

## Exercise for Patients with an ICD

The simple answer to this question is yes, but the full answer is influenced by the cause and the type of your heart rhythm problems and the type of exercise you perform. The likelihood of an arrhythmia is no greater during moderate exercise than during resting but there are certain types of exercise that may increase the risk. If you exercise vigorously from rest, without a warm-up, and immediately cease exercise, without a cool down or active recovery period you increase the likelihood of arrhythmia.



## How might exercise affect my ICD?

Your ICD can detect an abnormal heart rhythm (arrhythmia) in a number of ways, one of which relates to the speed of the heart during the arrhythmia. Most arrhythmias treated with ICDs will be significantly faster than your normal heart rate would reach, even with strenuous exercise. Occasionally however, the ICD needs to be programmed to recognise abnormal heart rates that are close to those that can be achieved with exercise. For this reason, it is worthwhile to check how your ICD is programmed before undertaking anything other than recreational exercise or exercise to lose weight. If you are concerned about your safe exercise level, you should ask your cardiologist, cardiac physiologist or arrhythmia/ICD nurse specialist.

For most forms of exercise it is recommended that someone who knows that you have an ICD accompanies you. You should ensure that you have your ICD card with you AT ALL TIMES, in case you need to be taken to hospital for any reason. You should not undertake any contact sports. Although the ICD itself is very tough, bruising or breaking the skin over the implant site may lead to infection. Swimming can be undertaken once the implant wound has healed fully.

You will not be able to take part in any form of competitive motor sport, as you will not be eligible for an appropriate licence. Regular driving should be discussed with your cardiologist. Latest regulations for ICD patients can be found on the DVLA website: <http://www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRulesForDrivers/index.htm>. You should also avoid any sport (or indeed any situation) where you might be exposed to strong magnetic or electrical fields or a powerful radio source (radio-controlled planes, cars, boats, etc. may be a problem).

## Contributing Your Story to Defibber News

If you would like to share your experience of living with your ICD and Heart Condition with the Support Group in the Newsletter, please either e-mail me or post to:

Mr George S Davies  
103 Redearth Road  
Darwen  
BB3 2AR

Georgedavies48@sky.com

## Feedback from ICD Patients

After every meeting of our Support Group, questionnaires are filled in by Patients and sent back to the Committee with their comments, suggestions and questions.

Following our most recent meeting in March, a whole number of Patients raised the issue of ICD Specialist Nurses in Clinic an how to contact them on a regular basis.

The Chairman of the Group was asked to write a letter on behalf of the Committee to Dr Neil Davidson, asking him if he would comment on the points raised. Printed below is the Committee's letter to Dr Neil Davidson and his reply.

Dear Dr Davidson

I am writing to you to seek your help with a question that was raised at our last group meeting, where we gave out sheet asking the members for their views on the meeting speakers and things in general. A number of members raised the point that in looking for an answer on, now that Jeanette Hornsey has gone and that it won't be long before Lindsay Waddle will also retire, what, if they needed help or advice, who would they ring.

Thanking you for any help you can give on this matter

Kindest Regards

Bert Thompson Chairman

Dear Mr Thompson,

Many thanks for your letter dated 30 March. We are fortunate to have such a strong ICD support Group and the work you do to lead this is impressive. I welcome your comments and feedback, which we will use to try to provide the best care possible with the resources we have.

With regards to your specific comments on our Specialist Nurses I just want to clarify a few points:

(1) Our Specialist Nurse Team, led by April Hopkins, deal with a large group of patients who have a range of heart rhythm disorders and the scope of their roles has increased significantly over the years.

For example we now have a nurse-led cardioversion service for patients with atrial fibrillation and nurse-led community palpitations clinics. To deliver these services the team are working very hard and we have had excellent feedback from the patients involved.



(2) With the expanded role of the specialist nurses, it is not possible to have the same level of availability for all ICD patients to spend time with them at every clinic visit, but as you know there will always be experienced cardiac physiologists, who are experts in ICD management at the clinics, in addition to the medical staff.

(3) I would ideally like to have more specialist nurses but as you may be aware there are serious financial challenges to the NHS which will increase in coming years so there is no prospect of a significant increase in staff numbers unless we get additional income.

