

Defibber News

Summer Edition 2021

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from my ICD by Adrienn



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Thompson



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Tributes & How valuable is
knowing how to perform CPR

When you arrive at A&E, tell
the triage nurse that you have
an ICD or CRT-D and show
them your ID card.



**Our current
Committee Members**

Now you have all asked this question – what do I do if my ICD goes off.....?



ADRIENNE ADVISES YOU TO READ THIS

Introduction

Hi everyone, we have had quite a few calls recently from patients who were in situations in relation to their ICD or CRT-D where they did not know what to do. So, I thought I would compile a few scenarios for you so if you are ever in one of these situations, you will hopefully feel better prepared.

Firstly, a lot of the important stuff can be found in the ICD booklet. This has been sent out for the last 5 years to new patients. If you have had your device longer than that, you can read the booklet on the website under USEFUL LINKS. We are currently in the process of updating this, to include anything to do with the COVID pandemic. Once this has been completed, we will replace the old version with the new one.

Secondly, it is important that you know what to do in case you are in an emergency, even if it has nothing to do with your device. Make sure you know where your nearest hospital is if you are travelling away from home, either in this country, or (if we get back to some sort of normal holiday travel), abroad! You should always carry your ID card with you, wherever you go and tell any doctor, nurse, dentist, paramedic or other health care professional that you have an ICD or CRT-D. If you lose it, or change address, contact the Cardiac Physiology department for a new one. You can call them on 0161 291 4615 Monday to Friday (except bank holidays).

Years ago, these devices were not commonly known about and brought fear to some doctors. But now most health care professionals know about them and how to deal with them. One of the scenarios we will cover is what to do if your doctor doesn't know how to look after an ICD or CRT-D. Please read scenario 1.

SCENARIO 1 – WHAT TO DO IF YOU GET A SHOCK

Nowadays, this is not an emergency if you have had only 1 shock. We advise that providing you feel okay, once you have gotten over the shock of having the shock (!), you do a download from your remote monitor and call the Cardiac Physiologists to let them know what you have done. They will have a look at the download, call you back and advise you what to do.

If you do not have a remote monitor, then call the Cardiac Physiologists and seek advice. You do not need to come to your nearest hospital unless you feel very unwell and you are not panicking and distressed.

Once we have seen what has happened, we will decide what to do. The options are as follows:

1. Nothing. Carry on taking your medicines and we will review you as previously planned in clinic. If you have had an appropriate shock, we will advise you on driving bans and contacting the DVLA.
2. We will arrange either a telephone or face to face consultation in clinic to review you, your medicines, and your device.

Depending on how quickly we need to review you, we will send out an appointment in the post.

3. If you have had an inappropriate shock, we will arrange an earlier review by telephone than previously planned. There are a few reasons why you can have an inappropriate shock, most of them are not serious.
4. If there is something wrong with your device, such as a broken lead or the battery is extremely low, we will review you sooner, rather than later. But please rest assured, we have systems in place to prevent your battery getting dangerously low. The main reason why a battery runs low much quicker than we had anticipated is because one of your leads is fractured or you have had several shocks. Delivering a shock uses battery power. Your download will give us information on how low your battery has depleted.

One of the main reasons why people get an appropriate shock is because they have either stopped taking their medicine or have forgotten to take it. Your medicines go hand in hand with your device. Medicines like beta blockers reduce the chance of you having a dangerous heart rhythm, but if you do have a dangerous heart rhythm, the device will deliver life saving therapy, such as a shock or anti-tachycardia pacing (ATP).

If you receive 2 shocks or more, then we do advise you are driven by someone else to your nearest hospital with an A&E. Ambulance services are extremely stretched and it could take some time for an ambulance to arrive as having a shock from a device is not classed as an emergency. If you receive shock after shock you should call 999, or if you live alone and

there is no-one to take you to hospital. If you do not recover after a shock(s) or you are not breathing, then someone should call 999. This is extremely rare.

When you arrive at A&E, tell the triage nurse that you have an ICD or CRT-D and show them your ID card. This should always be with you, wherever you go. Explain that you have received shocks from your device. If the hospital has a Cardiac Physiology department, and it is during daytime hours, they may be able to interrogate your device, but this may not always be possible. The doctor can contact the on-call Registrar at Wythenshawe hospital for advice if required. Patients are not permitted to contact the on-call doctor at Wythenshawe. You can contact either the Cardiac Rhythm Management (CRM) team or the Cardiac Physiology department for advice, Monday to Friday. These helplines are not emergency contact numbers and we may not be able to return your call the same day.

