

# North Gloucestershire ICD Information and Support Group

## Newsletter - April 2009

### 1. Notes of the Group Meeting on 19<sup>th</sup> February 2009

As a break from our usual pattern, we held a Group Lunch at the Wheatstone Inn, Barnwood, Gloucester on Thursday 19<sup>th</sup> February 2009. This was successful and attended by 25 members. We met in a separate area of the pub and ordered reasonably priced meals from a 'Special Deal' menu. This was an opportunity to get to know each other better and to exchange our experiences/pass on useful information in a very friendly and relaxed environment. It was a good opportunity for Audra Rumming, recently appointed as the Arrhythmia Nurse for Gloucestershire, to introduce herself. (Note: Audra is based in the Cardiology ward of Gloucestershire Royal Hospital and can be contacted on 08454 22 8420 or via email at [audra.rumming@glos.nhs.uk](mailto:audra.rumming@glos.nhs.uk))

It is obvious that this Group collectively has a significant accumulated experience of the trials and traumas of living with an ICD (or, for our long-suffering carers, the struggle of living with someone who has one!). Whilst many of the stories we shared now seem hilarious in retrospect, for people new to living with an ICD, this seems to be a great source of reassurance. We aim to repeat social meetings like this, possibly with a barbecue in the summer.

On a more serious note, one view expressed by several members concerned guidance on appropriate physical education and exercise for ICD patients – particularly those suffering from quite severe arthritis. It seems different advice is given by different hospital. A widespread complaint concerned lack of 'rehab' following ICD implantation- particularly for those who had their first ICD several years ago. We know this is a complaint expressed by others around the country. (See also Sections 7 & 8 below)

*As an aside, but relevant nonetheless, at the end of last year, I (Colin) was asked if my Rotary Club would jointly fund (with other Rotary Clubs in the area) the production costs of a Cardiac Rehabilitation DVD for people recovering from surgery or treatment following heart attack or open-heart surgery. We all willingly agreed to this, and a sum in excess of £7000 has been raised for the task that will be co-ordinated by Gloucester Royal Hospital in the first part of 2009. A copy of the DVD will be given free of charge to all people upon discharge, so that they can follow the recommended exercise regimes at home. It is generally believed that most people possess a DVD player these days. This is felt by the hospital to be very important for such patients who are unable to attend Rehab Centres due to mobility- or accessibility problems. When I was first confronted with the request I specifically asked if a module of recommended exercises for ICD and Pacemaker recipients could be also included in the DVD, as we all know, this area has been virtually totally neglected across the country, except for a few exceptions. I also offered to get experienced hospital physiotherapists who have specifically addressed the needs of ICD patients to provide recommended programmes. Sadly, I have been informed this cannot be included in the production of the Cardiac Rehab DVD, and I am not sure why. One can only conclude that it is felt the rehabilitation needs of patients following cardiac surgery are much more significant than those who have only ICDs or Pacemakers. Personally, I disagree. If you have any views or experiences, do let us know.*

A view expressed by several was that there are persistent problems of adverse effects of drugs we take in conjunction with the ICDs, particularly in combination. Mood swings, sleep disturbances, frightening dreams, muscle pains, light-headedness are common, but seemingly there are no clear patterns we can identify, except that these have been experienced by some for several years. We will continue our quest to try to get further insights from hospital pharmacists as well as pharmaceutical companies and also by using our national networking, but as far as we can identify at this stage, there is nothing published that is authoritative or useful. This is becoming a major concern of several of us that seems to be beyond the capabilities of the experts to explain. To help us with acquiring more information on this, we would welcome individual members to relay to us (by letter, phone or email) their own experiences – we already have some of these published anonymously on our website.

## 2. Replies to Questionnaires

A Questionnaire was compiled and mailed out before Christmas 2008 (with stamped, addressed envelopes, aimed to improve responses) to 60 ICD Recipients and Carers. Replies were received from 37.

