanted to know what to do with the remote monitor after her husband had passed away. We started chatting about what happened on the day he passed away. She was happy to do this, and she agreed to let me share our conversation with others.

This is an important and sensitive article. I apologise if anyone has had a recent bereavement and finds this article upsetting to read. This is not my intention.

I will call them Jimmy and Carol to maintain confidentiality.

Firstly, I gave her my condolences.

Jimmy had an ICD, and all was ok as far as the device was concerned. He needed to go for a scan (not related to his heart). He found the event quite stressful as the scan had to be cancelled so he was sent home in a hospital taxi.

He started to feel unwell at the front door. Carol and her neighbour managed to get Jimmy inside. He looked unwell. Carol thought "Don't worry, we've got the ICD, and this will sort him out if he has a dangerous heart rhythm".

He then lost consciousness and became unresponsive. Carol called 999 and told them he had an ICD. The 999-phone responder told Carol and her neighbour to start CPR (cardiopulmonary resuscitation), which they found confusing. Why would he need CPR if he had an ICD? But they started CPR, following the instructions of the responder.

An ambulance came quickly

and the paramedics took over. Unfortunately, Jimmy didn't come round, and he sadly died.

So, why start CPR if you have a device like an ICD or CRT-D?

This is because there are potentially 4 different heart rhythms which can cause a person to have a cardiac arrest. These are:-

1. VF (ventricular fibrillation)
2. VT (ventricular tachycardia)
3. Asystole
4. PEA (pulse-less electrical activity)

Only VF and VT will be treated by the device (or an external defibrillator if you don't have a device) if you have these heart rhythms. You should be aware of this. However, asystole is when there is suddenly no electrical activity whatsoever within the heart. Americans sometimes call this "flat lining". This causes the heart to stop pumping and there is no circulation. There will be no pulse and no visible breathing effort.

Getting a shock from your device will not treat asystole. The device can recognise asystole and should not try to deliver a shock. The built-in pacemaker will deliver pacemaker beats, but your heart may not respond or pump out any blood.

The treatment for asystole is CPR and intravenous medications such as adrenaline. CPR is stopped when the patient either recovers (gets a heart rhythm which is compatible with a cardiac output), they go into VF or VT (and the heart is given a shock by a defibrillator or their device) or the decision is made that CPR is unsuccessful.

If patients recover, they will be taken to hospital for assessment of their condition and their device. If they go into VF or VT, the device will shock them. If CPR is unsuccessful, the patient will pass away.

PEA is when the heart is producing electrical activity, but insufficient to cause the heart to beat. The device may not deliver pacemaker beats because it has detected electrical activity and thinks it does not need to do anything. The device will not know that there is no circulation or cardiac output.

Getting a shock from the device will not treat PEA. Again, the treatment for PEA is CPR and intravenous medication like adrenaline.

Jimmy may have gone into asystole or PEA. His device would not have given a shock because he was not in VF or VT. Carol did the right thing in calling 999. She did the right thing in starting CPR. A post-mortem will be performed, and his device will be interrogated to try to determine the cause of his death.

So, what if you collapse and you have a device? What should your family do?
In the first instance, they should stay near to you, within arms distance.
They should wait 10 seconds and if your body does not jolt suddenly (indicating you have had a shock), they should follow the principles of CPR. It is a good idea to learn how to do CPR and you can find a lot of free CPR courses online. See below for details.

One of the most important things to do is to call for help. This means calling 999 and asking for an ambulance. If you are alone, you should do this first, and then start giving CPR. The call responder will ask some important questions to ascertain that the person is in cardiac arrest. They will then give clear instructions on what to do while they dispatch an emergency ambulance.

Giving CPR effectively gives a person the best chance of survival, as it "bides time" until emergency services attend. Remember though, even with superb CPR skills, CPR may not be successful.

If, at any point, the collapsed person shows signs of recovery (breathing, gasping, groaning, coughing, speaking and/or moving), you should stop CPR and put them in the recovery position, again following the principles of CPR and first aid.

To recap:-

- Not all cardiac arrests are caused by VF or VT. Patients with a device are more at risk of developing/having VF or VT (this is the reason why they have the device), but they can also have asystole or PEA.

- A device will only treat VF and VT - it will not treat asystole or PEA

- If someone collapses who has a device and they don't start to come round after 10 seconds, follow the principles of first aid and call for help. Start CPR. Wait for the ambulance crew.

- I hope this article has been helpful and you have found it informative. If you would like to know more about CPR, look at the websites below on how to learn to do CPR for free. Some websites may charge for this, but as far as I know, all these websites offer free sessions on CPR.