(4) As you know we have discussed these matters in some detail at a previous meeting and as a result of this I believe that some members of your group have undertaken training as volunteers to enable them to provide support for patients in a similar way to the excellent work done by the Ticker Club.

Please let me know if there is anything that I can do to support this important initiative.

(5) I will look into the issue of telephone advice and try to ensure that all patients are made aware of the correct numbers to call. Realistically given the issues outlined above, I am afraid that we are not in a position to have a specialist nurse sitting by a phone all the time.

I hope you find this response addresses your queries.

With kind regards

Dr Neil Davidson



## Heart Patients & Managing Stress

### Gill Monk – Senior Occupational Therapy Lead in Cardiac Rehabilitation

“As part of my role within Cardiac Rehabilitation I deliver education talks – Risk Factors for Heart Disease, Healthy Hearts and Minds, Stress Management and Relaxation. Stress Management runs for four weekly sessions and helps patients to deal with stress more effectively by teaching coping strategies to use and build into their everyday life. I hope that by talking to you at the support group I can help you to look at stress as something that you can change and not just tolerate”.



Next Meeting  
Wednesday  
June 11th  
Education & Research Centre  
Wythenshawe Hospital  
2.00pm Start  
1.00pm for Tea & Biscuits

# Lindsay is retiring

Senior Arrhythmia Sister  
Lindsay Waddell is retiring



Lindsay Waddell

Lindsay has worked over many years with ICD and Biventricular pacemaker patients; many of you will have met Lindsay prior to your ICD implant and again in your clinic visits and at the ICD support group meetings. Her in depth knowledge of cardiac rehabilitation, cardiac conditions and the effects of heart failure has been a great asset to all patients and the cardiology service.

Lindsay always showed great warmth and empathy with all patients and will be greatly missed.

We are certain you would all like to join us in thanking Lindsay for all her hard work and support and wish her a wonderful, fulfilling and healthy retirement.

As our long standing and familiar nurses retire, the cardiac nurse arrhythmia service has now new nurses taking over the role and support for patients and they are:

April Hopkins - lead Arrhythmia Nurse 0161 291 5998

Adrienne Unsworth Arrhythmia Nurse 0161 291 5443

Nicola O'Gorman Arrhythmia Nurse 0161 291 5076

As a Patient's ICD Support Group we look forward to working with the new Nurses in a way, which will help to see the Support grow and flourish.



Meet April, Adrienne and Nicola

At the Meeting in June, some of the new Nurses will be in attendance to briefly introduce themselves and there will be an opportunity for Patients to ask them questions about the service.



# A Car Accident Saved My Life...

It was the 19th January 2012, a very cold evening; it had been sleeting and the temperature had dropped. As a self employed Plumber, I had been called out in the evening to weather related boiler problems. After finishing the last job, I drove the short journey to collect my wife from her friend's house in Stockport. By now it was approximately 10pm. We were on the return journey home in my van when we approached a familiar 40mph road near home. The road has three sharp bends, known locally as 'the Bakery Bends'. I slowed my van in anticipation of the first of the three bends, as I approached the second, I became aware of an oncoming vehicle speeding around the bend towards me, the driver of that vehicle lost control and hit our vehicle with an almighty crash, head on. A couple of seconds later, the vehicle following behind then crashed into the back of our vehicle with an almighty bang. My driver air bag activated and I recall the van filling with smoke, I thought it was on fire but the smoke was from the air bag. My wife was screaming she could not breathe and the situation was extremely frightening. We were both taken to Hospital in an Ambulance, very lucky to escape with injuries, which could have been much worse; my wife had fractured her sternum, sustained a shoulder injury and had bad bruising to her chest and legs. I had broken my right hand and also sustained a bad neck injury not to mention the shock to both of us. My vehicle was a complete write off due to the impact of the two collisions.

In the ensuing weeks, we were both in a lot of pain and discomfort, my wife is retired and I could not work due to my injuries. I was in a lot of pain throughout my body but one particular night I woke up in the early hours with excruciating stomach pains which ended up with me collapsing, my wife frantically dialed '999' and she said afterwards that she thought I had died having gone grey and making a strange gurgling noise. I was rushed to Hospital in an ambulance yet again and underwent tests presuming the pains were chest related from the impact of the airbag during the collision. The Hospital could not find the cause of the pain nor the collapse and I was discharged and asked to go straight to my GP.