The questions were designed to establish if there is a continuing need for the Group to operate, whether we were meeting the expressed needs of members, and how we might go forward.

- **Only 2 members saw no useful function served by the Group** – one of which who was unable to travel to meetings. Members voted roughly 3 to 1 in favour of continuing meeting at Hatherley Church Centre, as opposed to Gloucester Hospital. A small number found the usual time of meetings (16.00 on a Thursday) an inconvenience.

*(Note: We will investigate at some time soon the option of holding some of our meetings at Gloucester Royal, subject to a room being available, as this might then facilitate the attendance of Dr Petersen, Dr Nuta and other clinical staff).*

- **20 of the recipients used the Group Website, and 17 did not** (most of who did not have Internet access). All who were not on email said they would value receiving by mail copies of items published on the website.

*(Note: We recognise that several of our members do not possess or use computers, and so do not visit the Group website. We do not see this as a problem, as we are happy to continue use the postal service and telephone to convey information to such members. A summary of the information that is currently published on our website is given below – please contact us if any paper copies of any of this are required.)*

- **Outstanding Questions from Members** – generally these were few, as several members possessed several years experience of living with an ICD and had come to terms with this. – some written guidance on recommended physiotherapy; - guidance on which types of machines/appliances that emit electromagnetic radiation should be avoided; latest salient findings from heart research; value in exchanging experiences on stress and anxieties experienced
- **16 recipients regularly attended the Patient days at the JRH and 19 did not.** This included those who no longer were invited as they had switched to Gloucester. There was a general request for summaries of the papers at Oxford to be made available either via the website or by mail
- **6 of the recipients indicated that they would not attend further Group meetings**, for 4 this was due to inconvenience of time, or as the venue was not easily reached by bus
- **More than half of those replying said they would attend social meetings** – such as for meals, or possibly trips.
- **Almost all respondents agreed they would be prepared to make a small contribution** to the running costs incurred by the Group.

*(Note: We are not in favour of charging an annual subscription, as this would automatically require us to open a bank account, produce an annual balance sheet, appoint a treasurer and an auditor. Under the present way we operate, each meeting costs us in the region of £35-£40 pounds – to cover hire of the hall, catering costs and costs for postage, printing and computing. We are of the view that if attendees at the meeting were to contribute of the order of £1.50 per head, we can operate within our budget).*

- **Only one member volunteered to help** with the organisation of the Group.

### 3. The Automated External Defibrillator (AED) Project

#### Introduction and Background

In the UK, like many other countries, Heart Disease is the number one killer. Most of these deaths happen with little or no warning and the most common cause is Sudden Cardiac Arrest (SCA) where the heart rhythm is disturbed. The most common heart disturbance is ventricular fibrillation (VF) and it is dangerous because it cuts off the blood supply to the brain and other vital organs.



Normal Heart Rhythm



Heart in Ventricular Fibrillation

Within the heart, the ventricles are the chambers that pump blood from the heart into the blood vessels. The blood supplies oxygen and other nutrients to organs, cells and other structures. If these are starved of blood, they start to shut down or fail. If the blood flow is not restored quickly, permanent brain damage or death is the result.

SCA can often be treated by applying an electric shock to the chest, a procedure called defibrillation, which generally restores normal heart rhythm. Early defibrillation is the key to surviving SCA.

Most patients in a hospital coronary care unit who experience SCA will survive because defibrillation is performed almost immediately. However, outside of a hospital setting, the situation may be reversed, depending upon how swiftly the Emergency Services arrive on the scene. It is generally accepted that for every one minute the person remains in VF without defibrillation, the chances of a successful resuscitation drop by almost 10%. After 10 minutes, the chances of survival are near zero.

