

North Gloucestershire ICD Information and Support Group

Newsletter August 2009

1. Notes on Group Meeting on 21st May 2009

The meeting at Hatherley Church Centre was attended by 20 ICD recipients/carers, of which 3 were new to the group. We noted that several expected members failed to show up, and others had given their apologies due to holidays, other commitments and ill-health. We do clearly appreciate that living with an ICD is never trouble-free, and we hope that those in the group who currently feel off-colour will soon bounce back. We all walk that path regularly – you should always feel free to share your anxieties with us if you wish. Ring us or email us.

The feeling after the meeting was that this was probably the best one we have had so far – not only did we have first class speakers, but most importantly we are all feeling confident and comfortable enough to discuss our various issues and problems with other members, and particularly the clinical and professional staff who always make the point of attending. We had vigorous, friendly and light-hearted discussions at the end of the meeting over a cup of tea.

Many thanks, again, are due to Nicola Meldrum for struggling against the traffic from the John Radcliffe Hospital Oxford to join us (Nicola has never missed a meeting); moreover, Audra Rumming from Gloucester Royal Hospital came along and particularly emphasised the strong local capability that we also now have for ICD/Pacing at Cheltenham and Gloucester Hospitals. It seems the membership of this group is roughly split between those receiving downloads and continuing care at Oxford and those who are now receiving this from Gloucester. We think this is fine, as we seem to then get the best of both worlds. One thing that does strike us particularly is the wealth of experience and know-how we have amongst our ranks for ‘things that might happen’ when you have an ICD. We are regularly in touch with many other support groups. This means that when members come to us with questions or problems, we feel we are well-networked enough to get answers, particularly from patients themselves, as well as the precise clinical views. There has been an overwhelming increase in the overall information available and ‘after-sales service’ following ICD implantation that the ICD Implantation Centres and their professional staff are now offering us. How this contrasts with that which was available the early years of this century (or before), when some of us had our first ICDs implanted.

We were also lucky to get Nicky Knowles, Senior Lecturer in Physiotherapy at University of Coventry, to give an updated talk on exercise for the ICD patient. Her talk is summarised below too. However, should anyone require copies of what any of our speakers present, feel free to ask – we will send these my mail to those who do not use email, or electronically to those who do.

Audra Rumming. Since her appointment in January, she has been addressing particularly the *National Science Framework ‘Chapter 8’ Guidelines* for improving the scope for treating patients susceptible to Sudden Cardiac Arrest from the standpoints diagnosis, patient support, and treatment. This has also meant interfacing with pre-existing capabilities for heart failure, psychological treatment, genetic services and bereavement.

Patient information; Audra has supplied the wards with the Arrhythmia Alliance (A-A) booklets to ensure that the most current information is being given to the patients. A particular short-coming is that the A-A does not provide any of their information on audio format for the visually impaired. However she has managed to get one of the booklets (CRT-D) transcribed on to audio CD through the Gloucestershire County Association for the Blind. She will aim for more of this in the future.

Patient Support Group; All patients with ICDs or CRT-Ds are directed towards the North Gloucestershire ICD Support Group - this comes under the quality requirements of Ch 8.

The aim is to achieve: Timely assessment & diagnosis by appropriate clinicians; clearly defined explanation of patients' condition & treatment plans; ongoing, high quality support, information & reviews by a nurse, thus ensuring continuity of care.

Work is in now progress towards Telephone follow up - This will be in the form of a 'virtual' clinic to enable the hospital to monitor CRT patients' progress by assessing their symptoms using a standardised proforma. This service will expand and future plans will include recruitment of another Arrhythmia Nurse; a Nurse-led AF clinic; a Nurse-led Cardioversion list; blackout clinics; rapid access Arrhythmia Clinics

Nicola Meldrum described some of the staff changes that have taken place at the JRH. Dr Tomlinson is now a consultant at Plymouth, Dr Pacey is at Bournemouth and Dr Timperley is at Northampton. The 2 Specialist Registrars are Drs Joe de Bono and Norman Qureshi. Angela Griffiths and Tara Meredith are the arrhythmia nurse specialists. Angela has worked with Dr Bashir for the past 7 or 8 years and was one of the original arrhythmia nurses in the early 1990s. Tara joined the team in 2007 and works closely with Angela. They see patients with arrhythmias who do not require an ICD eg: with atrial fibrillation, assist in ablation procedures and run nurse-led arrhythmia clinics alongside the Consultants. They do not deal with pacemaker or ICD patients unless they also require an additional procedure such as ablation. And of course there are always Nicola and Elaine Watson, the ICD Specialist Nurses who are always on call for us.

Nicola also gave a comprehensive overview of the various additional conditions that are may also be encountered by arrhythmia patients (heart failure; heart block; diabetes; coronary heart disease; atrial fibrillation etc.) and the ways in which such conditions are managed and the drugs that are used. We were reminded that each person's arrhythmia is unique, each with its own repertoire of indications, and each requiring a unique treatment regime.

