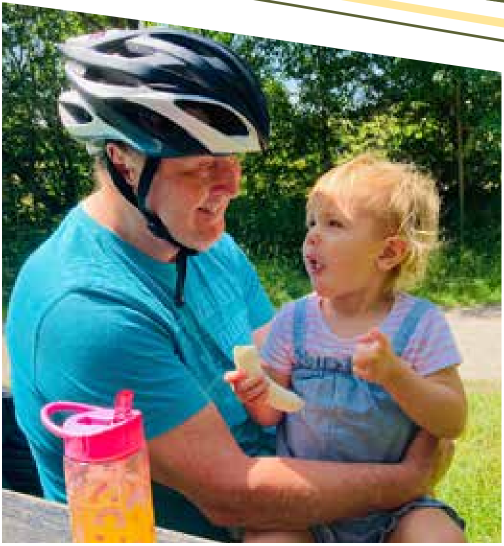
Defibber News

March / April 2022



Welcome to the latest edition of Defibber News which we hope you will all enjoy reading. In this issue we share

(1) Glyn Fitzpatrick's story as written by his daughter Claire, to whom we are most grateful.

(2) An article helping to explain how to try and get back to normal after having a shock from your ICD – written by Adrienne

(3) Questions on 'What to do if you are at the end of your life and you have an ICD or CRT-D – written by Adrienne

Welcome to all our ICD Patients and carers. Have you managed to have a look at our Wythenshawe Hospital ICD Support Group Website? The Website has access to among other items Newsletters; ICD Information; News Items; Useful Links, Communication, Support Group Committee Members; Meetings

https://wythenshaweicd.wixsite.com/icdsupport

Have a look and let us know what you think about it? Do you have any ideas to make it more useful to you? More essential to you in living with an ICD or CRT-D? What would you like to see it include that would be helpful to Patients & Carers.

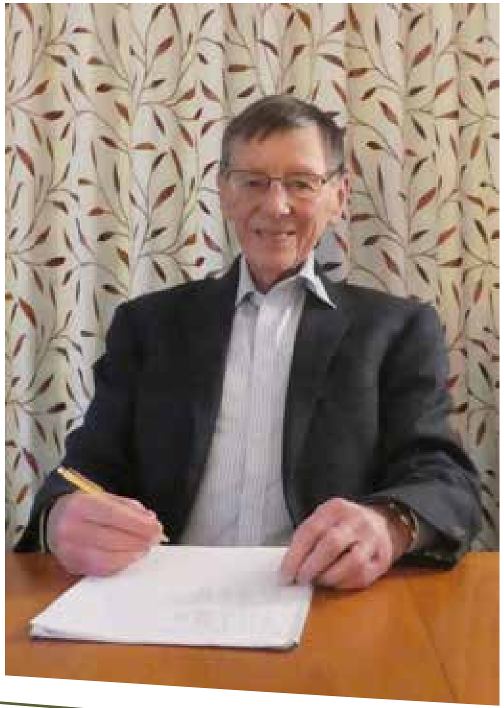
Send in your thoughts and ideas about the Website and we will do our best to try and accommodate them. If you feel that you would like to share your health journey, how you came to be implanted with an ICD or CRT-D, what it has meant for you as a patient and/or a carer, then please just email your story, with a photo to:
Georgedavies48@sky.com

Welcome from our new Chairman of the Wythenshawe Hospital ICD Support Group

I am delighted to welcome you to our Spring issue of Defibber News, which contains some excellent guidance on the issues that could face all of us. A special thanks to the Fitzpatrick family for sharing their experiences of prompt CPR action in saving Glyn's life.

I also want to take the opportunity to introduce myself, Jeremy White, as the new Chairman of the ICD Support Group. I have lived in Altrincham for 25 years, and have spent all my life in this area having grown up in Sale. I was fitted with an ICD device in November 2016, and have been delighted in how it enables me to carry on with my normal life.

