

How to Start a Multiple Myeloma Patient Group – A Practical Guide

Introduction:

Unfortunately if you have decided to read this guide, you or someone you love has been diagnosed with multiple myeloma (MULTIPLE MYELOMA). This is a difficult time for you and your loved ones. However, those affected by this disease will gain hope and inspiration from your interest in considering creating an organization that will provide comfort, support and a source of strength in a time of need.

Multiple myeloma is a big challenge for everyone involved – patients, families, and friends. However, with appropriate testing and review, a clear diagnosis can be established; patients without symptoms can be monitored without aggressive treatment; patients with symptoms can try therapies with high likelihood of controlling the disease for many years; and new therapies can be considered which may offer the opportunity for longer disease control or even a cure.

Emotional and social support for people living with multiple myeloma is as important as medical care. Patients, their families, friends and caregivers can learn to better manage their cancer experience by increasing their familiarity with the disease, gaining a positive attitude, and developing coping skills. Support can come from family and friends as well as health professionals, support groups, or your place of worship.

Asking for support is one way to take control of the situation. If you can't find a support group in your area, perhaps you can consider starting one. We offer you this guide with our hope that it provides you the information you need to decide whether starting a support group is for you. The community of support you create and grow can help all that participate learn to work through their feelings of fear and frustration and to ultimately live life more fully.

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Purpose of this guide

This guide is intended to help you take the first steps if you are considering starting a support group for those living with multiple myeloma and their caregivers. Because the needs and goals of patient groups vary and the environment varies from country to country, this manual intends to give you some general information to help you decide whether you want to set up such an organization. It also provides some pointers that will help ensure your success.

Why form a support group?

Living with cancer is difficult whether you are the patient or caregiver. Everyone involved needs and deserves all the help they can get to still enjoy a full life. Patient support groups offer people facing multiple myeloma many benefits, such as:

- The ability to meet others in similar circumstances
- The opportunity to share methods of coping and adjusting
- The chance to develop new personal relationships at a time of potential isolation
- A place to share information about treatment options
- Opportunities for solving problems in dealing with the health care system
- Improvement of mood and quality of life

What kind of support group should I form?

Support groups exist for all types of diseases and all forms of cancer. Groups offer mutual support and share what they've learned with others whose share the same diagnosis and experiences.

Some groups meet for just a certain number of weeks and others form an ongoing programme. Some programmes have closed membership and others are open to new, drop-in members. Health professionals may participate regularly in group discussions or may be invited as guest speakers.

Groups may be formal and focus on learning about cancer, or they may be informal and social. Some groups are composed only of people with cancer and some include caregivers, spouses, family members, or friends. There is no right or wrong way to start a patient group, so your group can share in the design and change it along the way.

Where can I find other members?

You may feel that starting a patient support group is too much to take on with all your other responsibilities, or you may feel intimidated by the idea of doing something new. That's OK. You don't have to do it alone. The good news is there are plenty of resources and people to assist you along the way.

Start by finding out about local services in your area that may make the process easier for you. There are resources with information about starting a patient group. Also, there are people to introduce you to other patients interested in starting or joining a group, direct you to information

on treatment options, give you insights on fundraising, share meeting space with you, share techniques on coping with loss and serve as meeting guest speakers.

To find others to start a group, consider putting together a simple flyer that includes location of the meeting and the time; who is invited to attend; the purpose of the meeting and a contact name and telephone number to answer questions. Also, conduct research on the Internet or visit your local library for information. There are numerous ideas out there and just as many people willing to share them with you.

Contact suggestions:

- Patients at your local hospital
- General practitioners and health centres in your area
- Established cancer support groups
- Health education units
- Voluntary health groups
- Charitable groups
- Social workers
- Citizens' advice bureau

What should we do first?

First, hold a meeting with the other interested people you have found. Who you invite will depend on the type of group you plan to set up, and likely will include patients and their caregivers. They will be people who share your commitment to making things better for people affected by multiple myeloma.

What kind of group is best for us?

At your first meeting all the participants can brainstorm what they hope to gain from the meetings. Let the mood of the group determine how best to move forward. No two multiple myeloma support groups will be the same and that's a good thing. Not everyone has the same needs or same level of commitment. As a group you can decide what will best for you.

Some groups simply give patients and their caregivers the opportunity to share their stories and experiences. Others offer practical help such as transport to doctors' offices and hospitals. Other groups may be more active in fund raising for more research or to help support patient programmes. And still others might simply be a place to "escape" to where you do not feel the need to explain what you are going through because everyone there understands.