Free CPR training available:

- Heart Matters
- St John Ambulance
- British Heart Foundation
- Unicef
- British Red Cross
- UKRC (UK Resuscitation Council)

Adrienne

Remote monitoring update

Hi everyone, we just want to update you on new developments regarding your remote monitors. As you know, most of you have a remote monitor which is situated in the room where you sleep. Every night, it has a quick look at your device to check everything is ok.

Most of the newer remote monitors allow us to programme the remote monitor to do a download automatically which replaces a clinic visit. You can also do a download if you think you have had a shock. You should always call the Cardiac Physiologists if you have done an unplanned download, so they know to look for it and analyse the download.

One of the companies that makes ICDs and CRT-Ds (Medtronic) has been looking at ways to reduce its carbon footprint and environmental waste. We used to tell you and your family to throw away your remote monitor if you have passed away, if your current remote monitor is faulty or if it is broken beyond repair. Medtronic has now agreed to recycle old remote monitors if they are no longer needed.

Take a look at their website for returning remote monitors below, which gives details of how to return old remote monitors.

GO GREEN WITH CARELINK:

(https://europe.medtronic.com/xd-en/c/emea/cardiac-rhythm/go-green-carelink.html)

If you have a brand-new device implanted, or your remote monitor is broken beyond repair, or you have a box change, you may be offered a new remote monitor in the form of an application (APP) for your mobile phone.

Here is the website for further information:-

MYCARELINK HEART MOBILE APP:
(https://global.medtronic.com/xg-en/mobileapps/patient-caregiver/cardiac- monitoring/mycarelink-heart-app.html)

Medtronic is the first of the device companies to introduce an APP which replaces the traditional remote monitor machine. If you are not very technical, or do not want the APP, you can have the traditional remote monitor.

Remote monitoring is part of the care package we give to you, and you are not able to opt out of having a remote monitor (either traditional monitor or APP), unless you do not have wireless (Wi-Fi) or telephone technology where you live.

Only patients with a Medtronic device can be offered the APP if they have an iPhone or Samsung mobile phone. However, some of the other defibrillator devices are compatible with App monitoring. This is dependent on the implanted device and your mobile phone, but the Cardiac Physiologists will speak to you about which monitoring system you'd prefer to use.

We strongly advise that you contact your implanting hospital and return the old remote monitor to them. They will then return the monitor to the company.

So, if you have a Medtronic remote monitor and it is no longer needed (due to reasons listed above), you should call the Cardiac Physiologists at your implanting hospital (MRI or Wythenshawe). They will advise you to either drop the remote monitor off at their department and they will return it to Medtronic, or you can arrange to send the monitor back to Medtronic by contacting BeConnected using the link above.

Medtronic will then recycle the parts of the remote monitor where possible, reducing the amount of environmental waste.

The other device companies still advise you to take the remote monitor to your local recycling centre and dispose of it in the correct area of the facility.

You must not return or remove your remote monitor without our knowledge unless you are having a new monitor or APP supplied by us. Remote monitoring is extremely important and will alert us if there are significant problems with your device.

We hope you have found this article useful. As always, stay regular! Adrienne

Dear Patient

As mentioned in our previous Newsletter we are working to update the Group's Website, making it more accessible and user friendly for all of our patients.

In this regard we have made an application for funding to help us to not only improve the website but to enable us continue posting out editions of the Defibber News to all our device patients rather than publishing them solely on our website as stated in our March edition.

In the meantime, we do believe it is a good idea to firm up our contact details with all patients – one of the ways being by e-mail. At our next meeting we will have forms for you to fill in which will ask for your agreement in giving us your e-mail address. Ideally, we would have the possibility of informåing patients directly, all details of Support Group meetings and/or when a newsletter is loaded onto the website. For this to happen though, we would need an email address. We can assure you that we will save the details in a protected database. If you are unable to attend our meetings, but still wish to be informed of the Support Group's activities, please send your name and email address to our Treasurer --emma.boswell@gmail.com

Looking forward to seeing you on October 11th and in the meantime, if you would like to contribute your story to the Defibber News – either as a patient or carer --please just e-mail it to :

George S Davies georgedavies48@sky.com (with a photo if you can) and it will go into the next edition. If you wish to send by mail please post it to: 103 Redearth Road, Darwen, Lancashire BB3 2AR

Message from the Treasurer

From time to time, members of our Support Group have asked if they could make a donation to help finance the Newsletter and assist in the cost of organizing our Group's Meetings.

Members, if they so wish, can now make a donation direct to the Support Group's Bank, the details of which are

LLOYDS BANK

WYTHENSHAWE ICD PATIENT SUPPORT GROUP

Sort Code: 30-91-91

Account Number: 30781868

Emma Maiden: Treasurer, 12 The Willows, Cranwell Village, Lincolnshire, NG34 8XG