Nicky Knowles gave a practical presentation on Physical Exercise from the particular standpoint of an ICD patient. She covered:

- Why is exercise important (Reduce osteoporosis; Help with arthritis; Increase energy levels; Improve sleep; Increase sense of well being; Increase self esteem and confidence; Improve fitness, mobility and strength)

- What happens when we exercise (Body prepares for exercise; Muscles demand more oxygen; Start to breath more deeply; Start to breath more rapidly; Heart rate starts to increase; Blood flow is redistributed; Blood pressure starts to increase)

- How Should We Feel When Exercising? (Slightly warm; A little sweaty; Slight breathless; May be aware of heart beating; An awareness of exertion) After exercise, we may feel tired; May feel a little muscular aching)

- Stages of sensible exercise; Warm-Up (15 minutes-Pulse raising,Gentle stretching); Exercise (15-30 minutes, RPE 3-4; Intermittent training); Cool-Down(10 minutes -Gradual decrease in heart rate, RPE less than 3)

- Type of exercise to avoid (Avoid contact sports; Swimming unaccompanied; Lifting over heavy/ static weights; Think safety). And particularly; Don't just stop!; Keep feet on the move; Warm up for longer during cold weather; Decrease intensity during hot weather; In hot weather and take care to extend cool down time.

- Exercise caution (Take medications with you; Take ICD card with you; Don't exercise if you feel unwell; Don't exercise after a meal; Wear the right clothing; Not if its too hot or cold; Be aware of how you feel compared to how you usually feel)

- Be particularly aware of shoulder problems(Immobility; Joint stiffness; Capsule tightness; Muscle weakness; Muscle inflammation; Surgery; Placement of ICD)

2. Recent and future activities

1. Automated External Defibrillator Project. The generous funding of several of our members, plus donations from a local choir and Townswomen's Guild has been augmented by financial support by Cleeve Vale Rotary Club. With the specific help of the Gloucestershire Great Western Ambulance Service (GWAS) we have identified locations within the north of the county where placement of an AED might well save lives from people suffering from sudden cardiac arrest (SCA). This has allowed us to identify a local school, and the project is now near completion. Two AEDs have been purchased and installed in cabinets at Cleeve School, a school in Bishops Cleeve in a semi-rural environment, with about 1800 pupils, a staff of about 200, and a popular sports centre that is open in the evenings with several hundred members. In addition, we have provided two oxygen therapy kits and, importantly, specialist staff training by St Johns Ambulance (in CPR, Oxygen administration and AED usage) – see illustrations below. We have followed the expert advice of the Ambulance Service and the AEDs are now identified on their emergency CAD system - within 2 weeks of installation the equipment was called into use (thankfully the patient did not suffer SCA and recovered).



Cleeve School, Bishops Cleeve, Gloucestershire



Sports Centre, Cleeve School

We have sufficient funds committed for a further placement of an AED in the near future – generously supported by the Rotary Club and also plan to have a Choir Concert next year to raise further funds. The Gotherington Singers has very generously agreed to dedicate a 2010 concert to fund raising for AEDs. Those of us who have successfully overcome the traumas of SCA appreciate the opportunity we have to help other potential victims of SCA in the future.

We would welcome suggestions from members (as well as donations!) regarding future placements of AEDs in the local community.

2. The Next Meeting of the ICD Group. This will be on Thursday 17th September at the Church Centre, Up Hatherley, starting at 16.00 and finishing by 18.30. Our main speaker will be Mr Nick Butler, the Pharmacy Manager at Gloucester Royal Hospital. Nick will continue further from his presentation at an earlier meeting by addressing the drugs commonly employed to control cardiac arrhythmias, particularly how they interact and any adverse reactions.

Subject to operational commitments, we hope to have John Middleton, a GWAS paramedic, to come and talk to us about SCA and the kit they carry with them to help in such emergencies. John is well equipped to do this and has a vested interest as his father has recently had an ICD implanted.

As we now have several new members whom we hope will attend, we also plan to show a couple of recent DVDs we have obtained that deal with ICD placement and usage. These are very watchable (ie non-gory!) accounts of the latest technologies that are available.

We hope that the Specialist ICD Nurses from Oxford and Gloucester will also be able to attend, so that over a cup of tea we can exchange our views and experiences with them, away from the clinical environment.

We also wish to discuss and plan our next social activity – possibly a lunch at a centrally located restaurant some time early in the New Year. So please, try to come along.

3. Financial contributions to running the Group. We were somewhat taken aback by the generosity of attendees at our last meeting by the donation of £57 towards running the Group. This is greatly appreciated, as it goes a long way towards covering our printing/postage, catering, room-hire and web-site costs.

4. Communication is a '2-way Street'. We are always happy to hear from any members, with suggestions, articles of note for the News letter and web-site. Most particularly, please let us know if you intend to come to our next meeting – this really helps us in sorting out the hall and the catering beforehand.

Colin Prottey, Robin Harvey 20 August 2009

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