Defibber News

MARCH 2023

MESSAGE FROM THE CHAIRMAN – JEREMY WHITE

The Support Group is delighted to send you our first Defibber News for 2023. It includes an article about a patient's experiences, and also the recent transition of Wythenshawe Hospital to MFT. You will also find details of the next Open Meeting in Hale Barns on 22nd March at 2-00pm. We will look forward to seeing you there.

The Support Group has been seriously considering the practicalities of our future operations. As we all know, the cost of posting newsletters has become very expensive. We wish to change to publishing them on our website in 2024.

In order to maintain contact with ICD patients, we are planning to establish a database for members' e-mail addresses. The Newsletter includes details of how you can ensure that you are included in future. Strict confidentiality will of course be maintained.

"UNDERSTANDING CARDIOMYOPATHY"

Dr Aneil Malhotra

Wednesday March 22nd 2023

2.00pm

All Saints Church Hall,
Hale Road, Hale Barns WA15 8SP
(Tea & coffee served from 1.15pm)

Cardiomyopathy – the topic of our next Meeting

The NHS Website tells us that Cardiomyopathy is a general term for diseases of the heart muscle, where the walls of the heart chambers have become stretched, thickened or stiff. This affects the heart's ability to pump blood around the body.

The abnormal heart muscle seen in cardiomyopathy is not caused by blocked arteries in the heart (coronary artery disease), high blood pressure (hypertension), disease of the heart valves (valvular disease) or congenital heart disease.

Most types of cardiomyopathy are inherited and are seen in children and younger people. The different cardiomyopathies are described as:

DILATED CARDIOMYOPATHY

In dilated cardiomyopathy the muscle walls of the heart become stretched and thin, so they cannot squeeze (contract) properly to pump blood around the body.

HYPERTROPHIC CARDIOMYOPATHY

In hypertrophic cardiomyopathy, the heart muscle cells enlarge and the walls of the heart chambers thicken. The heart chambers are reduced in size so they cannot hold much blood, and the walls cannot relax properly and may stiffen. Also, the flow of blood through the heart may be obstructed.

RESTRICTIVE CARDIOMYOPATHY

Restrictive cardiomyopathy is rare. It's most often diagnosed in children, although it can develop at any age. The walls of the main heart chambers become stiff and rigid and cannot relax properly after contracting. This means the heart cannot fill up properly with blood.

It results in reduced blood flow from the heart and can lead to symptoms of heart failure, such as breathlessness, tiredness and ankle swelling, as well as heart rhythm problems.

In many cases the cause is unknown, although sometimes the condition can be inherited.

ARRHYTHMOGENIC RIGHT VENTRICULAR CARDIOMYOPATHY

In arrhythmogenic right ventricular cardiomyopathy (ARVC), the proteins that usually hold the heart muscle cells together are abnormal. Muscle cells can die and the dead muscle tissue is replaced with fatty and fibrous scar tissue.

The walls of the main heart chambers become thin and stretched and cannot pump blood around the body properly.

People with ARVC usually have heart rhythm problems. Reduced blood flow from the heart can also lead to symptoms of heart failure.

ARVC is an inherited condition caused by a change (mutation) in one or more genes. It can affect teenagers or young adults and has been the reason for some sudden unexplained deaths in young athletes.

There's increasing evidence that prolonged, strenuous exercise makes the symptoms of ARVC worse. It's important that people with or at risk of ARVC discuss this in detail with their heart specialist (cardiologist).

Treating cardiomyopathy

There's usually no cure for cardiomyopathy, but the treatments can be effective at controlling symptoms and preventing complications. Some types of cardiomyopathy have specific treatments and early diagnosis is very important.

Not everyone with cardiomyopathy will need treatment. Some people only have a mild form of the condition they can control after making a few lifestyle changes.

Lifestyle changes

Whether the cause of cardiomyopathy is genetic or not, it should generally help to:

- eat a healthy diet and do gentle exercise
- quit smoking (if you smoke)
- lose weight (if you're overweight)
- avoid or reduce your intake of alcohol
- get plenty of sleep (as well as diagnose and treat any underlying sleep apnoea)
- manage stress
- make sure any underlying condition, such as diabetes, is well controlled.

Medicines

Medicines may be needed to control blood pressure, correct an abnormal heart rhythm, remove excess fluid or prevent blood clots.

Find out more about:

- treatments for high blood pressure
- beta-blockers to treat an irregular heartbeat or heart failure

- diuretics – a type of treatment for high blood pressure to remove excess fluid from your body, if that is causing swelling
- anticoagulants such as warfarin to prevent blood clots
- medicines to treat heart failure

Dr Aneil Malhotra – our Guest Speaker - is a consultant cardiologist at Wythenshawe and Manchester Royal Infirmary Hospitals. He is also a professor at Manchester Metropolitan University and an MRC Clinician Scientist at The University of Manchester.