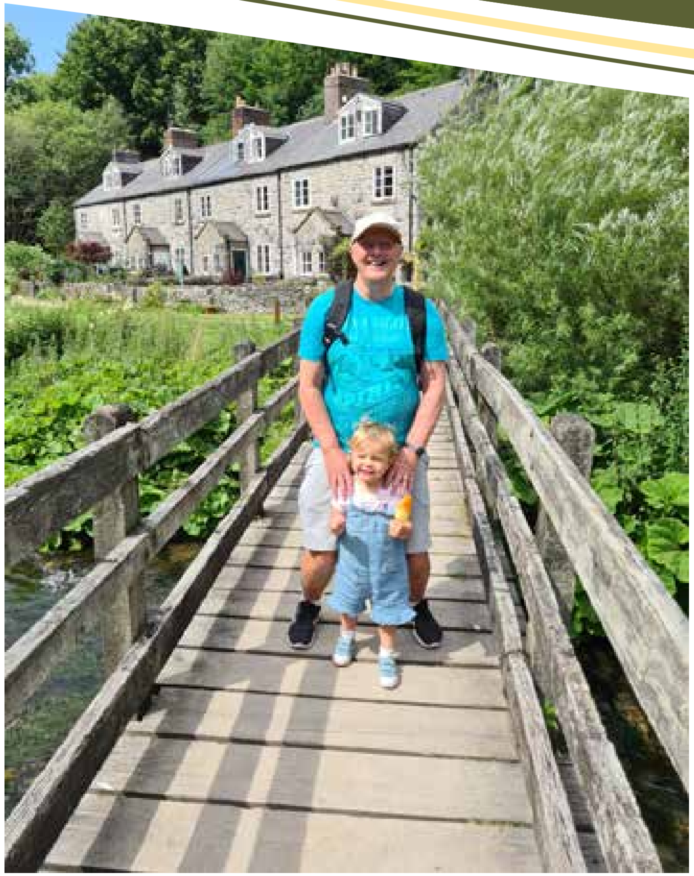
My involvement as a Volunteer at Wythenshawe Hospital dates back to 1992, following a spell as an in-patient. I have been a member of the Chaplaincy Team in a role which has involved visiting patients in the wards.



The ICD Support Group Committee is very keen to arrange Open Meetings again for our members. We were aiming for a meeting before Easter. However with due consideration to the health and safety issues involved, we have reluctantly decided that this is impossible. Our members include many who would be classed as vulnerable to Covid, and we do not wish to take any unnecessary risks. Let's hope that by late summer the situation will have improved, and we can look forward to meeting up again.

With very best wishes,

Jeremy White



Wednesday 13th January 2021

Due to being extremely clinically vulnerable I had my Covid jab booked for 9:25 in the local area. My husband was working the late shift and therefore was looking after my youngest daughter Brea at our home and I had taken Brooke to my Mum and Dad's house to get her ready for school as they look after her whilst I work and take her to school. My plan was to drop Brooke with my Mum, get her ready for school and then head over to have my first Covid-19 jab before heading home to look after my youngest whilst teaching remotely from home due to shielding.

That morning everything seemed rushed and stressful, the girls were arguing over the Barbie dolls and I decided to head to my Mums a little earlier than usual. As we pulled up outside the house, I had a sudden urge of feeling bad that we had arrived earlier rather than normal time as I suspected they would still be in bed. As I entered the kitchen area my Mum shouted for me to come upstairs, "Claire come up quick". From her tone I knew something wasn't right and I explained to my daughter Brooke to wait here whilst I went to help Nana out of bed as she had recently had her hip operation. I ran up the stairs wondering what had happened and what the panic was, no thoughts were going through my head as I ran up the stairs and when I entered the bedroom, I would never have imagined what I was walking in to.

My Mum was pulling at the covers trying to get dad off the bed and there was a 999 responder already on the phone on loud speaker my mum was screaming at him and shaking him to "Don't leave me!"

I told my Mum to go downstairs with Brooke, open the front door for the paramedics and to ensure Brooke does not see anything! The 999-call handler started to speak to me and telling me to get my Dad on to the floor. I tried to get my Dad up off the bed and was talking to him asking for his help to put his arms around me, but when I saw his face, the realisation hit me that he was not conscious or breathing. The colour from his face had drained, his lips were tinged blue and his eyes were rolled back. I realised that I had to get him off the bed myself and that even if he landed funny, it wouldn't hurt as he was not conscious. I managed to drag him to the side of the bed and hooked my arms under his armpits and dragged him onto the floor.

