Guidelines to Establish a Local Support Group

www.heartrhythmcharity.org.uk

Registered Charity No. 1107496 ©2011
Foreword

Arrhythmia Alliance (A-A),
The Heart Rhythm Charity
www.heartrhythmcharity.org.uk is a coalition of charities, patients, carers, patient groups, organisations, medical and allied professionals. These groups remain independent, however, they work together under the A-A umbrella to promote timely and effective diagnosis and treatment of heart rhythm disorders (cardiac arrhythmias).

In 2004, Arrhythmia Alliance was launched, at the start of the first Arrhythmia Awareness Week, after leading a significant and vital change in government policy. The charity was fundamental in pushing through one of the most essential policy issues to affect cardiology and cardiac patients, resulting in the inclusion of a new Chapter on Arrhythmias and Sudden Cardiac Death in the National Service Framework (NSF).

The work of A-A is guided by a multi-disciplinary international medical advisory committee and the organisation’s resources are fully endorsed by the Department of Health.

Each year we receive a growing number of enquiries from healthcare professionals and patients, requesting our guidance on how to establish and run successful patient support groups. These individuals seek access to reliable and consistent information, as well as support for bringing together patients and healthcare professionals, to benefit local arrhythmia services. Currently, no other organisation offers a parallel service, specifically designed for arrhythmia patients.

On-going and continuous support by A-A will guarantee an improved quality of services through the affiliated patient groups helping to empower patients and healthcare professionals to better understand and manage arrhythmia care. In turn, providing accurate and appropriate information and support, will reduce the demand and cost-impact on NHS arrhythmia services.

Promoting better understanding, diagnosis, treatment and quality of life for individuals with cardiac arrhythmias
Introduction

There are two million people affected by heart rhythm disorders in the UK alone. A fundamental role of the A-A is to inform, support and guide arrhythmia patients through their care pathway; from diagnosis, to treatment and on-going management. In order to achieve this, the charity has established a Patient Support Group project.

This project works to:

- Create and support the development of patient information groups, affiliated to the A-A
- Guide patients towards a support network that will enable them to access information and advice through a patient group
- Promote a balanced partnership between patients and healthcare professionals, to ensure consistent, accurate and standardised information
- Provide educational materials and on-going recources and advice

This booklet has been produced to assist with the development of these groups and to raise awareness of the services that exist to support patients and healthcare professionals, across the arrhythmia pathway.

Benefits of a Support Group

Support groups provide invaluable service to arrhythmia patients. Meetings represent a forum for patients, their carers, friends and families to gain information, emotional support, share common experiences and learn more about their condition.

A patient support group offers a medium for honest discussion about personal experiences and feelings and a place to share common concerns with people who are going through similar experiences.

Probably the biggest advantage of a support group is in helping a patient realise that he or she is not alone, that there are other people who have the same problems. This is often a revelation and a huge relief to the patient or carer.

They can help to reduce feelings of aloneness which are commonly linked with heart rhythm disorders.

Who should run the Group?

The most successful groups are run in partnership between patient/carers and healthcare professionals. This ensures that correct medical information, support and advice are given at meetings. Medical professionals are also often able to assist with securing meeting venues, signposting of patients to the group, advertisement of group meetings and events and supplying speakers. It is important to have a patient/carer also leading the group because they have invaluable personal experience which members will relate to.
Background

Implantable Cardiac Defibrillators (I.C.D.’s) are implanted in patients who have presented with life-threatening arrhythmias and who may have had a cardiac arrest.

They are also implanted in patients who have a high risk factor for sudden cardiac death such as Cardiomyopathy and other hereditary conditions. These complex devices are able to deliver shock and pacing therapy in the event of a recurring life-threatening arrhythmia and may also support the heart rhythm with other modes of therapy.

The nature of the therapy that they deliver, together with the condition for which they are implanted has significant psychological impact for both patient and immediate family as well as the potential for being traumatic if an arrhythmia does arise. Patient support in this group is essential and for this reason a patient/professional group was set up to address their needs.

