

Setting up a Support Group

This Infosheet explains what to do if you are thinking about setting up a AL amyloidosis Support Group and how Myeloma UK can help you.

Introduction

Myeloma UK facilitates over 90 Support Groups around the UK; of which around half a dozen are amyloidosis specific. The Groups exist to provide mutual support, friendship, information, advice and a listening ear to all those affected by myeloma, haematological cancers and AL amyloidosis.

Support Groups bring together patients and their families who share a common need for information, support, reassurance and to meet others. Some of the benefits of attending a Support Group can include:

- Feeling less isolated
- Finding reassurance and support from others with similar experiences in their local area

- Learning new information about living with myeloma or AL amyloidosis, its treatment and complications/side-effects
- Feeling empowered and more self-confident to cope with issues relating to living well with myeloma and AL amyloidosis.
- Having the opportunity to help and give support to others

Things to consider

Although setting up a Support Group can be extremely rewarding, it is not without its challenges and may seem a bit daunting, especially if you've never done anything like it before. However, people have successfully established a group and it can be straightforward, especially with the help and support we provide at Myeloma UK.

Is there a need for a Support Group?

To help get a Support Group off to the best possible start, find out which local support and/or services exist in the area. This will help work out what, if anything, is needed in addition to what already exists and what help might be available. Here is a list of people and organisations you can contact to find out more:

- Patients/carers at your local hospital
- Healthcare professionals at the hospital, including your specialist nurse or Macmillan nurse
- GPs and health centres in your local area
- Other established cancer Support Groups
- Macmillan or Maggie's cancer drop-in centres
- Your local PALS (Patient Advice and Liaison Service) at the hospital
- Other voluntary health groups
- Social workers

Other considerations

When you have this information, and are satisfied that there is a need for the group, there are a number of additional points that you should consider before committing to setting up the group:

- Do you want to lead the group as well as setting it up, or do you plan to ask someone else to lead/facilitate/organise the group, or do it jointly? You may decide that you need at least one or two other people

- What experience and skills do you have and what additional training, support and information do you need?
- How much free time do you realistically have to devote to the group?
- Where will the group meet, how often and at what time?
- How much money you will need, if any, to start the group?
- How will you publicise and promote the group?
- How will you get the support of the local doctors and nurses?

Who can be a Support Group Leader?

Anyone with the desire to set up a Support Group can become a Support Group Leader. Current Leaders include:

- Patients
- Family members and friends of patients
- Haematology and clinical nurse specialists
- Cancer volunteers
- Other healthcare professionals

What are the different types of Support Group?

All groups are different and, for the most part, groups reflect the nature and needs of the people in them. Due to the fact that AL amyloidosis is very uncommon, most groups are very small, mainly concentrating on meeting and chatting, to learn from one another and share experiences, hints and tips.

Groups are led by different types of people and have different formats. The four main types are, patient/family/carer-led Support Groups. Healthcare professional-led Support Groups, groups that are co-led by a patient/family/carer and healthcare professional or ones that are set up by a healthcare professional and then handed over to a patient/family/carer or committee to run.

What are the aims of the Support Group?

Thinking about what you want the Support Group to achieve will help to structure meetings and ensure you achieve what you have set out to do. It's very easy to go off-track and end up achieving something you didn't want and/or need to, or even achieving nothing at all.

Also, clearly knowing what you don't want to happen at meetings is very helpful. This will help recognise in the future when meetings are off-track.

Bear in mind though that it may be the original objectives were wrong for the group and achieving something different may actually be better. Write down the aims of the group and then revisit these regularly to make sure they are being met or, if necessary, revised.

A Constitution or not?

Support Groups do not have to be formalised by putting in place a Constitution and many groups choose not to have one. However setting out a Constitution for the group can help you to determine and think about how the group will operate and under what parameters, it can also be useful if approaching organisations for funding.

Where to meet?