Once I had done this, the 999-caller asked whether I knew how to do CPR. Ironically, it was my Dad who first put me on a first aid course when I was younger to help with my employability within education and sport. Despite doing it on a course nothing had prepared me for the situation I was currently in, looking at my Dad on the floor I knew I had to do my best if he was to survive.

The 999-call handler was amazing and talked me through everything, counting with me to ensure I was doing it at the correct pace. My Dad was not breathing and I kept looking at him and talking to him as if he could hear "come on Dad, you are OK, just breathe!" but despite my efforts there was no response, I checked his airways and continued doing CPR for what felt like a lifetime.

My Mum kept coming in, the look on her face of fear that My Dad was dead and she kept asking, "is he dead?" I felt strangely calm and in control and remember telling my Mum "No he is fine, he breathed a minute ago, go downstairs with Brooke" although in my head, I thought oh my God he is dead, he is, but I'm not going to give up on him! After, what felt like ages, my dad breathed in, it wasn't normal breath or a gasp, but more a gargle, I thought, that's his last breath. I informed the call handler he had breathed in, but not out and after a few seconds he gargled in again. I looked hoping to see him come round, but nothing, he was still lying there grey, eyes rolled back and again he stopped breathing. I pressed harder, thinking I mustn't be doing it right and felt and heard his ribs crack beneath the palm of my hand. I apologised to my dad's lifeless body and the call handler said

"Don't worry his ribs will mend, just keep going you are doing great!" He had stopped breathing again and fear started to kick in "where's the Paramedics?" I screamed before apologising. I didn't mean to shout, but I was now exhausted and breathless myself, but knew I couldn't stop, she assured me they were almost there, so I carried on and again my dad took in some air! This time he breathed in and out about 4 or 5 times. I started to talk to his lifeless body "Come on dad, you can do it just breathe, it's like playing 5 a side, you're exhausted at the end, but you need to try" I don't know why, but I thought if he can hear me, he might just hold on, but despite this he is stopping again. I felt like I was doing something right, but then getting it wrong and again pushed harder to hear more crunches in my desperate attempt to revive him once again. I was watching his whole-body flop like a ripple in the water every time I pushed down and again asked the call handler where the paramedics were? She assured me they were on the way and that once they arrived not to stop, but to keep going until the paramedic took over.

Finally, after what felt like a life time, the first responder came in sight, I continued whilst trying to tell him information and he seemed to be working in slow motion, putting down his equipment and checking my dad. I continued and he fitted the defibrillator and told me to move back. The defibrillator went off and my dad's body left the floor like a fish out of water and crashed back down to the floor. I was gasping for air, exhausted and sweating looking down at my dad thinking come on dad but still he lay unresponsive, then more paramedics came in and I left to give them the space they needed to continue working on my Dad. I didn't want to leave him, but I also didn't want to stay. I collected all information, name, address, medication to give to the paramedic I asked if he needed anything else to which he responded next of kin. My heart sank and I swallowed back the lump in my throat before going to reassure my mum that he was ok (despite thinking otherwise). The paramedic came to speak to me to ask if he was diabetic as his sugars were low and also praised me for saving his life. I cannot explain the feeling but a shadow of realisation and upset came over me, but I couldn't cry I had to stay strong for my mum and Brooke. My mum wanted to see him; I didn't want her to, but I couldn't stop her she wanted to say goodbye before he went in the ambulance.

The paramedics took my dad and continued to work on him in the ambulance in front of the house. A man came in to update us and explained that he was critical and that next of kin needed to head to the hospital in about an hour to talk for him. I knew my dad was alive, but I also knew his life was hanging on a thread. My mum looked at the clock and it had stopped at 7.50. She commented and I snapped thinking she thinks it's a sign and my dad has passed away as she thinks things like this.