Although it can be very unpleasant when you get a shock from your device, remember that if an appropriate shock was given it has just saved your life. Many patients feel great comfort knowing this but if you feel overwhelmed and anxious, it is very important that you try to avoid letting negative feelings build up. It is normal to feel anxious for a while after getting a shock. Getting back to normal quickly helps you to focus on positive things and improves your physical and emotional well-being.

During these difficult Covid pandemic times, none of us have been able to do the things we enjoyed previously, like going out with the family for a meal, or seeing friends and loved

ones. Make sure you have a good support network (or bubble) if possible and talk to the people who are important to you about how you feel. They will have their own feelings and fears and good communication is key to returning to a “normal” life.

If you still struggle to cope, help is available, either through performing mindfulness techniques, your General Practitioner (GP) or through the CRM team. We can see if you can have Cardiac Rehabilitation (CR), psychological support through the Cardiac Physiotherapists and CR department or refer you on to one of our Specialist Counsellors. The Wythenshawe ICD Patient Support Group can offer you support and listen to you. You can ask for this kind of support through the CRM team. Remember though, they are fellow patients and are not professionally trained in formal counselling. Sometimes, just having a friendly ear to listen to you can make the world of difference!

So finally, to recap:

1. If you had 1 shock, do a download, and call the Cardiac Physiologists.
2. If you had 2 shocks or more, someone should drive you to your nearest hospital with an A&E. Take your ID card with you.
3. If you have multiple shocks, you do not recover or you live alone, (someone) call(s) 999.
4. Take your medicines regularly.
5. If you're struggling to cope, ask for support.
6. Appropriate shocks from your device have just saved your life.

Take good care of yourselves

Adrienne

Members of our Support Group have enquired about how they could make a donation to help finance the cost of the Newsletter and assist in the cost of organising our Groups Meetings.

Members, if they wish to, can now make a donation direct to the ICD Patients Support Group Bank, the details of which are:

“Wythenshawe ICD Support Group”

Sort Code 30-91-91

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**Emma Maiden (Treasurer) 12
The Willows, Cranwell Village,
Lincolnshire NG34 8XG**



The Impact on a Life

BY WAY OF A TRIBUTE TO DR NEIL DAVIDSON

My husband, Duncan Thompson, myself and our family owe everything to Dr Neil Davidson. We cannot begin to imagine how unbelievably tough it must be for his family. Nor can we imagine how terribly hard his passing must be for the team around him at Wythenshawe.

Without Dr Davidson Duncan would never have lived to see three beautiful daughters grow up, graduate, set off on adventures in life, or see four amazing grandchildren enter this world and flourish.

Following a heart attack in 2002, Duncan's life changed overnight. At 45 he was suddenly not a very fit runner and mountain biker, with a love of the outdoors balancing a busy work life. With his usual determination he fought hard to regain some sense of normality, but by 2006 was very unwell.

Then Dr Neil Davidson entered our lives. I remember vividly sitting in the older part of Wythenshawe hospital, before the new wing was built, and feeling a sense of calm as this kind man, with a patience and a clarity which meant

everything simply stating, “We will try to give you your life back. It may not be just as it was, but we will do our best to make it the best it can be for you.”

Dr Davidson and his team did just that. Over the following 13 years, Dr Davidson glued Duncan back together, encouraged him, at times making him see a way forward, and gave him his life back. At appointments they would often enquire about their respective daughters. It breaks my heart that Dr Davidson gave Duncan the chance to see his daughters grow into wonderful young women, and that his own daughters will be missing their father so much.

From being told to climb stairs sedately, Duncan went on to paddle the Caledonian Canal, mountain bike in wild and amazing places in the UK and abroad, and live life again.

Before Duncan set out on these adventures, I would always grass him up to Dr Davidson and the Team! In turn, they always found a way to let him go on them! Yes, there were stipulations

(more sleep, little alcohol) and advice (do not lose your medication!) but they told him to go out there and enjoy life!

Despite all Dr Davidson's care for his adventurous patient, there were some tough times. Duncan's ICD "fired" several times over the years. I remember as if it was yesterday the week in Acute Coronary Care while they fine-tuned just how Duncan and the ICD would best work together.



As part of it, Duncan was to do a tread mill session, to test the new settings. His eyes lit up! Running! Dr Davidson smiled that slow smile and gently reminded him that the "run" was to stress test the ICD, and it wasn't a fell race in the Lake District! Dr Davidson explained that there was a likelihood that the ICD may fire. He disappeared for a moment and returned with a group of doctors and nurses... and had them stand around the tread mill. "Right Duncan, start slowly and then we'll increase the

speed of the rollers.

Don't worry, we here to catch you if it doesn't go to plan."