My GP was unhappy so sent me for further tests at Hospital, namely an Endoscopy and Colonoscopy. It was during these procedures that it was noted my pulse rate was close to 200 BPM and was causing the professionals some concerns. I was released from Hospital, the procedures being inconclusive and again referred back to my GP.

My GP carried out an ECG in surgery and was in a quandary; he said to me he did not know whether to phone for an Ambulance for me or to get an urgent appointment to see a Cardiologist. He frightened the life out of me when he stated the ECG was abnormal and showed signs of a condition named Brugada Syndrome (better known as Sudden Death Syndrome). He did say Brugada Syndrome is very rare and unlikely but that I needed further investigations.

In the ensuing months, I was examined at Wythenshawe Hospital and after undergoing extensive tests and seeing numerous specialists, I was confirmed with having

confirmed Brugada Syndrome. It was during this time I met the lovely Jeanette who coincidentally shares her name with my wife. Jeanette went to the same Primary school as me and after chatting we found her brother was in my class.

In March 2013 I underwent surgery to have an ICD fitted in my chest, the surgery went well and I recovered with no complications. It was explained to me that Brugada is hereditary and my three grown up children all needed to be tested with a 50/50 chance of inheriting the faulty gene. I was also asked whether there had been any sudden and unexplained deaths in my family - there have been several, in particular on my mother's side of the family. My Mother's Father died suddenly aged 42 years, my Mother herself died suddenly aged 64 years after having heart problems and a subsequent pace maker fitted in the 80's, my Sister died suddenly in 1988 aged 34 years and her daughter passed away suddenly in 2012 aged 38 years, just before I was diagnosed with Brugada. All these deaths now appearing to be more than a coincidence. My Father also died suddenly aged 40 years although we do not think this was related as he had other health issues.

I had previously collapsed in a similar manner 20 years previous - on that occasion following a high fever. I have since been told this is consistent with Brugada Syndrome and one Doctor believed I am lucky to have survived to be 57 years old.

My youngest daughter Amy, aged 29 years, is currently undergoing genetic testing and has been diagnosed with having Long QT Syndrome, the heart condition having been passed on from me. Amy has a history of collapsing also. Of Amy's siblings, Claire, aged 34 years, is still undergoing tests and my son Daniel has fortunately been given the all clear.

I am one of six children, my sister sadly passing away reduced that to five. Two of my siblings have been given the all clear, the other two do not seem to want to know but have no history of collapse. In conclusion, little did I know that the awful car crash, that horrible cold evening would ultimately extend my life and prevent any future sudden deaths in my family. I feel very lucky to have been diagnosed and fitted with my ICD, I was told by the specialists that had I have suddenly died, it would have been very difficult to establish a cause of death as

Brugada relates to an electrical malfunction of the heart which leaves no trace once the heart stops beating - my heart is structurally fine. Based on this information, other members of the family who have passed away are likely to have had the same condition but we will never know for certain. I am grateful that we have the chance to diagnose and treat other family members and prevent other sudden deaths.

I would like to thank Wythenshawe Hospital for all the expert care and treatment I have received, from the bottom of my faulty heart! Coincidentally, I was brought up in Wythenshawe and used to deliver newspapers to the wards in the late 60's so have fond memories of Wythenshawe Hospital and have great confidence in the ongoing care I will receive. I also think the support meetings are very helpful.

My daughter Amy has been undergoing genetic testing and it has been confirmed this week that she has inherited a defective heart gene from me but in Amy it has come out in something called Long QT Syndrome, both Brugada and Long QT are caused by the same gene. It has been confirmed that this gene has been passed down through generations of my family. Amy is currently expecting her first child who also now has a 50/50 chance of inheriting the defective gene. Amy has started on medication and as a result will be having her baby boy earlier than expected being closely monitored and receiving specialist care. I am very much looking forward to meeting my latest grandchild.

Although I am very concerned that this defective gene exists in our family I am also grateful for the knowledge of this as awareness and treatment can ultimately save lives of many others. Kind regards and good health.

PAUL DAVIS