He graduated from the University of Cambridge (Emmanuel College) in 2006 and having spent time at both MIT and Harvard Universities in Boston, he spent his Foundation years working in Cambridge (UK) and Papworth before moving to Oxford to continue his specialist training in cardiology. Along the way, he completed a Masters in Medical Leadership at the Royal College of Physicians (2013). He completed his PhD in inherited heart diseases and sports cardiology at St. George's University of London.

Aneil's research areas include investigating the electrical, structural and functional features of the adolescent athlete's heart with data derived from analysing the Football Association's cardiac screening programme, the largest of its kind for elite junior athletes in Europe. His work has achieved Young Investigator Award and best abstract prizes at international conferences in Europe and America. Aneil is the European Association of Preventative Cardiology young ambassador for the UK and sits on the sports cardiology nucleus for the European Society of Cardiology.

He has over 80 peer-reviewed publications and has co-authored and contributed to books in cardiology and medicine.

Aneil is the lead cardiologist for a number of elite sports teams including Manchester City, Leeds United and Burnley football clubs, as well as British Cycling. Aneil also works closely with Manchester United and is regularly involved in the cardiac care of athletes for Team GB, English Institute of Sport (EIS) and numerous professional football, cricket and rugby clubs.

Dr Aneil Malhotra

MyMFT
Healthcare in your hands

Hi everyone, I hope you are all keeping well and enjoying life as we know it following the Covid pandemic. I want to tell you about a new patient access service we have introduced at Manchester Foundation Trust (MFT). As you may be aware, Manchester Royal Infirmary (MRI) and Wythenshawe have joined together and are now one Trust.

We have just implemented a new computer system called Hive. Hive is a big step towards a paperless Trust. Attached to Hive is a new service for patients called MyMFT. We are still getting familiar with this new system so you may notice that we spend some time at the computer when you visit us, but we are still looking after you and assessing your device and symptoms in the same way!

You can sign up to MyMFT, although this is not compulsory. You may have already received an email, letter or text about it. Some of our patients have been reluctant to sign up as they thought it was a spam email. If you have any doubts about whether any communication is genuine, check the web address or ask us when you come to clinic. You can also search Google by typing in "My MFT FAQ" or "MYMFT Your Patient Portal". It is easy to use and takes only a few minutes to sign up. You then need to create a username and password.

If you have received an activation code, use this to start the activation process as the code will expire after a certain length of time. Once it has expired, you will have to get a new code.

You can contact mymft@mft.nhs.uk – or – call our MyMFT Patient Support Line at 0161 529 6000

Once you are signed up, you will be able to access certain information. The Trust takes great care to ensure your information is safe and secure. It is free to join MyMFT and you can access the information using a computer, laptop, tablet, or mobile phone app. Once you have signed up to MyMFT, you will be able to see the information about you and your condition. Please be aware this is not access to your medical records. If you wish to view your medical records, you must apply for these, stating what information you wish to see. There is a charge for requesting to view your medical records and a strict process which must be followed. So, what are the benefits of using MyMFT? You can manage your clinic appointment, you can receive letters from us about your device, clinic review, progress and treatment. You can also check in via MyMFT for your clinic appointment.

Appointments which you have attended and those which are planned are also on MyMFT. Receiving communication via MyMFT will be much quicker than waiting for a letter in the post. As soon as we have electronically signed your letter, it will appear on an email.

The Trust may decide what information to give you access to. This is because some information may be sensitive. For example, if you are being investigated for cancer and cancer is found, you wouldn't want to read this on MyMFT. You would expect to be told your diagnosis in front of your consultant in an appropriate environment and manner.

So, there it is! MyMFT will hopefully give you lots of information about you, your and stay regular!

MyMFT by Adrienne Unsworth

A Patient's Story told by Adrienne

There are often times when a patient who has been diagnosed with a heart condition requiring the implantation of an ICD / CRT-D wants to share their story, their experience but don't wish to write it themselves. This next Patient's story is a case in point.

This article was written by me after going to see a patient on the ward at Wythenshawe hospital in November 2022. The patient did not want to write his story but agreed to talk to me about his experience of recent events and he gave me permission to write his story for him. To protect his identity, I have changed his name.

John was admitted to the ward at the beginning of November, after losing consciousness at the wheel of his car. His car crashed into the crash barrier on the motorway. Thankfully there were no serious injuries as it was during rush hour and traffic was slow moving.

He had absolutely no recollection of what had happened. He did not remember losing consciousness, feeling unwell before passing out, or the crash itself. He just remembers waking up on the ground with several strangers surrounding him. He remembers blue lights flashing and thought he had been arrested by the police. However, he did not know why the police would be arresting him! He remembers trying to sit up to ask what was going on, but the strangers kept telling him to lie back down, stay still and everything was going to be ok.