How should we run our meetings?

Your group may have an official format or you may decide to keep things very informal and let the mood of the participants drive the format. Either way, a few simple tips will help you run a patient group successfully. Make sure you encourage everyone to play a role, use your meeting time wisely, show mutual respect for all involved, and, most importantly, enjoy each other's company.

Following are several key things to consider:

- Elect a leader or co-leader who will be responsible for running each meeting, but be sure to share tasks and include all group members to take on revolving responsibilities. Invite members to use their skills – ask bakers to provide snacks, aspiring writers to create a newsletter.
- Start slowly, e.g. monthly meetings will build momentum without too much time demand.
- Introduce each person and share information about your diagnosis and treatment, family and loved ones, and details on hobbies/interests
- Prepare an agenda for each meeting that includes topics to encourage attendance, allows participants to prepare in advance, and stays focused to ensure the best use of the time.
- Share your experiences. A knowledgeable patient is a powerful partner in their treatment.
- Welcome newcomers. Encourage existing members to share about their treatment before asking newcomers to share theirs; offer words of encouragement to make them feel comfortable in a new setting; remind yourself what it was like when you were the new person.
- Set an inviting mood by arranging the chairs to foster conversation; providing refreshments and perhaps playing soft music.
- Re-assess the group's aims on a regular basis as new members join, leave or needs change.
- Above all, please enjoy your meetings! Have fun. Celebrate life. Enjoy the comfort of emotional and social encouragement from friends and loved ones.

What is the role of caregivers in the group?

Caregivers need care, too. Research shows that caregivers who have participated in support groups feel more confident and informed in their roles. So it is important that family and friends, especially the caregivers, feel equal ownership of the group. Many support group leaders find that the most successful support groups involve the full circle of people affected by the disease. Remember, the multiple myeloma caregiver is an individual who has a personal connection and commitment to someone with cancer and provides care outside of a medical or hospital setting. This busy schedule often does not leave time for the caregiver to take care of themselves, so the support group is time for them, too.

What sorts of special activities can we do?

Sometimes it helps to bring new people and ideas into the group to keep it interesting for everybody. Here are a few ideas to consider:

Stimulate conversation

Consider these questions to encourage discussion:

- How long have you been living with myeloma?

- What was your reaction when you were first diagnosed?
- Where did you turn to for information on the disease?
- How do you stay optimistic?
- Have your family/friends sought out support?
- Has anyone tried (insert treatment option)? What was the outcome?

Encourage other interests

At some meetings you may want to have people share details of their interests outside of their life with cancer. Perhaps they can share photos of a new grandchild, a special trip they took, a new book they have read and so forth.

Invite guest speakers

Consider the following guests:

- Social worker -- provide insights on services offered in the community for completing insurance forms (contact local hospital or cancer clinic)
- Dance/yoga instructor – the benefits of dance for pain relief, expression, stress reduction
- Physical therapist -- advice on relaxation or pain relief techniques (contact local hospital or rehabilitation facility)
- Physician – overview of disease (contact local doctor offices)
- Nutritionist – guidance on healthy foods (contact local hospital)
- Clinical researcher – details on clinical trails (contact local cancer research centre)
- Spiritual leader – benefits of spirituality (contact local church or house of worship)

How can we keep the group going?

Everyone has many appointments and responsibilities so it may be difficult for members to remember the next meeting or stay involved. Here are a few ways to keep people connected.

Phone calls

Create a phone tree to remind members about the time and location of the next meeting, stay up to date on the status of treatment, and life in general so you can report back to the group on the well being of any absent members.

Newsletters

You may want to consider a group newsletter with member updates and other information depending on the type of group you have.

Membership lists

Consider creating membership lists with names, addresses, phone numbers, and e-mail addresses.

How should we cope with loss?

One of the hardest tasks for members of a patient support group is saying goodbye to a partner or friend who dies. In an odd way, grief is actually helpful to the human spirit; it makes us notice that something that was important to us is now gone. It is normal to feel overwhelmed, and good to express your feelings.

The Grieving Process

There are four stages of grief that occur during the grieving process. They will vary in intensity.

1. Shock and numbness: Distress and anger, impaired judgment and concentration and feelings of panic are typical of this stage.
2. Yearning and searching: Feelings of restlessness, impatience and uncertainty occur at this stage.
3. Disorientation and disorganization: Feelings of depression and guilt surface. The person may lose their appetite, sleep poorly and have a lack of interest in doing anything.
4. Resolution and reorganization: This stage is marked by feelings of being more in control, with more energy to cope and make effective decisions.

