

# THE ROLE OF HOSPITAL-BASED PATIENT SUPPORT GROUPS

## HOW DOES A PATIENT BENEFIT?

A support group is formed as a forum and point of contact where patients are able to share feelings and experiences with other patients in the same predicament. They can talk about issues common to each other. Real fears and anxieties can be discussed with other group members who will share their personal ways of coping. The ready availability of information and education can provide knowledge and thus help members to better understand their condition and play a part in controlling their stress levels.

### Key points:

- Patients can meet other patients with similar problems.
- A problem shared may be a problem halved.
- Patients are often able to supply information to each other about ordinary daily needs that healthcare workers cannot, e.g. travel insurance.
- A sense of belonging may reduce stress and anxiety.

## HELPING THE LESS GREGARIOUS AND MORE DISTANT PATIENTS

Not everyone however likes to attend large gatherings or to discuss their problems and feelings with people that they are not familiar with. They may shy away from mixing in groups but this does not mean that they do not need support. Such people require a different type of support and may feel more comfortable sneaking in the odd question at clinic or from time to time telephoning for information or advice. The provision of a telephone helpline with a familiar and friendly voice on the end of it, will go a long way to reassuring and supporting these patients. This form of contact is also helpful for those patients who welcome group activity but live at such a distance from a centre that travel to meetings may be a problem. For these people the ideal would be that a support group be set up in their area but this is not always possible. Arrangements can be made for individuals to make one to one contact in an effort to give advice and support. This type of contact has to be arranged with the mutual agreement of the parties concerned.

### Key points:

- Group meetings don't suit all patients.
- Patient support nurses should have the ability and resources to provide more one-to-one support.
- Long distances currently prevent some patients from getting ready access to support, and telephone and e-mail contact may help.
- Development of local services, in line with the vision of the Fifth Report of the BCS and RCP, should include fully functioning hospital based, nurse-led patient support systems, especially for ICD patients.

## METHODS OF KEEPING IN TOUCH

A newsletter is another way of keeping in contact. By reading about the experiences of others people realise that they are not alone in their problems. Up-to-date information and items of interest can be circulated and events advertised. Advice on sympathetic insurance companies, cheap travel and places to visit is always welcome. Booklets that provide

specialised advice and information regarding specific medical conditions can also be made available.

**Key points:**

- Newsletters should be encouraged, leaders tend to emerge and provide a focal point.
- E-mail is useful “asynchronous” communication.
- A full range of leaflets should be carried for every disease and treatment, and kept up-to-date.
- A support group website and links to national forums are very valuable.

## **HOW TO PROVIDE PATIENT SUPPORT FOR ARRHYTHMIA PATIENTS**

To enable Centres to set up the types of support described it is necessary to have a person in position whose remit it is to provide a complete package of care for all the differing needs of their patient groups. To fulfil this role electrophysiology specialist nurses are being appointed. The patients who they care for can suffer from minor rhythm disturbances to ones that are life threatening. Various degrees of support are required dependent on the nature and the type of intervention required. The role of the specialist nurse is to assess the individual's needs and provide the appropriate support and guidance.

**Key points:**

- Electrophysiology (EP) nurse-specialists provide an invaluable resource for patient support.
- A cardiac-care background is usually needed.
- EP Nurses can “fill-in” the gaps in care left by busy doctors and others.
- EP Nurses can develop the skills to recognise and differentiate serious and minor arrhythmias and provide explanations and reassurance where appropriate.

## **WHO NEEDS THE MOST SUPPORT?**

The patients requiring the greatest level of support are those who have life threatening arrhythmias, which necessitate them having an ICD implanted. Most, but not all, of these patients who have had one of these devices implanted have already gone through the experience of a sudden death situation and the resuscitation that was initiated at the time of the event. A period of hospitalisation and a multitude of diagnostic tests and procedures then follow. Others have had an ICD implanted because they have been shown to be at high-risk of developing a life-threatening arrhythmia in the future. Some of this group have had the devastating experience of losing a loved one as a consequence of the condition that they themselves have. All these patients are aware that the device will not prevent or cure their arrhythmia, but that it is there to control the consequences of such an event. These patients come from various social and ethnic backgrounds and range from young children to the elderly. The implantation of an ICD can affect their lives to different degrees and to minimise these effects it is essential to have an infrastructure of support place which becomes available from the day that the decision is made that an ICD is required.

**Key points:**

- Patient with life-threatening arrhythmias need the most support.
- Such patient will often have an implanted ICD that might discharge at any time, and may also have other conditions, such as heart failure.
- ICD patients need a lot of input to get a good result from their treatment, in terms of an active life with stable psychology.

*Win Bell, ICD Support Nurse, Manchester Royal Infirmary*

- EP nurses can support these patients in many ways, before implantation with detailed explanations of the treatment they will get, after implantation in follow-up clinics, and after a device discharge.
- ***Timely support by EP nurses may enable an ICD patients to remain at home, greatly improving the cost-effectiveness of ICD treatment.***

## HELPING NEW CENTRES PROVIDE HIGH-QUALITY CARE

As the workload grows it is becoming increasingly hard for tertiary centres to cope with the extra work. DGHs are going to be required to develop infrastructures for the care and support of these patients. They will need a team of specialised staff dedicated to this task. The appointment of EP specialist nurses is on the increase but there is a need for many more if we are to provide a quality service for our patients and their families. The provision of the service offered by specialist nurses, as well as providing a high quality of care, reduces the overall cost of the service by ***minimising hospital stays and readmissions***. A relatively small investment in support can save money in the long run.

### Key points:

- EP nurses will need to be trained to support new ICD services in DGHs.
- The best people to undertake this training are existing EP nurses.
- Failure to provide good support in new ICD services will produce less satisfactory results, ***including many unnecessary admissions after ICD discharges***.

At the Manchester Heart Centre we have developed a multi disciplinary team approach to the support and care of our arrhythmia patients. We have four specialist nurses adding up to a total of just over two full-time staff. Their remit covers all the support mechanisms already discussed plus the running of nurse lead pre-admission clinics, participation in consultant lead clinics and a tilt testing service. We are also there as a resource to other centres that are starting to set up new services. The setting up of more local services is to the benefit of our patients as they can be cared for at centres nearer to home and receive the same standard of care as they would in tertiary centres.

### Key Points:

- Effective EP nurses are a vital part of a high quality EP/ICD service.
- EP nurses can support all the activities of the EP team, and arrhythmia management both life threatening and more benign, (this may seem all the same to patients unless they get sympathetic care!).
- Good EP nurses can learn to take on all aspects of arrhythmia care.

## WHAT PROVISION IS NEEDED FOR EFFECTIVE PATIENT-SUPPORT GROUPS?

### Experience suggests:

- An EP nurses specialist is needed to support a new service undertaking ICD implantation and follow-up
- A second nurse will be needed when more than 75 patients are being followed
- Further appointments will be needed on a pro rata basis
- More nurses are needed to establish pre-admission services and to care for patients with CRT devices and heart failure