

## **Establishing a Group**

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

**There is no 'correct' way to set up a patient group – each is very different in format and function and dependent upon the needs of its members. The following is some advice and recommendations as to how to establish and lead a successful group.**

### **KEY QUESTIONS:**

- **Is there a need?**

Are there many patients in need of information and support?

Is there already a similar group running in your area?

Are there any other groups? – always check with your nurse/physiologist

When establishing a group, the first step is to check whether there is a group already set up in the local area. If there is, do some research and discover what was successful and what did not work for them, and whether it is necessary to establish another group.

- **Who should run the group?**

The most successful groups are run in partnership between patient/carer(s) and healthcare professional(s). 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.

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- **How do we recruit volunteers ?**

It is sometimes difficult to find individuals who are willing to take on a leadership role. For information on the recruitment of volunteers, please contact the Arrhythmia Alliance on +44 (0)1789 451823

- **Where should group meetings be held?**

Often, groups that are led in partnership by a medical professional are able to secure a room within the hospital. If not, it might be necessary to charge a small amount to members to cover costs, or to run an annual fundraiser to cover the cost of hiring a room. Arrhythmia Alliance is unable to assist with funding, but is able to provide fundraising advice to those who wish to apply for funding grants or hold fundraising events.

Meetings should never be held in an individual's home.

- **How can we ensure membership?**

Advertisement and word of mouth is key to engaging members. Medical professionals can help you to determine how much interest and need there is for the group and can also signpost patients to the meetings. They can also help to spread the word amongst other healthcare professionals, who, in turn can signpost patients.

It is important that membership is also open to carers, friends and families. It is not only the patient that needs to have support and share experiences with others.

Holding an initial planning meeting for anyone interested is often a good way to determine how members will be engaged. Those initially interested will be motivated to help to encourage new members and it might be possible to determine which activities will attract individuals. Your healthcare professional, local arrhythmia nurse may agree in 'advertising' this meeting in clinics. They may also agree to mail pre-paid letters to past patients.

- **How can meetings be advertised?**

There are a number of ways in which the group meetings can be advertised:

- Medical professional signposting
- Posters in GP surgeries, in the hospitals, arrhythmia clinics and cardiac rehabilitation centres
- Affiliation with Arrhythmia Alliance – website and helpline signposting to affiliated groups & e-bulletin advertisement
- Free local paper

- **What should the aims and objectives of the group be?**

This should be determined at a launch meeting and members should be invited to have a say about what they want 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.

- **Should the group structure be formal/informal?**

The structure of the group should be dependent upon what the members wish for and what will work for those involved. There is no 'right' or 'wrong', but is dependent on the size and needs of the group.

An informal group has leadership, but all members make decisions and participate in the running of the group.

Formal groups usually elect a committee and write a constitution outlining the aims and objectives of the group. Individuals take on different roles; Chair, Secretary, Treasurer. Such formalities are useful for larger groups.

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- **What should we do at meetings?**

The answer to this lies in the desires and requests of the group members. For those groups that have a more formal structure and that focuses on patient education and information, meetings usually consist of speakers. This can often be a 'hook' to attract members to the meetings.

Some groups meet on a more social basis – perhaps in a local café – and simply chat and share experiences. The emphasis for these groups is often on emotional support.

Other groups have a good mixture, meeting both for informative presentations, technical advice from medical professionals and to socialise.

Fundraising/ Social events (Offer fact sheet on Fundraising etc) could take place and your group can help spread awareness by taking part in Arrhythmia Alliance Awareness Weeks.

- **When should meetings be held? How frequent should they 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 that have a more formal structure meet bi-annually, whereas some informal groups that hold more social activities meet bi-monthly.

- **Who will support the leaders?**

The Arrhythmia Alliance affiliation scheme was developed partly out of a need for more support for those running groups. Having a patient/carer and healthcare professional led group has benefits for both parties as the work can be shared and support given. Through the affiliation scheme, leaders can gain support from the Arrhythmia Alliance and from other affiliated groups.

For more information on the benefits of affiliation for groups, (websites, case studies, Improved local services, information booklets and information on Heart Rhythm Congress) or for further advice on establishing and running a group, please contact the Arrhythmia Alliance on +44 (0)1789 451 823 or email [campaigns@heartrhythmcharity.org.uk](mailto:campaigns@heartrhythmcharity.org.uk)