Cardiopulmonary Resuscitation (CPR) does provide temporary artificial breathing and circulation as it can deliver a limited amount of blood and oxygen to the brain until a defibrillator becomes available. **However, defibrillation is the only effective way to resuscitate a victim of SCA.**

#### Chain of Survival and the Role of the Emergency Services

The Chain of Survival is a series of actions that when performed together, gives the SCA victim the greatest chance of survival. The steps are:



- Early Access: Early access means alerting the Emergency Services through a 999 call immediately and stating the victim is unconscious and not breathing.
- Early CPR: Performing CPR is essential to resuscitation from SCA as it buys time before defibrillation is available. The mouth to mouth breathing and chest compressions help oxygenated blood flow to the victim's brain, lungs and other organs. Appropriate Oxygen therapy during CPR is an effective way of increasing the oxygen in the blood flow.
- Early Defibrillation: This is the most significant link in the chain and is the only action that can restore the hearts disturbed rhythm to normal.
- Early Advanced Care: Paramedics from the Emergency Services provide this care which includes basic life support, defibrillation, administration of cardiac drugs and the insertion of endotracheal breathing tubes. This type of care can help the heart maintain a normal rhythm on the way to the hospital where more definitive diagnostic evaluation can occur.

### **Manual Defibrillation**

Manual defibrillation is a complex skill and in a hospital environment requires the operator to interpret ECG heart rhythms and understand the abnormalities that require defibrillation and those that do not.

In the 1970's, defibrillators began to be used outside the hospital environment by carefully trained paramedics. This was a significant step in increasing the chance of survival of SCA victims. However the inherent delay in getting a paramedic to a SCA victim within the first critical minutes still means that many SCA victims die.

### **Automated External Defibrillators (AEDs)**

In the mid 1980's a new generation of computerised defibrillators became available. These AEDs are capable of analysing a victim's heart rhythm and automatically delivering an appropriate defibrillation shock with minimal input from the operator. It also means that the operator of an AED does not necessarily need to understand or interpret ECG rhythms. Modern AEDs are not expensive, are easy and safe to use and will not deliver a shock unless it is appropriate.



Despite these advances, the problem still remains of the need to get a defibrillator to the victim within those first critical few minutes.

### **Public Access Defibrillators**

The recognition that AEDs are extremely easy to use has led to the concept of placing them in public places. The provision of AEDs in airports, railway stations, sports facilities and where large numbers of people congregate is a developing programme and in the UK, many thousands have been deployed. In the ideal situation, members of staff and first aiders would be trained to use the AED and CPR techniques. Whilst training is recommended, operating an AED with its clear spoken commands can be undertaken by untrained members of the public.

### **Interest of our Group**

Many members of the of the N Glos ICD Group have been exposed in one way or another to the trauma of Sudden Cardiac Arrest (SCA). We are all mindful of the shocking statistic that 100,000 people in the UK die every year from SCA. At one of our group meetings we arranged for the Great Western Ambulance Service (GWAS) and St John Ambulance to talk to us about SCA and more importantly, what can be done to improve upon the present 5% survival rate of SCA victims outside of a hospital environment. The Arrhythmia Alliance has also described to us their efforts to help organisations to install AEDs in the community.

The secret of SCA survival is the rapid access and use of an Automated External Defibrillator (AED). However, as the chances of survival drop for every 1 minute before defibrillation is administered - and in many instances the emergency services may not be able to get to the victim in under 8 minutes - for rural areas this time can be considerably longer.

Some of our members decided to raise funds to purchase AED's for placement in locations where the chances of saving a life might be enhanced. We are very grateful for the advice we have received from the GWAS on best placement and a strategy of use that can complement their work. Moreover, we appreciate the help and expertise of the Arrhythmia Alliance, and also the SADS Trust and the British Heart Foundation.