We took my daughter to school; I went to have my covid jab and headed towards Tameside with my Mum. We rang on the way to check and they said they needed someone to speak for him and to come straight to resus. I dropped my Mum as didn't expect to be allowed in due to covid rules, my mum asked me to stay and wait and I did. I rang her and she said she was just in the family room waiting. I came off the phone and broke down in the car. They only take you in the family room when its bad news I thought and suddenly all my emotions poured out. That was the last memory with my Dad, the image of him lying on the floor haunted me and I believed my dad had died my phone started to ring and through the tears I saw my mums name, I was filled with dread answering it and she told me to come in to resus to see him. I asked if he was Ok? She reassured me and said the doctors had asked me to go in to see him. I walked to A and E and asked for my dad a lady walked me through and I asked her is he definitely Ok. As I went in and saw my dad I felt relieved to see him with colour in his face, he lay on the bed with an oxygen mask on and was breathing.

The doctors congratulated me on what I had done, but I just did what I had to do. They couldn't believe what I had done and how long I had continued to help my dad fight for his life. My dad kept coming in and out of consciousness whilst we were there and we were talking to him, but there was no response, I asked him to squeeze my hand if he could hear us and again no response. I felt sick and looked at my mum, trying to reassure her that he hadn't gone longer than 7 minutes without oxygen but in my heart, I thought he had brain damage due to lack of oxygen. He kept coming in and out, but nothing. The nurse was trying to reassure me explaining about brain hypoxia, but I was desperate and impatiently wanting to know he was OK. He was coming round and started to move his legs in a bicycle motion so I knew he could move, but when it seemed like he wanted to talk he couldn't and it was as if his tongue was too big for his mouth. He kept going for scans, brain, lungs and heart I think and as he came back from one, he tried to roll over and shouted out in pain it was the best thing me and my Mum had heard! We left shortly after to allow the doctors and nurses to do what they had to do and later on he was moved to a ward.

The next few days he was very confused and not sure why he was there or what had happened. He rang me 4 times that night, the first thing he said was "my ribs hurt the doctors said you nearly killed me" I said "What you nearly killed me after doing CPR for that long I couldn't breathe either" I didn't mind having the same conversation over and over again, because I was talking to my Dad, something that 12 hours previous I thought I would never do again. He was very confused and thought he was in my late grandad's nursing home at one point and another time rang my brother
in the early hours asking why he had left him in London on his own. He was trying to fix the TV whilst messing with the heart monitor and his memory wasn't great, but he did know his date of birth and his pin to access his phone so despite earlier concerns of brain damage I was reassured that this would come back after a few days.

The doctors and nurses at Tameside were amazing at keeping us updated whilst trying to solve the medical mystery that is my Dad. Yes, he is 63 but he is fit and healthy, why has this happened to him? The scans and tests are clear, there is nothing wrong so why had this happened?

He was then transferred to Wythenshawe he wasn't happy as United were about to kick off when they came to collect him and again the doctors and nurses there were fantastic. We were relieved when they decided to fit the ICD as in my mind it reassured me that I would never experience what I had that morning at 7.25 on 13th January and my girls still have their Grandad and my dad is still here too.

Claire

What to do if you are at the end of your life and you have an ICD or CRT-D.

This is a sensitive subject, one which few of us like to talk about. It is hoped that you will live a full and long life. However, if you have an ICD or CRT-D device, you are at risk of having dangerous, life-threatening heartbeats. The device will treat these heart rhythms if they occur, but what if you are diagnosed with a terminal illness, your heart condition becomes worse or you become very sick?

What if you enter the last stages of your life?

You need to have some potentially difficult and distressing conversations with your loved ones or important people in your life, preferably long before you enter this last stage of your life.

There are several important reasons why you should do this. If you are coming to the end of your life, it is possible that you could experience a dangerous, fast heartbeat such as ventricular fibrillation (VF) or ventricular tachycardia (VT). This could be painful, distressing and could prevent you from having a natural death. To avoid this, you can have the shock lead of your device turned off. This is always best when it has been discussed and planned.

If you come to the end of your life and you have had discussions about what you want to happen, your loved ones do not have to worry about making the wrong decisions about your care and treatment if you are unable to do so.

It is normal for them to feel upset at the thought of losing you. It is part of the grieving process and for some people, can occur long before you die. They may want to persuade you to keep the shock function on because they don't want you to die. But remember, this decision is yours.

As professionals, we are here to help you come to a decision and we will not try to influence your choices. We have a duty of care to support you and give you honest, unbiased information. Sometimes, this involves telling you that you are dying and that turning off the shock lead is the right thing to do.

