

Guidelines to establish a local support group



Working together to improve the diagnosis, treatment
and quality of life for all those affected by arrhythmias

Foreword

Arrhythmia Alliance, www.hearhythmalliance.org is a coalition of charities, patients, caregivers, patient groups, organizations, medical and allied health professionals. These groups remain independent, however, they work together under the Arrhythmia Alliance umbrella.

Arrhythmia Alliance was launched in 2004, at the start of the first Arrhythmia Awareness Week, after leading a campaign which resulted in a significant 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 Arrhythmia Alliance is guided by a multi-disciplinary international medical advisory committee and the organization's resources are fully endorsed by the Department of Health.

Each year we receive a growing number of inquires 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 organization offers a parallel service specifically designed for arrhythmia patients.

Ongoing and continuous support by Arrhythmia Alliance 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 arrhythmia services.

Introduction

More than four million people have a heart rhythm disorder in the US. A fundamental role of the Arrhythmia Alliance is to inform, support and guide arrhythmia patients through their care pathway; from diagnosis, to treatment and ongoing 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 with Arrhythmia Alliance
- 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 standardized information
- Provide educational materials and ongoing resources 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 an invaluable service to arrhythmia patients. Meetings represent a forum for patients, their caregivers, 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 helping a patient realize 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 caregiver.

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

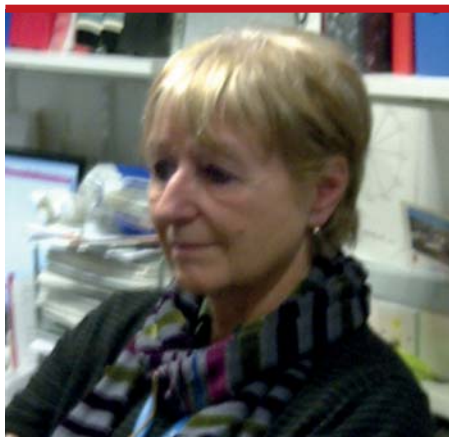
Who should run the group?

The most successful groups are run in partnership between patient/caregivers 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/caregivers also leading the group because they have invaluable personal experience which members will relate to.



Case study one

BackUp - St Georges ICD Support Group Sue Jones, Pacing and ICD Services Manager



Sue Jones,
Pacing and ICD
Support Services Manager,
St Georges Hospital, London

Background

Implantable Cardiac Defibrillators (ICDs) are implanted in patients who have been 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 can 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 can have a significant psychological impact for both the 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 patient/professional groups are needed to address their needs.

St. George's Hospital ICD support group – Backup

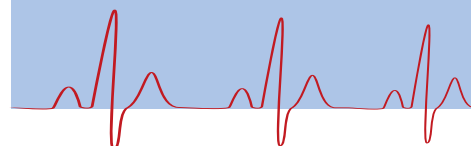
In 1997 we realized that as our ICD patient numbers were growing and that the need for more patient support was absolutely vital. We invited as many patients who were interested to attend a patient focus group. We asked those who attended to set the priorities that, they felt, were important in setting up a support group. A steering group was put in place with a mixture of professional and patient representation and volunteers, were sought, for an editor of a newsletter. A program of meeting dates was set and some provisional dates for newsletter publication. It was agreed that two to three meetings a year would be held; one of which would be a full day meeting

A partners group was also established with a helpline and contact numbers. Funding was sought from manufacturers of ICDs 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 ICD patients and their partners and families to discuss their concerns and problems.
- To help patients with ICDs 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 ER departments, Intensive Care Units (ICU) and EMS crews in order to promote better understanding of patients with ICDs implanted.
- To provide a partner support group.



A key issue was how to measure the outcomes and whether we were achieving the objectives defined. It was agreed that patient surveys would be conducted and at each subsequent meeting feedback was invited for criticism or approval and suggestions for further development.

Discussion

The group now provides support for approximately 1000 patients. A newsletter is published when we can, and all 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 counseling prior to and following implant.

An annual all day meeting is held with key speakers and break-out groups for different types of patients to address the changing indications for implantation and follow-up of ICD patients. This covers inherited conditions, heart failure and a session for partners.

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 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 counselor and sessions have been organized for both patients and professionals to provide some basic listening/counseling 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 nearly 20 years but has continued to grow and develop. The scientific literature and guidelines still stress that patient support should be available for all patients with cardiac arrhythmias but most particularly for ICD patients.

More and more centers now have patient groups and all major implant centers have either an arrhythmia nurse specialist or specialized physiologists who provide support and counseling. Backup as the first support group in the UK has had an important part in helping to develop other groups and will continue to do so.

Case Study 2 **Sheffield ICD and AF Support Groups** **Jean Maloney, Arrhythmia Nurse Specialist**

The joys and labor of setting up a patient support group

As a cardiac nurse, 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.

While 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 nursing 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 primary care physicians 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.