In the mean time, our fundraising efforts have been very successful and we are exceedingly grateful for donations received or pledged from a number of individuals and organisations, which now run into several thousand pounds. These include:

- The Rotary Club of Cheltenham Cleeve Vale
- Gotherington Singers and Polysteel Band
- Cheltenham Pittville Townswomens Guild
- Bredon Bridge Club
- Personal generous contributions from individuals

## Project Details

Finding a suitable placement of an AED is not straightforward and there are a number of deployment models we considered. One model, generally supported by the Emergency Services, is to provide Community First Responders with AEDs that they can use when called out. Another model, particularly suited for remote communities, places AED's in secure, vandal-proof containers outside prominent local buildings such as a village shop, and provides training of community volunteers on how to use them in an emergency. A further model addresses public access defibrillators in areas where large numbers of the public can be found, such as railway stations, airports and theatres.

Guided by Mr Kevin Dickens of the GWAS, we have identified locations in the north of the county where the emergency services might experience difficulty in achieving their target response times. The location chosen for this project is Cleeve School, Bishops Cleeve, a large modern comprehensive school with at any one time around 2,000 people on a large campus in a semi-rural location. It also has an attached sports and activities hall that is used by the school as well as the local community at evenings and weekends, when the School is closed. Sadly, we know that SCA can strike indiscriminately youngsters and adults alike and at any time.

We are pleased to announce that the Governors and staff at Cleeve School fully recognise the risks of SCA and have accepted our offer to use the funds we have raised to equip Cleeve School with AED's and train 12 members of staff on their proper and efficient use.

We are now working with the Rotary Club of Cheltenham Cleeve Vale, GWAS and Cleeve School to complete the project by July this year. Particularly, this project entails the purchase and installation of two AED's, one in the School's First Aid Centre and one in the Sports Hall. Both installations will also include an Oxygen Therapy kit. Initially, 12 members of the School and Sports Centre staff will receive training by St John Ambulance on the use of Cardio-Pulmonary Resuscitation (CPR), how to use an AED, and administration of Oxygen therapy.

We anticipate a commissioning ceremony, attended by a local personality to which representatives of those who have helped with raising the funding will be invited. We hope this event, through suitable media publicity, will raise the profile of SCA in the minds of the general public. Further details and progress of this project can be found on our website

## 4. ICD Support Group Leaders Meeting, Jan 29 2009, Burford

We have maintained contact with several other ICD Support Groups in recent years, and we attended a meeting of the leaders for an opportunity to exchange ideas and seek ways of helping each other with information exchange. This was in the convivial atmosphere of the Angel over lunch (well, it is a tough job, but someone has to do it!) The meeting was also attended by Ben Fry of the Arrhythmia Alliance – Ben is responsible for co-ordinating the efforts of the various affiliated Groups in the AA. His summary of the meeting is given below.

We look forward to greater synergy between these groups, and we would urge any interested parties to visit their various web-sites which can be accessed via the Arrhythmia Alliance website [www.heartrhythmcharity.org.uk](http://www.heartrhythmcharity.org.uk).

The participants in the meeting were: *Colin Prottey and Robin Harvey – North Gloucs.; Sam and Rosie Shunmoogum – Milton Keynes; Bryan Longson – High Wycombe; Geoff Shaw – Oxford; Ben Fry – Arrhythmia Alliance*

- Livewires link on AA website to be investigate
- How does one raise the profile of the work of Arrhythmia Alliance in hospitals; such as: High Wycombe - Perhaps approach each PCT and have a contact for each
  - It is a common problem that local support group details are not always being distributed to all ICD patients by the implantation centres.
  - There is no funding available for support groups. Support groups funded mainly through donations. It is not uncommon for the leader of a support group to be left paying for expenses out of his/her own pocket. Funding is required for: Postage costs, Venue hire, Refreshments, etc. North Gloucs. ICD SG have approached industry (Medtronic & St. Jude) in the past and have been successful in receiving small amounts of funding.
  - It has been recommended that support groups should meet quarterly for optimum attendance.