The Backup group

A meeting was set up and all ICD patients were invited to attend. At this time there were about 150 patients. A brain-storming session was held and all patients were asked to set the priorities that they felt were important in setting up a support group. A steering group was put in place with a mixture of professional and patient representation and volunteers for a newsletter editor were sought. A program of meeting dates was set and some provisional dates for newsletter publication. It was agreed that 2-3 meetings a year would be held one of which would be a full day meeting.

A partners group was also established with a help-line and contact numbers.

Funding was sought from manufacturers of ICD’s and by voluntary contributions from the patients themselves.

Aims of Backup

Some Aims and objectives were set for the group which have been modified with time and experience. These are as follows:

- To provide a forum for all ICD patients and their partners and families to discuss their concerns and problems.
- To help patients with ICD’s to regain their confidence and morale when experiencing problems or during times of trouble.
- To provide literature and information on all topics that are relevant to ICD patients.
- To provide information about driving, insurance, holidays, interference and any other areas where ICD patients may experience problems in day-to-day life.
- To provide emergency and technical information to other healthcare workers such as A & E departments, ITU’s and ambulance crews in order to promote better understanding of patients with ICD’s implanted.
- To provide a partner support group
A key issue was how to measure the outcomes and whether we were achieving the objectives set. It was agreed that patient surveys would be conducted and at each subsequent meeting feed-back was invited for criticism or approval and suggestions for further development.

**Discussion**

The group now provides support for approximately 600 patients. A newsletter is published twice a year and all of the objectives set at the beginning have been met. A full set of patient literature is available and all patients who have an ICD implanted are given full information and any necessary counselling prior to and following implant.

A patient network is available and all new patients are offered the opportunity to discuss their fears or anxieties with other patients in similar circumstances.

A set of A & E and emergency guidelines has been implemented as the number of ICD patients increases so that healthcare workers in primary and secondary care are able to cope with patients experiencing problems. One of our support members is a full-time counsellor and sessions have been organised for both patients and professionals to provide some basic listening skills experience.

A recent patient survey from the ICD clinic showed a high level of satisfaction from all patients attending.

**Conclusion**

This group has now been established for 13 years but has continued to grow and develop. The National Service Framework for Cardiac Arrhythmias published in 2005 stressed the importance of patient support being available for all patients with cardiac arrhythmias but most particularly for ICD patients.

More and more centres are starting patient groups but with the appointment of more arrhythmia care co-ordinators as a result of the NSF it is planned that this will become a national issue with national patient representation. Backup has played an important part in helping to develop other groups and will continue to do so.
THE JOYS AND TOILS OF SETTING UP A PATIENT SUPPORT GROUP

As a cardiology ward sister, from 2003, who very much enjoyed working ‘on the front line’ so to speak, it soon became very clear to me that there was a huge gap in the advancing service we provide in Sheffield for patients with heart rhythm disturbance.

Whilst medical and surgical therapies and procedures are very much backed and supported by research and finance, in my opinion, no one seemed particularly concerned that these patients suffer a great deal from anxiety and depression with no resource for help other than the ward staff who are often too busy to do basic tasks such as talking to patients.

In Sheffield, we have psychologists assigned to some speciality areas but cardiology is not one of them, therefore it has until recently been left purely to GP’s to refer patients requiring support to psychotherapists based in the community. The problem here is that the waiting times can often run into 12 months or longer.

A Patient support group offers a medium for honest sharing of personal experiences and feelings and a place to share common concerns with people who are going through similar experiences.

It is evident from several studies looking at psychological impact of issues such as acute diagnosis of heart disease, new onset heart rhythm disturbance, inherited heart conditions and the need for implantation of heart devices that the earlier support is provided, the less chance of them developing depression and other disturbances such as panic attacks and inability to sleep. Along with this, we must never forget that the whole concept of cardiac illness does not only provide trauma for the patient, but for the family as well.

Just over two years ago, I became an Arrhythmia Nurse Specialist based at Sheffield Teaching Hospitals Trust. This role has provided me with the opportunity to address my concerns and a large proportion of my time is spent talking to, listening to and educating patients and their families in how best to deal with changes in medical and psychological changes.

Whilst I consider myself lucky to have the ability to empathise, I never underestimate the fact that the only people who fully understand what a situation can possibly be like, is another person who has experienced the same or similar circumstances.