The speed was increased, and Duncan walked, then ran! I closed my eyes. After what felt like an age, I heard Dr Davidson say, "I think we'll stop there, Duncan. You'll be pleased to know you hold the record for anyone on the tread mill now!" The ICD did its job, and Dr Davidson had given Duncan yet another chance to go on enjoying life.

"We'll catch you if it doesn't go to plan," were words that echoed down the years. When Duncan rode off a bridge in the wilds of Spain, falling eight foot into a ravine and breaking his pelvis, I yet again rang Dr Davidson's Team, the wonderful Specialist Nurses, and explained what had happened. "Don't worry, just don't let them turn the ICD off!" came the reply!

"We'll catch you if it doesn't go to plan" in many ways sums up the indescribable impact Dr Davidson had on Duncan's life, and the lives of all our family. Duncan was back in hospital the night before Dr Davidson was removing the first ICD, which had worked hard to give him such adventures, and implanting the second one. We knew there were some potential complications due to Duncan's particular condition and we

were walking through the darkened corridors trying to reassure each other that it would all be fine.

Out of the gloom came Dr Davidson. "Hello there, I'm looking forward to seeing you in theatre in the morning." He looked at us keenly and then with those calm patient words picked up on our worries and gently blew them away into the darkness.

He knew Duncan well. He knew that many things didn't worry him, but when they did, he was there. He understood that Duncan saw himself as a well person, not someone to spend time in hospitals and at appointments. He always asked him about his whole life. They shared a dry sense of humour. Dr Davidson was much more than the Consultant at Wythenshawe. He was the man who understood Duncan, caught him when it didn't go to plan, and who gave him his life back.

Duncan went out for what was to be his final bike ride in October 2019 and passed away a few days later of an unexpected and unrelated condition. Once again, though those final days, Wythenshawe and particularly April Hopkins, were there for Duncan as he fought one last unsuccessful battle in a hospital far away, but they were always

there on the end of the phone.

Dr Davidson called me the day before the funeral. His words are still in my head. He asked if I would like to make one more visit to Wythenshawe to meet with himself and April, to help me unravel the unimaginable.

So, for one last time, I took that familiar train and tram journey, and walked up the path to those welcoming doors in the big green building. I came, as we always did, early, and had a coffee from the lovely ladies at the Friends Café. Then, those calm and patient words gathered me in. Helped me face the unthinkable. Understood Duncan even though he wasn't there. Along with April, Dr Davidson once more caught us when things hadn't gone to plan.

Duncan and I were so lucky, unbelievably lucky, to have come to Wythenshawe, and to the world of Dr Davidson and the outstanding team he built around the ICD programme. With Jeanette, Susan, Adrienne and April, Dr Davidson gave Duncan his life, and gave him to us as the centre of our lives.

Ruth and the Duncan's daughters, Nicola, Helen and Kay.



WYTHENSHAW ICD PATIENT SUPPORT GROUP

TRIBUTES & APPEAL



Hi everyone,

Welcome to the latest edition of your Defibber News. I hope you find the articles interesting and helpful.

On behalf of the ICD Patient Support Group committee, I would like to begin by thanking Laurence & Pauline Smythe and also Paul Davis who have all recently left our committee. Laurence and Pauline were amongst the

founder members of the Support Group when it all began some nineteen years ago and both have worked tirelessly for the group throughout all this time. I'm sure many of you may well remember Laurence when he was our Chairman between 2006 and 2012 and of course his trademark joke to open the meetings, whilst Pauline was so often the face to meet and greet us with her welcoming smile. However, both have decided the time has come to finally retire and they leave with our thanks and very best wishes for the future.

Sadly, we also have to say goodbye to Paul Davis who has been our Chairman since 2015. I have no doubt a good number of you will have spoken with Paul at some time or other, either at one of our open meetings or on the telephone and he also leaves us with a big gap to

fill and our gratitude for all his hard work and dedication these past six or so years. Which brings me on to my appeal.

The ICD Patient Support Group Committee now have just six members, several of whom have either been actively involved from those early beginnings in 2003, or are now long standing and we certainly aren't getting any younger! Our role, although entirely voluntary, is very rewarding as we endeavour to try and provide help and support to our fellow device patients ably guided by Adrienne Unsworth, our Senior Specialist Nurse, wherever possible. Clearly the pandemic has prevented us from holding our regular and popular open meetings, however, the committee have continued to meet remotely throughout the pandemic restrictions and have been able to produce and circulate the newsletter to around 1300 device patients.

Therefore, we are appealing to any of you who may be interested in volunteering and joining our committee to come forward and get in touch. For those of you who may be a little hesitant and are perhaps wondering what this all entails, let me assure you that from a time aspect it probably equates to no more than

two or three hours per month in pre-pandemic times when we were able to meet up together and stage our triannual open meetings. For the time being with committee meeting involvement held remotely the time impact is considerably less.