- The production of a newsletter is a great way of keeping all members up-to-date and informed of current activities.
- How do we recruit younger members to an ICD Support Group? - Through ICD clinic direct (proven to not be 100%) - Posters of ICD Support Group (AA to supply upon request)
- "What happens after death?" People don't like to talk about it but the issue needs to be addressed and leaflets/information needs to be more readily available.
- Are mood-swings are a common problem with having an ICD implanted / Drug treatments. Thus highlighting the importance of 6 monthly checks.
- AA to advise Support Groups of ICD Message Board Procedures.
- Stories from members to be uploaded to a Support Group's website and to AA website.
- Possible introduction of a 'Members' News Page' on the A-A page.
- Sam Shunmoogum to write up and send his personal experience of having an ICD implanted, as also given in Dublin, Ireland.
- Video footage of FAQs, and ICD-relevant footage would be desirable for presenting at future Support Group meetings.

## 5. Recent experiences of one of our members (Dave Bailes)

### WHAM!

That does not adequately describe the feeling when your ICD gives your heart a big jolt, but it certainly wakes you up fast! It was about three in the morning. I had had a strange dream about emergency telephones and detectors. Then, sort of half awake, I knew that I was suffering a "dizzy spell", I can remember thinking, "This is a long one." Thirteen seconds it seems; thirteen seconds of my heart in Ventricular Fibrillation before the ICD decided to do something about it. Then that "WHAM!"

By the time I had registered that I had received the shock it was all over- I was wide awake and there was no residual pain, just the memory. I could not remember the protocol, was I supposed to call 999 for a single shock, or only for two in a short time? I could not find the ICD clinic number so I left a message on the consultant's secretary's answer phone.

I did not feel any anxiety, luckily I never have in the years since the MI, but within an hour I felt lonely (I live alone) and vulnerable. I called NHS Direct and ended up in A&E. Tests showed no lasting problem; by the time the last results came through the clinics were starting.

I called into Cardiac Investigations and the technician asked me to wait in the cardiac outpatients' area. They called me in as soon as they were ready (just after nine) and downloaded the info from the ICD. Dr Nuta joined us as soon as he arrived and they discussed the events. It seems that this was the third event since the beginning of March, I had not even noticed the other two! But this time my heart was buzzing away at 240bpm, hence the dizzy feeling.

Anyway, after another wait Dr Nuta saw me to discuss changes in my medicine and options for the future. I also confirmed that this meant a six month driving ban. Strangely that did not bother me much; I don't use my car much over a three or four times a month, and rarely is it essential then. But pub lunches will be restricted to those on bus routes from now on . . .

There is one positive aspect, though some might not see in quite that way. Whilst I waited to see Dr Nuta the ICD technician wrote a note on the board to say that the ICD clinic was running half an hour late. That was my fault, they gave me the first session ahead of the first person on the list. Dr Nuta also made room in his list during the morning and did not rush things for me.

I am never going to complain about late routine clinic appointments again, perhaps someone who had a greater need than me may have caused that delay. In future that's perfectly OK by me!

And, of course, there is the knowledge that my little electronic friend is doing its job properly; as Dr Nuta said, "But for that you would not be sitting here now."

## 6. Topics covered by the N.Gloucestershire ICD Group website

(visit [www.icd-gloucestershire.org.uk](http://www.icd-gloucestershire.org.uk)) or contact us direct for further details.

- Home page (background to how the Group was formed)
- Members stories (accounts of individual experiences of living with an ICD)
- What is an ICD (a simple explanation)
- A New Lease of Life (how to live with an ICD)
- Drug Therapy (part 1 of a planned series on how the drugs we take alongside an ICD work)
- Physical Therapy (an article by a chartered physiotherapist on how to rehabilitate after ICD implantation)
- Driving (the DVLA guidelines and recommendations)
- Travel Insurance
- Frequently Asked Questions
- What is an AED
- Glossary of terms
- Useful Links (how to seek further advice and information)
- Contact us

## 7. And news of yet something else that ICD recipients should not do!

Vibrational training, first developed in the 1970s utilise a vibrating plate upon which you stand. The vibrations are transferred to the body and cause most of the body's muscles to contract involuntarily between 30 and 45 times per second. As a result the muscles are exercised without utilising much effort and without eliciting sweating. Manufacturers of such devices (which retail at up to £1000) claim that 10 minutes usage is equivalent to 1 hour in the gym, and burn upto about 350 Calories.