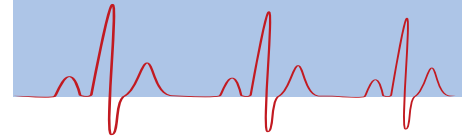
It is evident from several studies looking at the psychological impact of issues such as acute diagnosis of heart disease, new onset heart rhythm disturbance, inherited heart conditions and the need for implantation of heart devices that the earlier support is provided, the less chance of them developing 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 their 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, listening and educating patients and their families on how best to deal with changes in medical and psychological changes.

While I consider myself lucky to have the ability to empathize, 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 recognized 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 realize that there are many other people who are suffering as much as they are.

"I recognized the need to link patients up with each other."



I have developed and now successfully run support groups in Sheffield for patients with ICDs, and patients with atrial fibrillation (AF). 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.

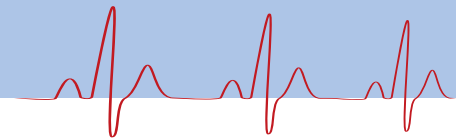
The ICD groups are held twice yearly, and the AF groups are held quarterly.

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."



Case Study 3 Bournemouth Area Defibrillator (BAD) Group Gaynor Richards, Arrhythmia Nurse Specialist

Bournemouth Area Defibrillator or the BAD group was established in 2006 following the development of an ICD service at the Royal Bournemouth Hospital. Myself and my colleague identified early on in our Arrhythmia Nurse career that people with ICDs required a unique level of support.

The main aim of the BAD group is to provide support, information and friendship to people and their partners who have an ICD. The provision of support is an integral part of the Arrhythmia Nurse role and the BAD group is an extension of the level of support we can offer to patients. The BAD group offers a forum to share personal experience with others who may have been through similar experiences.

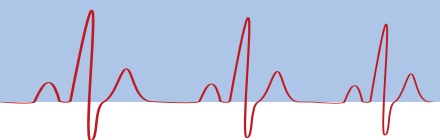
The BAD group was born following an initial meeting involving ICD patients, their partners and specialist nurses. Ideas were exchanged and decisions were made about the name of the group and its main objectives. Ground rules for meetings were also established and a group of volunteers stepped forward to act as the committee. The committee developed a constitution for the group, a specific logo and opened a bank account following the appointment of a treasurer. Although we have been fortunate to have retained some of our original committee members, there have been times when committee recruitment has been difficult. Fortunately, this has never been to the detriment of the group and we have continued to meet three times a year, hold social events and issue regular newsletters since 2006!

One of our biggest challenges is the engagement of younger people with ICDs. We hope to become a step closer to this by joining forces with other local support groups. We are fortunate that the committee and the group enthusiastically embrace new ideas and still, even after ten years, we are always finding new ways to promote the group and engage new members. This year we are planning a ten year anniversary celebration to thank all our members for their continued contributions and support over the last decade.

The BAD group does not receive any funds from the National Health Service in England. It relies on contributions from people attending our meetings, voluntary donations and money raised from social events and activities. Money raised is primarily used to pay for the hire of venues and postage of newsletters. However, we also use our funds to support projects and resources that will benefit people with ICDs and raise awareness of sudden cardiac arrest. Recently, the group has used some of its funds to purchase an AED for a local golf club. We feel privileged to be able to make this donation and support the Arrhythmia Alliance's campaign to increase the availability of public access defibrillators in local communities. In the future, we hope to extend the level of support the group offers and continue to make lifesaving investments to our local community.



"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."



Frequently asked questions

How do we find a Medical Professional Leader?

Arrhythmia Alliance has 1000's of contacts in all areas of the US. 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 patients/caregivers to medical professionals.

How do we recruit members?

Arrhythmia Alliance can help by advertising your local meeting on their website, in the monthly e-bulletins and target local primary care physician practices and Health Centers. 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/caregivers.

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.



AFFILIATION APPLICATION FORM

Please complete and return this form to Trudie Lobban via trudie@hearhythmalliance.org
Alternatively, post a copy to: Arrhythmia Alliance, PO Box 5507 Hilton Head Island, SC 29938

Name of individual/organization:

Contact name (if representing a group/organization):

Address:

Zip 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 *

Declaration of affiliation

*if applicable

The

wish to become affiliated with Arrhythmia Alliance and agree to comply with the requirements as outlined in this document.

Signed:

Print name:Date:

Affiliation agreement for working with patient representatives/groups, voluntary/charitable organizations and industry allies

Arrhythmia Alliance works collaboratively with affiliates that support our global mission to promote better understanding, diagnosis, treatment and quality of life for individuals with heart rhythm disorders.

There are many benefits to entering a formal affiliation with Arrhythmia Alliance, and although you must comply with a few guidelines, independence is retained.