Where the group meets will be a balance between finding a venue that best fits the environment you would like for the group, versus what is available and/or affordable. Feedback from existing Support Group Leaders

has highlighted finding a suitable venue as one of the most challenging aspects of starting up a group.

Examples of where current groups meet are:

- Schools
- Church halls
- Community centres
- Town halls
- Hospital departments
- Cancer centres affiliated with the hospital
- Social clubs
- Sports centres
- Rugby/cricket/bowls clubs
- Hotel lobbies, cafes or restaurants

Meeting time and frequency - what is best?

Consider how often people want to get together and what time of the day may suit them. Evenings may suit people working, but some people may not like to go out at night, especially in winter. It is helpful to remember that it is difficult to please everyone.

The frequency of meetings varies from group to group. Some groups meet monthly, others quarterly. Meeting any less or any

more frequently would generally not be recommended due to the commitment required for each meeting. Most meetings tend to be a maximum of two hours in length: any longer or shorter can be ineffective for the group's aims and objectives.

What to discuss?

Treating the first meeting as an informal 'getting to know you' session can help create a relaxed atmosphere, as people may be nervous about attending and meeting new people. One of the most important points to emphasise at the first meeting is confidentiality. People attending Support Groups need to feel they are in a safe and trusting environment. Therefore all members must have a clear understanding of what is expected of them in maintaining confidentiality. Groups vary in size and nature and the rules around confidentiality will reflect this.

Consider putting together an agenda (even a very rough one) to ensure the meeting flows smoothly and to order the items for discussion and review.

Topics to consider in the first meeting are:

- Welcome everyone and state the group's possible aims, objectives and emphasis on confidentiality
- Open discussion by sharing your experiences that led to the interest in forming the group
- Give members the opportunity to introduce themselves and briefly tell their personal story if they wish. Some people may not be comfortable with this and it may take several meetings for them to share openly
- Discuss the name for the group
- Agree a meeting time and frequency that suits the majority and agree the next meeting date
- Dealing with organisational issues such as formation of committee or volunteers to help with the running of the group may be too burdensome for the first meeting but be prepared for members to volunteer their services
- Check the venue is agreeable with the majority of the group members or consider other applicable venues

After meeting for the first time

It is important to collate the details of those who attended. This can be easily done by passing an attendance sheet around during the meeting.

Let everyone know the date of the next meeting and even further ahead if possible so they can put the date(s) in their diaries.

After your first meeting contact Myeloma UK to let us know how the meeting went and future meeting dates on **0131 557 9988** or email **support@myeloma.org.uk**

How Myeloma UK can help

Myeloma UK can help anyone wishing to set up a Support Group by providing them with a number of practical resources and advice over the phone.

We have developed a Support Group Meeting Pack which contains a wealth of information and best practice guides to help Leaders set up, establish and maintain their groups.

We can also produce promotional material to advertise meetings, send out mailings to all those patients/families and friends on our database in the local area and can even attend a meeting to give a talk or facilitate the first meeting.

More information can be obtained by calling **Sara Morgan, Support Group Lead at Myeloma UK** on **01874 731202** or emailing **sara.morgan@myeloma.org.uk**

You can also view a short film on our website which explains how one Support Group Leader went about setting up a Support Group in Bath - **www.myeloma.org.uk/how-we-can-help/meet-others/myeloma-supportgroups/start-a-support-group/**

Although this example is a Myeloma Support Group, there will be many similarities with getting an AL amyloidosis Group started.

Other information available from Myeloma UK

Myeloma UK has a range of Infoguides and Infosheets available covering many areas of AL amyloidosis, its treatment and management.

To order your free copies or to talk to one of our Myeloma Information Specialists about any aspect of AL amyloidosis, call the **Myeloma Infoline: 0800 980 3332** or **1800 937 773** from Ireland.

The Myeloma Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK and Ireland.

Information and support about AL amyloidosis is also available around the clock at [www.myeloma.org.uk /amyloidosis](http://www.myeloma.org.uk/amyloidosis)

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