Talk to your loved ones about when you want the shock lead turning off, if possible, before you become too poorly to move or leave your home. You need to understand the importance of turning off your shock lead but there are lots of professionals who can help you make this decision.

The Cardiac Rhythm Management (CRM) team or Cardiac Physiology team can explain the benefits and drawbacks of turning off your shock lead. Your Consultant Cardiologist or Registrar to your Consultant can also discuss this with you. Your General Practitioner (GP) can advise you too, but the hospital team are the best people to advise you about your device.

If the shock lead is turned off, your device will not recognise or treat VF or VT. Shocks and/or anti-tachycardia pacing (ATP) will not be delivered you will die. The built-in pacemaker will still work, but this will not be effective in stopping dangerous heart rhythms.

Turning off the shock lead only takes around 5 to 10 minutes and is totally painless. It can be turned on again any time you want, for example, if your condition improves or you change your mind. It is not advisable to change your mind often though.

If you want your shock lead turned off, you should contact either the CRM team or the Cardiac Physiologists, so we can arrange to bring you to the hospital and turn off your shock lead. During Covid times, it should be ok for one person to accompany you into the hospital and be with you when the lead is turned off.

We will advise you of the current Government guidelines when we speak to you. You will be asked to sign a consent form once we are sure you understand the implications of the procedure. You will discuss turning off your shock lead with your consultant or the Registrar before you sign the consent form. This is a legal requirement. You can then go home, and we will tell your GP and everyone looking after you what has been done so they are aware.

If you become poorly very quickly, we can come to the place where you live to turn the shock lead off. While this is not ideal, it can sometimes happen. You will still need to be monitored after the shock lead has been turned off, but we can arrange for downloads to be done through a remote monitor if you don't already have one. This is to avoid bringing you to the hospital unnecessarily. It may also not be necessary to perform any further downloads if you do not want them.

When you have passed away, the remote monitor can be disposed of in your household refuse. Check with your local refuse collectors how to dispose of this safely. If possible, a member of your family should contact the Cardiac Physiologists or the CRM team to inform them you have passed away, so we do not send any future editions of the Defibber newsletter. It can be upsetting to receive the newsletter, as it reminds your family of you and their loss. We do have systems in place to try to avoid sending the newsletter out, but occasionally we may not find out that you have passed away and send the newsletter. If this happens, please call us and we will remove your name from our mailing list.

When it comes to arranging your funeral, the Funeral Director will need to know about your device. The device is completely turned off when you have died, either in a mortuary or at your home and is not usually left in your body when you are cremated or buried.

I hope this article has given you the strength to discuss the end of your life with your loved ones. This topic is as important as keeping you alive. If you want to discuss this further with us, please do contact the CRM team or the Cardiac Physiologists. In case you don't know the numbers, here they are!

CRM team 0161 291 5076 --- Cardiac Physiologists 0161 291 4615

Adrienne

Getting back to normal after a shock – Part 1.

If you have an ICD or CRT-D, you may feel some apprehension about having a shock. It is normal to feel like this. Your device was recommended because you were identified as being at higher risk of having dangerous, life-threatening arrhythmias. This may be because your heart pumping function is not good, or you have had a heart attack in the past. You may even have an inherited cardiac condition, such as Brugada syndrome, Long QT syndrome or hypertrophic obstructive cardiomyopathy (HOCM). Whatever reason your device was implanted, it is there to do a job – save your life if you have a dangerous heart rhythm.

If you have a shock, make sure you do a download from your remote monitor and call the Cardiac Physiologists on 0161 291 4615 to let them know. They will advise you what to do once the download has been received and examined.

Remember, if you have 2 shocks or more, then someone needs to get you to hospital (you cannot drive if you think you have had a shock). If you are very unwell after one or more shocks, you dial 999. We may need to review you in clinic earlier than planned. If this is the case, we will let you know.

Some people feel a great sense of security, knowing the device is there. Others may worry all the time about having a shock. Shocks can be painful if you are still conscious when the shock is delivered. You may not feel a shock if you have lost consciousness. Most people are not unconscious for long once a shock has been delivered. They are often a little disorientated at first. They may have fallen to the floor. Injury can occur if this happens.