Some benefits and opportunities of affiliation:

- | | |
|---|--|
| a. Develop the knowledge and skills of healthcare professionals concerned with heart rhythm disorders | e. Improve quality of life for those affected by arrhythmias |
| b. Assess and address the unmet need among patients | f. Share and exchange ideas, resources and successful practices to ensure maximum impact for initiatives |
| c. Promote centers of excellence for diagnosis, treatment and management | g. Build networks to ensure that the patient is at the center of health reform |
| d. Provide support to patients and caregivers and medical professionals | |

Arrhythmia Alliance offers affiliates the following opportunities:

- | | |
|---|--|
| ✓ Opportunity to join forces on relevant projects and campaigns | ✓ Monthly e-News and bi-annual newsletters |
| ✓ Support in advocacy and engagement | ✓ Opportunity to highlight events, conferences and meetings on the Arrhythmia Alliance website and e-bulletins |
| ✓ Help in identifying speakers and help to fund their travel if required | ✓ Links and contacts with other organizations |
| ✓ Supply of awareness materials for Medical Professional Leaders | ✓ Arrhythmia Alliance representation at events/meetings, where possible |
| ✓ Reciprocal advertising e.g. through websites and at meetings | ✓ Funding advice (but not provision) |
| ✓ Materials (publications, presentations etc) for translation, adaption and use to raise awareness and promote improved education | ✓ Participation in the annual Heart Rhythm Week (HRW) |
| ✓ An introduction pack for each new member | ✓ A reduced fee to Patients Day for members of the support group |

Requirements for affiliation - affiliates must:

- Have a medical lead to provide reliable and accurate information to patients
- Fully comply with the aims and objectives of Arrhythmia Alliance, to:
 - ➔ Raise awareness of cardiac arrhythmias
 - ➔ Improve diagnosis of cardiac arrhythmias
 - ➔ Improve treatment of cardiac arrhythmias
 - ➔ Improve quality of life for people with cardiac arrhythmias
- Provide an outline of your aims and objectives/governing document or intentions for working with Arrhythmia Alliance
- Request permission and approval from Arrhythmia Alliance, on any occasion, to edit, copy, distribute, translate, adapt or reproduce any intellectual property or branding owned by the organization, including charity and campaign logos, websites and publication content
- Ensure that communications on joint initiatives include Arrhythmia Alliance's mission and involvement
- Encourage members to fundraise to place an AED in their community
- Fundraise \$350 dollars a year for the charity
- Volunteers to help host charity events
- Help to promote the charity
- Share patient stories for us to promote the support group and help to recruit more members

Important information

**Affiliates may publish the phrase;
Affiliated to Arrhythmia Alliance
or, alternatively request an affiliate stamp once the declaration has been signed.**

Arrhythmia Alliance reserves the right to disaffiliate an individual or group at any time if it fails to satisfy the affiliation requirements or acts in such a way so as to bring the name and reputation of Arrhythmia Alliance into discredit.

Arrhythmia Alliance is unable to provide funding for affiliates
but will provide funding application guidance where appropriate.

Arrhythmia Alliance is not legally responsible for the actions, activities or insurance policies of its affiliates.

Medical Lead Please provide the name and contact details of medical lead:

Name:

Job Description:

Contact Number:

Email Address:



Arrhythmia Alliance US
PO Box 5507
Hilton Head Island, SC 29938
(843)415-1886
@ info-us@hearhythmalliance.org

Working together to improve the diagnosis, treatment and quality of life for all those affected by arrhythmias

Dear Sir/Madam

Would you consider becoming a Friend of Arrhythmia Alliance?

Arrhythmia Alliance is a non-profit 501(c)(3) charity that relies solely on donations, fundraising and successful requests to Trusts and Grants in order to continue its work. Becoming a Friend could play a critical part in our ongoing support by helping to fund the life-changing work carried out by Arrhythmia Alliance.

For as little as \$20.00 dollars per year or a monthly donation of \$3.00 dollars, we can continue to provide the services which are most needed by you. We have a dedicated helpline, patient friendly booklets, an annual conference, and a growing network of local support groups. We also bi-annually, publish the Arrhythmia Alliance newsletter, which will keep you up to date with medical articles, news, "top tips", shared comments and experiences.

Our patient friendly website, www.hearhythmalliance.org is very much part of our work and is updated daily with current news on conditions, local and national events, plus support from other Friends living with a similar condition.

Please consider helping us to continue to help you and many others by becoming a Friend of Arrhythmia Alliance.

Yours faithfully


Trudie Lobban MBE
Founder & Trustee





www.heartrhythmalliance.org

Working together to
improve the diagnosis,
treatment and quality
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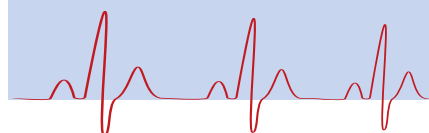
© Arrhythmia Alliance Published
November 2011,
Reviewed April 2018

Please remember that this publication provides general information only. Individuals should always discuss their own condition with a healthcare professional.

Acknowledgements: Arrhythmia Alliance would like to thank all those who helped in the development of this publication. In particular, thanks are given to Dr Adam Fitzpatrick, and Jean Maloney.

Founder & CEO:

Mrs. Trudie Lobban MBE FRCP Edin



If you would like further information or to provide feedback please contact Arrhythmia Alliance.