The introduction of new blood and people bringing fresh ideas to the table to take us forward can only be to everyone's benefit; so, if you are considering joining us and would like to find out more, we would love to hear from you.

Take care all,

Ian Woodward

Secretary,

Wythenshawe Patient ICD

Patient Support Group

Email ipw883@gmail.com

Interested parties may also contact

Adrienne on 0161 291 5443

DAVID GALLAGHER

We are sad to report that one of our long-standing committee members, David Gallagher, passed away at Wythenshawe Hospital on Friday 28th May 2021. David had struggled with his health for some time and will be sadly missed by his family, friends and all of those who had the good fortune to know him. Typically stoical, David never complained about his health difficulties and was a gentleman in the truest sense of the word.

David had been an active member of our committee for many years and was a familiar face whom many of you no doubt will have seen around at our open meetings. He was certainly a character, very humorous and often had a tale to tell, sometimes at considerable length! David was well liked and respected by us all and we will undoubtedly miss him.

Ian Woodward

Secretary, Wythenshawe ICD Patient Support Group



1935 - 2021

Community CPR Training – A local experience

Catherine Brownhill & Jenny Slee



Background

In the UK there are over 30,000 out of hospital cardiac arrests a year, only around 1 in 10 survive to hospital discharge. Early CPR and defibrillation can double the chances of surviving an out of hospital cardiac arrest. Resuscitation Council UK (RCUK) Guidelines 2021 state that “every person should learn to provide the basic skills to save a life.”

A UK wide survey carried out on behalf of Resuscitation Council UK in September 2020 revealed that over a third of UK adults (36%) have not received any type of training on how to help someone experiencing cardiac arrest.

On or around October 16th each year is the Restart a Heart campaign. This is now a world-wide event to engage the public in learning basic CPR skills and raise awareness. The UK embrace this initiative through the British Heart Foundation, the Resuscitation Council UK and many partners including St. John

Ambulance, the British Red Cross and regional ambulance services. As a result, thousands of people that otherwise may not access training are able to have a go. In 2019 291,000 people were trained in CPR through the Restart a Heart campaign in the UK.

Chorlton Lifesavers

Based on the desire to offer CPR training to our local community myself and a friend Jenny decided to set up Chorlton Lifesavers. We are a part of Chorlton Civic Society and we thought it would be a worthy community service. Jenny has overseen the installation of several defibrillators in Chorlton and the first 24 hr public access one in a cabinet outside the Unicorn grocery store.

Our sessions take place in a variety of locations; the library, local pubs, sheltered housing sitting rooms, sports clubs, the local theatre and a café. We also ‘pitch up’ at outside community events and do pop ups in the local shopping area. Jenny puts notices up in the local shops and the park, this attracts quite a few dog walkers to the sessions. I use social media to advertise the sessions. When we first started Jenny contacted all the local councillors, most of which did come for training and are in full support of what we do.

We limit numbers according to

what space we have and now we have to ensure we can deliver

them safely within Covid 19 guidelines.

The sessions are delivered in a very relaxed manner. Attendees are not pressured in any way to do anything practical if they do not wish. There is great emphasis on the fact that everyone can be of some assistance, even if it is telling someone what to do. All participants are valued. The session is usually about 90 minutes duration.

We cover the signs and symptoms of heart attack, assessing the collapsed adult, identifying cardiac arrest, calling the emergency services, quality chest compressions and how to use a public access defibrillator. We teach current Resuscitation Council UK guidelines.



As you can imagine attendees come from all walks of life, from family groups to interested individuals. The local undertakers came as a group which caused some amusement to the other participants. We have trained the staff at Manchester Crematorium and Southern Cemetery as defibrillators are available in the cemetery office and the small chapel.

To date we have trained over 500 people. Our next target post Covid is to train 100 before

the end of the year. We do not restrict our geographical boundary strictly to Chorlton. It's really nice when we get invites to our neighbours in

Stretford, Withington and Didsbury. We have also trained vendors of the Big Issue at their offices in Manchester City centre.

The Future

In England, teaching cardiopulmonary resuscitation (CPR) is part of the Health Education curriculum for secondary school students. This should ensure we are training future generations of potential lifesavers.

The Resuscitation Council UK and The British



Heart Foundation have excellent resources to achieve this with lesson plans for teachers, videos and the award-winning Lifesaver game. For more information visit their websites at:

www.resus.or

www.bhf.org

Lifesaver.org.uk

www.resus.org.uk/watch



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