North Gloucestershire ICD Information and Support Group

Notes on Group Meeting on 11th October 2007

The second meeting of the Group took place at Up Hatherley Church Centre, Cheltenham and was attended by 25 members, two visitors and 3 Health Care Professionals, Mrs Nicky Knowles (Chartered Physiotherapist and Senior Lecturer, University of Coventry); Mrs Nicola Meldrum (ICD Nurse Specialist, John Radcliffe Hospital, Oxford) and Mrs Chrissie Jones (Cardiac Rehabilitation Specialist Nurse, Gloucestershire Hospitals).

Physiotherapy for Cardiac and ICD patients

Nicky Knowles gave a comprehensive and very enjoyable talk on the value of exercise, the specific requirements for people with cardiac health problems and the specific prerequisites of an appropriate exercise regime for people following implantation of an ICD or Pacemaker. Full details of the presentation are given on the Website, and paper copies are available if you contact us below.

Recent Advances in the ICD world

Nicola Meldrum gave an overview of recent staff changes and additions to the Arrhythmia/ICD/Electrophysiology expertise base at the John Radcliffe Hospital.

Also, she covered recent innovations in defibrillator technology, particularly the 'Lifevest', a portable wearable Defibrillator that is suitable for patients who are at risk from sudden cardiac arrest, such as when waiting to have an ICD Implanted, where an ICD has been explanted due to infection, or where ICD indications are not met.

The Arrhythmia Alliance and ICD Support Groups. Nicola spoke of the Arrhythmia Alliance and the key role it plays in helping to set up and augment the role of ICD Support Groups, via affiliation to the Alliance. Details of the forthcoming Arrhythmia Congress were made available.

See the website for details of the above presentations.

Questions and Answers

This was a general session, by which members were encouraged to exchange experiences or seek guidance. Of particular note was the issue of a member requiring urgent abdominal surgery, but who was unable to undergo this as the hospital in question claimed lack of knowledge of how to inactivate temporarily an ICD during the procedure. Nicola Meldrum assured the Group that appropriate hospitals in the catchment area of JRH ICD Implantation capability had been informed and should be routinely aware of the means to temporarily inactivate an ICD. Should anyone have similar problems in the future, it is recommended that the hospital/medical facility concerned requiring further guidance should telephone either Nicola Meldrum directly (01865-221667), or alternatively the Cardiology Ward at the John Radcliffe Hospital (01865-220420).

A key area of concern was the need for advice and/or counselling for some patients when first informed that they would require ICD implantation – for many this came as a shock and was often not fully understood – usually lack of time or resource led to prospective patients spending several anxious weeks before a device was fitted. The group requested that any prospective ICD patients should be put in touch with us. We will work with Oxford and other hospitals (Birmingham, Bristol) that might carry out implantations for people from Gloucestershire. We will raise this with the Arrhythmia Alliance.

Actions

Members gave their unanimous approval to apply for affiliation to the Arrhythmia Alliance.

Telephone Assistance and Advice. It was also agree that a list of telephone numbers of those members who are willing to participate, will be made available to the current membership and prospective new ICD recipients, so that any individuals could phone a member to seek reassurance or advice as and when required.

We re-iterated our request for contributions to the group website from members.

Forthcoming Meetings. A general view expressed was that we should continue to meet at 2-3 monthly intervals. Continuing to use the Church Centre, Up Hatherley, Cheltenham has advantages, particularly the facilities and ample parking. We will seek sponsorship to meet the costs of hiring the premises and refreshment.

Projection and Information display facilities. We will investigate the costs of purchasing a laptop computer and projector and seek ways of raising the money to purchase these.

Future Topics. The following is a cursory list of topics and items that we believe will be of value and relevance to members:

- DVDs showing various aspects of arrhythmia, ICDs and cardiac health (there is a substantial number of salient DVDs that we have access to);
- Presentations by the major ICD manufacturers
- Talks by Dr Petersen, and other members of the professional staff of Gloucestershire Royal Hospital
- Talks by members/officers of other ICD Support groups in the region
- Repeats of selected topics hitherto presented at the JRH ICD Patient Days
- Talk by the Arrhythmia Alliance.

We both attended the recent Patients Day at the Heart Rhythm Congress and gleaned a lot of useful information from other ICD support groups and health care professionals. We plan to present a briefing at the forthcoming meeting. One salient point that arose all the time is the importance of support groups planning time for socialising. We are therefore planning our next meeting to include a buffet to help facilitate this. We have extended the time of our next meeting to give us plenty of time and recognising that some members do have to travel across Gloucestershire. We propose to start at 15.30 and finish by 18.30.

We continue to request you to make to us any comments, criticisms and suggestions for improving the value of this Group to its members.

The next meeting of the Group will be Thursday 24th of January, 2008, at Up Hatherley Church Centre, Cheltenham, when we hope Dr Mark Petersen of Gloucester Royal Hospital will speak to us on the topic of Arrhythmias and local developments in ICD monitoring. In addition we will be inviting an ICD manufacturer to give a presentation on ICD's and future developments. We also hope that Mrs Jenny Tagney, Consultant Nurse in Cardiology, Bristol Royal infirmary will talk to us on the subject of Support for ICD patients.

Robin and Colin

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