

Setting up a Support Group

Introduction

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 myeloma patients, their families and carers. This Infosheet gives you some basic information about starting a Myeloma 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 you area – they may be able to help you.

Ask the following about what is already available and what is needed:

- Patients at your local hospital
- GPs and health centres in your area
- Established cancer support groups
- Macmillan cancer drop-in centres
- 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 health 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.

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Many Support Groups invite a variety of guest speakers who will talk about subjects such as fatigue and how to cope with it or provide an update about the latest myeloma treatments. Some groups simply provide the opportunity to share stories and experiences.

Practical help such as private hospital transport and home visits might be organised. Other groups may be more active in fundraising, awareness raising or to help 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. Many 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. monthly or bi-monthly 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 member's skills
- Support members during treatment times
- Share your experiences
- Welcome newcomers
- Meet your member's needs
- Re-assess the groups' aims on a regular basis
- Stay in touch with Myeloma UK
- Above all please enjoy your meetings

What help is available to you

Myeloma UK can be a useful reference point and be helpful in starting 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 myeloma and Myeloma UK activities. Details of Myeloma 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 pack for Support Group Leaders 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 starting 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 for Support Group Leaders or need help at any time with any aspect of your Support Group please do not hesitate to contact rebecca@myeloma.org.uk or on 0131 557 3332 or 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's publications are extensively reviewed by patients and healthcare professionals prior to publication.

Other information available from Myeloma UK

Myeloma UK has a range of Essential Guides, Infoguides and Infosheets available, covering many areas of myeloma, its treatment and management. To order your free copies, contact the **Myeloma Infoline** on **0800 980 3332**. This information is also available 24/7 on our website at www.myeloma.org.uk

If you would like to talk to someone about any aspect of myeloma, its treatment and management, call the **Myeloma Infoline** on **0800 980 3332**. Your call will be answered by Myeloma Nurse Specialists who are supported by medical and scientific advisors. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK. From outside the UK, call +44 131 557 3332 (charged at normal rate).

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