From this, I recognised the need to link patients up with each other. The aim being to share experience, make friends who have a common interest, allow families to gain support and most importantly to allow patients to realise that there are many other people who are suffering as much as they are.

“I recognised the need to link patients up with each other.”
I have developed and now successfully run support groups in Sheffield for patients with Internal Cardioverter Defibrillator’s, and patients with Atrial Fibrillation. These were the two main areas that I felt needed the most support. Both groups started off with a small amount of attendance but have very quickly increased in numbers.

We usually begin the meetings with a formal topical presentation then have an open forum for questions with the opportunity for patients to then speak with various members of staff from all areas within cardiology on a one to one basis if they so wish.

The ICD groups are held twice yearly, and the AF groups are held quarterly.

I have received some very positive feedback from patients who feel that the support group provides them with a voice and a comfortable opportunity to open up their feelings. Many have said that knowing that other people have the same anxieties and fears about their illness is very reassuring.

My personal view is that if only one person, leaves the meeting feeling better than when they walked in, then my motivation and desire to carry on in my plight to ensure that psychological support can and should be available for our patients will have been worth it.

Jean Maloney, Arrhythmia Nurse Specialist, Northern General Hospital, Sheffield

“Patients feel that the support group provides them with a voice and a comfortable opportunity to open up their feelings.”
How do we find a Medical Professional Leader?

A-A have 1000’s of contacts in all areas of the UK. Initially, we contact the Arrhythmia Teams in the hospitals close to you and recruit a medical professional who is keen to support this initiative. We then facilitate the formation of the group, linking patient/carer to medical professional.

How do we Recruit members?

A-A can help by advertising your local meeting on their website, in the monthly e-bulletins and target local GP practices and Health Centres. Your medical professional leader will also be able to highlight the meetings to all their patients, both new and existing.

What should the aims of the group be?

This should be determined at the launch meeting and members should be invited to have a say about what they would like from the group and what the group meetings should offer. This will determine the aims and objectives of the group and as a result, the leadership style of the group.

It is important to remember that patient groups are there to complement the work of other available services.

What should we do at meetings?

The answer to this will lie in the desires and aspirations of the group. It is helpful to have a mixture of meetings, some educational and some social to ensure that the group appeals to the widest number of patients/carers.

How Frequent Should the Meetings Be?

Again, this decision will be made by the needs of the group members and will be dependent on the structure of the group. Some groups have a more formal structure and meet at regulated intervals whereas some more informal groups meet on a more frequent, social basis.

How Can The Heart Rhythm Charity Support Your Patient Group

- Accredited information booklets, fully endorsed by the Department of Health
- Involvement in the charity’s active projects and campaigns
- Helpline support and advice
- Free hosting and design of group website
- Advertisement of group events & meetings on A-A website and monthly e-bulletins
- Free patient & carer membership
- Signposting of patients to groups
- Funding advice
- Group management guidance & support
- Discounts on events/meetings the Charity are involved in; e.g. the annual Patients’ Day at the Heart Rhythm Congress
- Help in setting up new groups so that they may be affiliated to the nationally required standards
- Links and contacts with other groups in the UK to promote networking.
- Support at group meetings whenever possible
Name of group:

Group contact name:

Address:

Post Code:

Telephone: Email:

(Please note that contact details will be held in accordance with the Data Protection Act).

NB Please ensure at least ONE of the following is included with this completed form:

- Copy of Group Aims & Objectives (please also list below)
- Copy of Group Mission Statement *
- Copy of Group Constitution / Governing document / Trust Deed *

* if in place

Declaration of affiliation

The ......................................................................................................................................................................................... group wishes to become affiliated to Arrhythmia Alliance and agrees to comply with the requirements as outlined in this document.

Signed: ............................................................................................................................ Date: ....................................................

Print name: ........................................................................................................ Date: ....................................................
The following list of Arrhythmia Alliance patient booklets are available to download from our website or to order please call +44 (0) 1789 450 787.