He found this quite distressing because he wanted to "put the pieces of the jigsaw" back together. There were bits of his life that were missing.

Nothing made any sense. What had happened? Why was he on the ground? If he had crashed, had he killed someone?

After a few minutes of being told to slow down his breathing and stay still, it dawned on him that these strangers were in fact paramedics, and they were giving him treatment. They told him they'd had to give him a shock to his heart because he was in a dangerous heart rhythm. It was then that he realised his chest hurt a lot. He asked if he was having a heart attack as he had a heart attack 10 years ago. The paramedics said they weren't sure, but they couldn't see any signs of a heart attack on his ECG. They were taking him to Wythenshawe hospital to get him checked out, just to be safe.

At Wythenshawe hospital, his ECG looked ok and there were no new signs of a heart attack, so he was admitted for further tests. One of those tests was an echocardiogram (an ultrasound of the heart). This showed that the pumping strength of his heart was very weak. This is called left ventricular (LV) impairment. The LV impairment was described as severe. His heart was weak and wasn't pumping the blood around his body effectively enough.

As John had a heart attack 10 years ago, this could have caused him to have a dangerous, life-threatening arrhythmia like ventricular fibrillation (VF) or ventricular tachycardia (VT). John was in VF when the paramedics arrived.

The paramedics gave him cardio-pulmonary resuscitation (CPR) and delivered a shock to stop the VF. We know that scar tissue can form in the heart after a heart attack, and this can increase the risk of VF and VT in later years. The chest discomfort was due to the chest compressions during CPR. He also had 2 broken ribs caused by the CPR. John said to me, "it's a small price to pay for my life!"

John spent the next 3 days on the ward recovering and trying to piece together the events on the day of his crash. He found it really frustrating that he couldn't remember. When I went to see him, I explained that we may never know what happened. John was alone in the car. I advised him to focus on his recovery and getting home. John's consultant had finished all the tests and it was decided that John needed an Implantable Cardioverter Defibrillator (ICD).

The ICD would treat any dangerous heart rhythms in the future if they occurred. John had read the ICD booklet and we went through any questions he had. John asked me when he could drive again. I told him that because he'd had a dangerous heart rhythm, he was not allowed to drive for 6 months, and this was the law. He would have to let the DVLA know and surrender his driving license.

John was upset to hear this. He felt like he had lost his freedom and he would have to rely on his wife and family to "fetch and carry" him to where he wanted to go. He felt like a burden to his family because he had always been the one to ferry his kids to their various hobbies and activities. Now he would have to let them support him. I said to John that his family would want to do things like drive him to places because they loved him and wanted to support him. 6 months goes quite quickly, and he would soon be driving again.

John said although he wanted to drive again, he knew he would be nervous getting back behind the wheel because it would bring back memories of the crash. I said that was understandable and completely normal, but the accident was only a week ago and was still at the forefront of his mind. He would likely feel differently in 6 months' time.

John's wife and daughter came to visit him while we were chatting. We did the introductions and I asked them if they had looked at the ICD booklet on the ICD Support Group website. They had, but they had a few questions. We went through them all. John's daughter found it particularly upsetting to see her dad sitting in a hospital bed. She was really close to her parents and was the youngest of 3 children. She started crying which made John and his wife upset too. I ran off to fetch some tissues. When I came back 5 minutes later, tissues in hand, they had all gathered themselves together and started apologising to me. "Sorry about that Adrienne, I don't know what's wrong with me. I'm normally so strong!"

I said it was totally ok to get upset and was a normal response to what had happened. I said they would likely cry again before the week was out! The whole family had gone through a difficult, scary time. John was facing the fact that he was not invincible.

I said it was important that they focus on getting back to normal. Going home is a big step towards this. Many patients can't wait to get home, but some feel anxious about leaving the ward, where there are doctors and nurses to help them if anything happened. John couldn't wait to get home. His wife and daughter were anxious. What if he had a dangerous heartbeat again? Who would help them?

I said these were normal feelings and it was understandable for them to feel like this. I also said they must remember that once the ICD is implanted, John would be safer than all of us! If he had a dangerous heartbeat, his ICD would sort him out in about 10 seconds. They felt very reassured by this. I said John would be on medication for the rest of his life and he would have regular device checks too.

When John went home, he felt ready and was looking forward to a home cooked meal, a shower in his own bathroom and a sleep in his own bed. His wife cooked him his favourite meal, steak and oven chips, she put a freshly washed towel in the bathroom for his shower and jokingly put a chocolate on his pillow to pretend that he was in a hotel. When I saw them in clinic 6 weeks later John's wound was healing nicely, he was smiling and confident, and he was feeling much better about life.

