

Setting up a Support Group

This Infosheet takes you through what to do if you are thinking about setting up an AL amyloidosis Support Group and what help is available to you.

Support Groups can benefit patients, families and carers by providing emotional support, friendship and relief from isolation. They offer the chance to share information and experiences with those in a similar situation.

Myeloma UK is keen to help anyone interested in setting up Support Groups for AL amyloidosis patients,

their families and carers. This Infosheet gives you some basic information about starting a Support Group in your area.

Before you start - fact finding

To help get your Group off to the best possible start you should find out about local services in your area – they may be able to help you.

Ask the following groups about what is already available in terms of support and what the gaps are:

- Patients at your local hospital
- GPs and health centres in your area
- Voluntary health groups
- Charitable groups
- Social workers
- Citizens' advice bureau

Note: Your local library will be able to provide contact telephone numbers for most of the above groups.

Some points to consider:

- Why are you forming a Group?
- Who will your Group attract?
- Where will you meet?
- How often will you meet?
- How much time can you spare?
- What are your aims?
- What will it cost?
- Who will organise the Group?
- Will healthcare professionals be part of the Group?

Note: Time, energy and the help of non-patients may be required to start a Support Group.

Aims and activities of the group

Every Support Group is different and its members will determine its aims, goals and activities.

Many Support Groups invite a variety of guest speakers who will talk about subjects such as coping with side-effects of treatment, or provide an update about the latest AL amyloidosis treatments. Some groups simply provide the opportunity to share stories and experiences.

Other groups may be more active in fundraising and awareness raising or helping to support patient programmes at Myeloma UK.

Making a start

Decide on a venue. A hospital lounge, school, community hall or hotel bar are all possibilities. Some Support Groups exist from a supporter's home. Phone round to decide a convenient time to meet, ask someone to bring refreshments if needed and decide upon the Group's agenda and dates for future meetings.

Remember, it doesn't matter how few people there are at the first meeting, the most important thing is to make a start.

General points to consider when running a Support Group

- Elect a leader
- Start slowly e.g. bi-monthly or quarterly meetings
- Get to know each other
- Advertise your Group
- Share tasks
- Be flexible about times and venue
- Have an agenda/topic for each meeting
- Utilise members' skills
- Support members during treatment times
- Share your experiences
- Welcome newcomers
- Meet your members' needs
- Re-assess the Group's aims on a regular basis
- Stay in touch with Myeloma UK

What help is available to you

Myeloma UK can be a useful reference point and be helpful in setting up Groups. We can raise awareness of the Group, supply information and report about progress made. Myeloma UK staff can also come along to a meeting to offer support and give an update on AL amyloidosis and Myeloma UK activities.

Details of AL amyloidosis Support Groups are sent out to those who enquire, and are listed on the Internet via our website. We can also supply flyers to advertise your meetings in health centres, hospitals and libraries etc.

As a new Support Group Leader there is a pack available by request. This pack has been developed by Myeloma UK in consultation with a small group of Myeloma Support Group Leaders. It outlines key advice on setting up a Support Group and provides useful suggestions and practical examples of how groups have applied some of the best practice recommendations.

If you want to request a pack or need help at any time with any aspect of your Support Group please do not hesitate to contact **sara.morgan@myeloma.org.uk** or on **0131 557 3332** or contact the **Myeloma Infoline on 0800 980 3332**.

Myeloma UK hopes that this information has been of help to you and we wish you every success with the setting up of your Group.

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your medical team. They are the people to ask if you have questions about your individual situation. All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

Other information available from Myeloma UK

Myeloma UK provides a wide range of information covering all aspects of the treatment and management of AL amyloidosis.

For a full publication list visit www.myeloma.org.uk/publications

To order your free copies contact Myeloma UK. Our information is also available to download at www.myeloma.org.uk

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

Information and support about AL amyloidosis is also available around the clock at www.myeloma.org.uk/amyloidosis

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