- Arrhythmia Checklist - Could your heart rhythm problem be dangerous?
- Atrial Fibrillation (AF)
- AF Checklist
- Blackouts Checklist
- Bradycardia (Slow Heart Rhythm)
- CRT/ICD
- CRT Patient Information
- Catheter Ablation
- Drug Treatment for Heart Rhythm Disorders (Arrhythmias)
- Electrophysiology Studies
- Exercising with an ICD
- FAQs
- Genetic Testing for Inherited Heart Disorders
- Highlighting the Work of Arrhythmia Alliance
- ICD
- Implantable Device Recall
- Implantable Loop Recorder
- Long QT Syndrome
- National Service Framework Chapter 8
- CRT/Pacemaker
- Pacemaker
- Palpitation Checklist
- Remote Monitoring for ICDs
- Sudden Cardiac Arrest
- Supraventricular Tachycardia (SVT)
- Tachycardia (Fast Heart Rhythm)
Please help us to improve services for all those affected by arrhythmias and to save lives by making a donation today. Please complete the donation form below and return to P.O Box 3697, Stratford upon Avon, CV37 8YL or visit www.heartrhythmcharity.org.uk and click the donate icon.

Membership is free to individuals, however, if you would like to make a DONATION please complete and return.

I would like to make a donation to A-A and enclose: £

I have made a donation to A-A via PAYPAL at www.arrhythmiaalliance.org.uk to the sum of: £

I have arranged a standing order from my Bank/Building Society Account to A-A, (min amount £10p.a.) £

Please tick here if you agree to Gift Aid your subscription/donation

Gift Aid

Name of taxpayer: ................................................................................................................................................

Address: ........................................................................................................................................................................

................................................................................................................ Postcode: ..............................................

Gift Aid

Please allow Arrhythmia Alliance to claim an extra 28p for every £1 you donate at no cost to you. I want Arrhythmia Alliance to treat all donations I have made since 6 April 2000, and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. I currently pay an amount of income tax and/or capital gains tax at least equal to the tax that Arrhythmia Alliance recovers on my donations in the tax year. I may cancel this declaration at any time by notifying A-A. I will notify A-A if I change my address. Please note full details of Gift Aid tax relief are available from your local tax office in leaflet IR 65. If you pay tax at a higher rate you can claim further tax relief in your Self-Assessment tax return.

Standing Order Authority

My Bank:

Bank Address: Please Pay: A-A, Account: 02685818 Sort Code: 30-98-26, Lloyds TSB Plc, 22 Bridge St, Stratford upon Avon, CV37 6AG

The Sum of £/€/$: On (1st Date): / / 20......

And after this, every: Month / Year (delete) Account No.: Signature:

Date: Please hand this form in to your Bank

Credit Card Payment

Card Type: Expiry Date:

Card Number: Amount of £/€/$:

Name on Card: Address:
Executive Committee

President
Prof A John Camm

Mr Pierre Chauvineau  Dr Mathew Fay  Dr Gerry Kaye  Dr Francis Murgatroyd
Dr Derek Connelly  Dr Adam Fitzpatrick  Dr Nick Linker  Dr Kim Rajappan
Dr Campbell Cowan  Professor Michael Gammage  Trudie Lobban MBE  Professor Richard Schilling
Dr Wyn Davies  Mrs Angela Griffiths  Ms Nicola Meldrum  Dr Graham Stuart
Dr Sabine Ernst  Dr Guy Haywood  Prof John Morgan  Mrs Jenny Tagney
Mr Nigel Farrell  Mrs Sue Jones  Mrs Jayne Mudd  Mr Paul Turner

Trustees
Mr Mark Bullock  Dr Derek Connelly  Mr Nigel Farrell  Dr Adam Fitzpatrick  Mrs Trudie Lobban MBE

Patrons
W B Beaumont, OBE  Rt. Hon Tony Blair  Prof Silvia G Priori  Prof Hein J J Wellens

Arrhythmia Alliance
PO Box 3697  Stratford upon Avon
Warwickshire  CV37 8YL
Tel: +44 (0) 1789 450 787
e-mail: info@heartrhythmcharity.org.uk
www.heartrhythmcharity.org.uk

Supported by an unrestricted educational grant by ERT
www.ert.com

Published November 2011