Most people get some warning that they are about to pass out, but this may be mere seconds only. They feel suddenly unwell, dizzy, have palpitations, chest pain or shortness of breath. We advise that if any of these symptoms occur and you are sitting down or in bed, stay where you are. If you are standing, sit down in a safe place quickly.

Feeling a shock can be traumatic for some people. They fear having another shock. Others may fear having a first shock. The fear stops them leading a full, enjoyable life. Although this is understandable, it stops them doing things which bring them pleasure or happiness.

So, what can you do if you are feeling like this?

It would be very easy for me to say, "don't worry about it, go and do lovely things!". I don't have a device watching for life threatening arrhythmias. I haven't experienced any kind of defibrillator shock. I don't know what it feels like to have a shock. But I do have experience in dealing with the aftermath of a shock. The psychological impact of having a shock, for most of my patients was high at first. Read back through the old editions of the Defibber newsletter and almost everyone who felt a shock said it was painful. But as time has moved on, they are now stable, happy and are getting on with their lives.

Doing nice things. Here are some of the things my patients have said to me over the years after having a shock (names changed to maintain confidentiality).

Derek said "Adrienne, all this time I was waiting for another shock. It never happened. I spent all that time worrying for nothing and wasting my time. I didn't see my granddaughter for 3 months, because I didn't want her to see me when I had a shock. I didn't walk with my wife to the shops because I was afraid that I would get a shock in the middle of the supermarket and look like a fool! I have not had a shock for 8 months now and I think life is too short to worry about this kind of thing. My defib will save me if it needs to. That's enough for me".

Maureen said, "my first shock, I didn't feel it because I had passed out. So, I wasn't afraid of having more shocks. My second shock, 2 years later, I was awake, and I felt it. I saw a big flash across my eyes and a terrible sharp pain in my chest, only for a split second, and then it was over. It surprised me. I have a vague memory of shouting out. My husband was more shocked than me because he thought I was telling him off!

We had a laugh about it, once I had calmed down. I spent quite a few weeks after that, worrying about it happening again. My husband wanted to do everything for me, so I didn't have to get up. But that started to get on my nerves after a while and I told him to stop it. Now, we do lots of things together, enjoying our lives with our family. They all know what to do if I get a shock, which I hadn't really talked about much to them before. They feel prepared and confident about what they should do. And we talked to our grandchildren, who are only 5 and 7 about what an ICD is and why it is inside me. I let them gently feel the box of my ICD. They think Nana is Superwoman! But I think, most importantly, they are not afraid. That's priceless".

Geoff said, "I had lots of shocks, one after the other, over and over again. I think I had about 7. My heart was so unstable, my ICD could not keep me in a normal rhythm after the shocks. I knew I had to get to the hospital as soon as I could to get help. It's all a bit of a blur after the first 4 shocks, but I felt a bit numb and started not to feel the shocks as much. Maybe it was the endorphins kicking in. I was admitted and given strong meds in a drip which stabilised my heart. Once I'd had a few days to look back on it, I thought, I've got 2 ways of looking at this. I can live in fear that it will happen again, or I can get on with it, take my medicines and carry on with my life. I chose to get on with it".

Talking to the people close to you can help you cope with the feelings you experience. This will also help them to understand how you feel. Everyone will feel differently about experiencing a shock. There is no right or wrong way to feel about it however focusing on the positive things is very important for your psychological wellbeing. Shocks occur mainly because your heart is in trouble. Shocks are needed to restore a normal heart rhythm. Shocks are there to save your life. Take comfort in this. Enjoy your life!

Stay regular! Adrienne

Getting back to normal after a shock – Part 2.

After a shock, it is normal to feel nervous about getting back to normal. Take your time to do this. Talking to the people who are important to you can really help you to understand your feelings and it helps them too. Although we, as nurses and doctors are here to support you, we don't know what it feels like to get a shock. The Support Group Committee is made up of people who have, or have had an ICD or CRT-D. They understand what it is like to live with a device and the impact it has. They can be a great source of information, support, and advice if you are struggling to get back to normal.