His wife has stopped putting his towel in the bathroom and no more chocolates appeared on his pillow at night. She said she remembered what I had said about getting back to normal. "I didn't do this before his crash, so why am I doing it now?" she said. "I was spoiling him because I wanted to protect him. But that's not helping him, is it? To be honest, I was getting a bit fed up with it all. We are now doing all the stuff we did before, except he doesn't drive! And I'm so happy he's still with us. I'm so grateful to the paramedics, to A&E, to the ward staff, to the doctors and nurses."

Thank you to John and his family for allowing me to share their story, feelings, and sometimes raw emotions. This kind of experience is often frightening, stressful and fraught with heightened anxiety about what the future holds. But I think John's story shows that life can be good again, you just have to make a few adjustments and off you go!!!

FUTURE PLANS OF THE ICD SUPPORT GROUP

Dear Patient

These last few years have seen everyone having to navigate not only their own health conditions, but also, the traumas connected to Covid. This of course, is also true of those who work within the NHS – doctors, nurses and all other staff. Our Patient meetings had to be suspended during this time and much of the work and information we provided was confined to items on the Group's website at: (https://wythenshaweicd.wixsite.com/icdsupport) – and the occasional Newsletter. Recently we were able to return to having an open meeting for patients which was held on August 10th at All Saints Church and a report of that is on the website.

Even with the recent open meeting, all of this has prompted the group's Committee to assess how we go forward in a way which ensures that we can continue to support all of our patients. How do we do this?

First of all we need to be ready to provide support for any patient who may have difficulty in living with their ICD in a way which can give them confidence in the challenges they face. That could be by telephone conversation, by email or where applicable, by face to face meetings.

Members of the Committee have varied degrees of experience in coping with their underlying heart conditions and the ICD that accompanies them as part of their treatment. This can be particularly helpful when in contact with patients. This emphasis on direct support has always been, and will remain, our core function and we definitely wish to continue to do this with direction and assistance from our CRM nurses at Wythenshawe Hospital.

Taking into account the Support Group's history – some 20years now - its work and recent events, as well as considering the personal and financial issues that have arisen, the Support Group's Committee has decided to make changes to the way we work in supporting all of our ICD patients, their families & carers.

Going forward and taking into account that many people are now 'on-line' in their day to day activities and familiar with social media platforms, our aim is to implement the following:

(1) We will hold two public meetings per year which will take place in the Spring and Autumn

(2) We will produce two Newsletters (Defibber News) per year, one in Spring and one in Autumn, copies of which will be posted on the Website for you to read. In 2023, we will also produce two printed Defibber News which will be posted out to everyone. As of 2024 the Newsletter will be published on the Support Group's website.

(3) The Support Group's website will be expanded and used to pass on the latest and most relevant information continually, covering such issues as (1) living with your ICD and all the consequences that follow from that; (2) ICD technology developments; (3) understanding of the different heart conditions, medications and their evolution and (4) anything else relevant to our patients. The website will also include all copies of the Newsletter (Defibber News).

(4) We will consider the possibility of informing 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. This would only be introduced if a significant number of patients agree. We will save the details in a protected database. If you wish to do this, please let Emma know by emailing her at (emma.boswell@gmail.com)

REMEMBER – In providing your email address you are giving your consent to the Wythenshawe Hospital ICD Support Group to contact you by email and to store your email address in a secure database.

In this next piece we wish to bring your attention to the Support Group's Website and what it provides for our Patients.

Wythenshawe Hospital ICD Support Group Website

Have you had a look at the Support Group's Website? The website can be accessed via this link: https://wythenshaweicd.wixsite.com/icdsupport which will take you to this screen.

On the Home Page there is a Menu Box that takes you to the different items which may be of interest to you:

- Home
- About Our Support Group
- Committee Members
- Defibber News
- Your Device & Patient Quiz
- Latest news
- Next Meeting
- Feedback
- Useful Links
- Video
- Blog

On the site you can read all issues of Defibber News; get information that is relevant to you under Latest News; find out all the details of our Patient Open Meetings, get a copy of the Information Booklet for Patients having an ICD implanted and more.

Defibber News is always wanting to share the experiences of our patients, families and carers and if you would like to share your story, just send it to (georgedavies48@sky.com) and he will ensure that it is included in subsequent issues of Defibber News.

If you don't wish your name to be used, that's fine and we will publish anonymously. What really matters is that we all benefit from shared experiences and ways of coping in living with an ICD/CRT-D, those experiences being invaluable in supporting others who may have just been diagnosed and implanted.

Wythenshawe Hospital ICD Support Group Committee Members

Patients at our last meeting held in Hale Barns on August 10th 2022

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

Members, if they wish, can now make a donation direct to the Support Group's Bank

LLOYDS BANK

"WYTHENSHAWE ICD
SUPPORT GROUP"

Sort Code: 30-91-91

Account Number: 30781868

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