These devices, now popular in gyms and Health Clubs, would thus seem ideal for ICD patients who are relatively immobile. Or so we thought! Tricia Parsley has brought the following information, kindly and swiftly provided by Medtronic, to our attention...

*Thank you for your e-mail to Medtronic regarding the possibility of using vibrating body trainers with an implantable cardioverter defibrillator (ICD) which has been passed to me for response. Vibrating body trainers, or power plates, produce mechanical/physical vibrations, from which energy is transferred to the human body. This mechanical stimulus produces a stretch reflex resulting in the muscles constantly contracting vigorously. This phenomenon, called super-compensation, occurs when training on the Power Plate. The vibrating plate is powered by two electric motors which generate a vibrating frequency between 30 and 60 Hz. The vibrating frequency can be selected by the user. The G-forces produced by the plate are selectable between 1.86 and 6.24 G. Although Medtronic have not tested the effect of the Power Plates on ICDs we recommend that they are not used by individuals with implanted cardiac devices. The high G-forces at the high repeating frequencies may lead to mechanical stress of the lead(s) and ICD in the surgical pocket. Therefore, continuation of proper implanted system performance cannot be guaranteed for an ICD patient using the Power Plate.*

*(Kind regards, Lezlie Bridge, directo Manager, UK & Ireland, Medtronic Ltd., Suite One, Building 5 Croxley Business Centre, Watford, Herts WD18 8WW)*

So, at the risk of repletion – when will someone tell people with ICDs and Pacemakers what they **are allowed to do** in order to stay fit!

## 8. The Next Meeting of the ICD Group.

This will be on Thursday 21<sup>st</sup> May at the St Philip & James Church Centre, Cold Pool Lane, Up Hatherley, Cheltenham, GL51 6HX starting at 16.00 and finishing by 18.00. If you go to our website, there is a detailed map showing its location.

We are looking forward to welcoming Audra Ruming, "our" new Arrhythmia Nurse to the meeting when she will talk all about her new role and how we can mutually support each other to help ICD recipients and their carers.

The recent social lunch we enjoyed earlier this year raised a number of issues not at least the need for further help with Physiotherapy and exercise post ICD implantation. It is hoped that we will have a presentation covering both these topics.

Earlier in this letter, we told you about our AED project. We will give you an update on how the project is developing and how it may develop in the future. We will also update the Group on the SW Regional \meeting of the Arrhythmia Alliance, later this month that we will attend.

We urge members to actively participate in the Arrhythmia Awareness Week organised by the Arrhythmia Alliance, June 8<sup>th</sup>-14<sup>th</sup>. This involves a **'Post a Poster - Leave a Leaflet' and 'Know Your Pulse'** initiatives whereby we can contact our GPs and Health Centres, libraries, societies and recreational outlets so as to help raise the profile of Cardiac Arrhythmia and Awareness Week in our localities. The Arrhythmia Alliance will be at our meeting and will tell us all about this, as well as supplying us with material.

We have always believed that exchanging experiences, seeking answers to our problems by asking others, and just socialising are important parts of the meeting and we plan to allow plenty of time for this at the end.

Should there be any subject or problem that you would like us to air at the meeting, do let us know beforehand.

We look forward to seeing you all on the 21<sup>st</sup> May.

*Note: Dave Bailes (see section 5 above) is now 'off the road' for 6 months. Moreover, he will not be able to attend our next meeting, as public transport from Hardwick (where he lives) to Up Hatherley is not an option. If anyone attending our next meeting could possibly give Dave a lift, please let us know.*

**And finally, please let us know whether you will be attending the next meeting or not!**

Colin Prottey & Robin Harvey April 2009

[www.icd-gloucestershire.org.uk](http://www.icd-gloucestershire.org.uk)