If you would like to talk to a member of the Committee, it is recommended that you contact the Cardiac Rhythm Management (CRM) team on 0161 291 5076. We will be able to put you in contact with the person we think can help you most. For example, a lady might prefer to talk to another lady. Our Support Group members are a lovely bunch, they are friendly, approachable, and understanding. Although they are not medically trained, they know what you are going through. They may even have felt like you do at some time in their own journey!

All our Committee members are official volunteers at Manchester Foundation Trust (MFT) Wythenshawe site. They are all happy to talk to you about having a device. Since Covid came into our lives, we recommend all communication is done on the telephone to keep you all safe.

There is other help available too. You can call the CRM team to see if you can have Cardiac Rehabilitation (Cardiac Rehab). Prior to Covid, this was routinely offered to every patient who had a new device. If you are struggling emotionally, we can see if you can have a course of Cardiac Rehab, with a focus on emotional well-being, relaxation, mindfulness and developing coping mechanisms. You can be shown how to manage your anxiety and stress using Cognitive Behavioural Therapy (CBT).

Getting back to normal is different for everyone. Think of what your goals are and how you want to achieve those goals. Do you want to return to driving or go back to work? Or return to the same level of fitness that you had before? Remember, some people may have restrictions enforced upon them. For example, HGV drivers will permanently lose their licences if they have an ICD or CRT-D implanted. This is imposed by the Driver and Vehicle Licensing Agency (DVLA) and is the law. The DVLA also imposes a 6 months driving ban if you have a dangerous, life threatening heart rhythm (with or without a device in place). Again, this is the law.

Returning to work can be an important part of getting back to normal for some people. Speak to your Personnel Department and your Manager (if you have them). They should be able to advise you on any adaptations needed for you to safely return to your job. If your job involves driving, and you have a 6 months driving ban, you could see if you can return to "desk duties only" if this is possible. You may need to return to work for financial reasons. The Citizens Advice Bureau can be a good source of advice and information on financial matters. Some Solicitors offer free legal advice.

Even if you are able to return to work after you have had a shock, it is recommended that you take a little time off after the event, if possible, just so you can absorb what has happened and re-build your confidence.

For most people, doing exercise is good for you. There are some exceptions to this for people who have certain heart conditions. You will have been advised not to perform high intensity exercise if you have one of these conditions. It is recommended that any exercise is started at low intensity, where you get a little short of breath and sweaty and build up gradually. Always stop exercising if you feel unwell and seek help if you do not feel better. Swimming is great exercise but try to do breaststroke, so the leads of your device are protected from wear and tear. The leads are very sturdy, but are not invincible, especially if they have been in your body for a long time. If you play golf, you may need to adapt your swing. Please do not blame us if your handicap goes up though! Walking is perfect if you haven't done much exercise before. Stay safe though, with any exercise (Covid!). The internet can be really useful if you need information about your condition but be careful about what you research, especially information from other countries. The information in other countries can be vastly different to that in Great Britain! And be mindful of entering chat rooms online.

Some people may want to take a holiday after a shock. Since Covid, many of us have not been able to fly and have a holiday abroad. But if you can go on holiday, make sure you get travel insurance as soon as possible after booking your holiday. Declare ALL your medical conditions (and state that you have a device). Make sure you know where the nearest medical facility is if you need hospital treatment. Shop around as insurers' quotes can differ greatly. Some insurers are sympathetic to people with a device or heart condition.

Make sure that you take a good supply of your medicines with you on holiday too. Check if it is okay to store your medicines in your hand luggage so they are on hand if you are on a long flight. Pack at least enough for the duration of your holiday, and extra medicines too. Remember to take your medicines too. It is very easy to forget to take them when you are having a lovely time!

So, I hope this information has been useful. Having a shock may feel awful, upsetting and cause you anxiety. But remember, it has done its job and saved your life. Stay safe everyone and as always, stay regular!

Adrienne

Members of our Support Group have asked if they could make a donation to help finance the Newsletter and cost of our Groups Meetings. If Members wish to do this they can now make a donation direct to the 'Wythenshawe ICD Support Group'

LLOYDS BANK

Sort Code: 30-91-91

Account Number: 30781868

Alternatively, you can send to our Treasurer Emma Maiden:

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

Contact details for all Patients:
If you have any concerns, please contact the:
Cardiac Physiologists on
0161 291 4615
Cardiac Rhythm Management team:
0161 291 5076