There are small ways the group can help nurture members during low spots. One of the purposes of the group is to support you. Remember, though, if the healing process becomes too overwhelming, seek professional help.

Joining a national organization

Your group may eventually want to consider becoming a member of one of the national or international multiple myeloma organizations. This will give you an excellent opportunity to learn from other support groups and to see the range of activities available from different organizations. It will also expand the number of people you know who face the same challenges that you do and who share the same aspiration of making things better for people affected by multiple myeloma.

List of European multiple myeloma organizations

If your country is not included in this list, this does not necessarily mean that there are no multiple myeloma/plasmacytoma/Morbus Kahler patient organizations in your country. Please also check the list of patient organizations in the 'Links' section of the Myeloma Euronet website at <http://www.myeloma-euronet.org/>.

Austria

- Myelom Kontakt Österreich
c/o Elke Weichenberger
Josef Mayburgerkai 54
A-5020 Salzburg
Tel.: +43 (0) 664 / 4250161
info@myelom.at
<http://www.myelom.at/>

- Selbsthilfe Plasmozytom-Multiples Myelom Österreich
Ilse Hein
Bürglsteinstrasse 21/10
A-5020 Salzburg
Tel.: +43 (0) 662 / 845151
i.hein.mmshg@aon.at
<http://www.myelom-selbsthilfe.org/>

Belgium

- Contactgroep Multipel Myeloom Patienten
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Zonneweeldelaan 23 bus 32
B-3600 Genk
Tel: +32 / (0)89 / 35 43 66
Mobil: +32 / (0)494 / 59 49 57
E-Mail: jcreemers@belgacom.net
<http://www.cmp-vlaanderen.be/>
- Wildgroei vzw
Luigi Chirillo
Musstraat 9
B-3530 Houthalen
Tel.: +32 89/38 09 80
luigi.chirillo@pandora.be
<http://www.wildgroei-vzw.be/>

Denmark

- Dansk Myelomatose Forening
Arne Hansen
Torupvej 25, Hedensted,
DK-8722 Kopenhagen
Tel.: +45 75-892298

Germany

- Deutsche Leukämie- & Lymphom-Hilfe e. V.
Thomas-Mann-Straße 40
D-53111 Bonn
Tel.: +49 228 33 88 9 200
info@leukaemie-hilfe.de
<http://www.leukaemie-hilfe.de>
(Website includes a comprehensive list of self-help groups in Germany for leukaemia, lymphoma, multiple myeloma/plasmacytoma and other diseases of the blood and lymphatic system:
http://www.leukaemie-hilfe.de/SHI/SHI_BRD.html)
- Arbeitsgemeinschaft der deutschsprachigen Plasmozytom/Multiples Myelom-Selbsthilfegruppen (APMM)
Contact via
Weichenberger, Elke
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sprecherteam@myelom.org
Reimann, Brigitte
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D-67433 Neustadt an der Weinstraße

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 Zonneweeldelaan nr. 23 bus 32
 B-3600 Genk
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sprecherteam@myelom.org
<http://www.myelom.org/>
 (Website includes a comprehensive list of self-help groups for multiple myeloma/plasmacytoma in Germany, Austria, Belgium and the German-speaking part of Switzerland:
<http://www.myelom.org/unterseiten/adressen.html>)

Italy

- Associazione Italiana contro le Leucemie-linfomi e mieloma ONLUS
 Via Ravenna, 34
 I-00161 Roma
 Tel.: +39 06 4403763
ail@ail.it
<http://www.ail.it/>

Netherlands

- Contactgroep Kahler en Waldenström Patiënten
 Secretariaat CKP
 Landheer 65
 NL-3171 DC Poortugaal
 Tel.: +31 (0) 79 - 361 81 58
ckp@kabelfoon.nl
<http://www.kahler.nl/>

Sweden

- Blodcancerförbundet
 Sturegatan 4, 5 tr
 S-17227 Sundbyberg
 Tel.: +46 (0) 8/54640540
info@blodcancerforbundet.se
<http://www.blodcancerforbundet.se/>

Switzerland

- Stiftung zur Förderung der Knochenmarktransplantation Schweiz
 Candy Heberlein
 Vorder Rainholzstr. 3
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or

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- Myeloma UK
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myelomauk@myeloma.org.uk
<http://www.myeloma.org.uk/>

How Myeloma Euronet can support you

Myeloma Euronet can be a useful reference point if there is no national organization in your country. It can be helpful in starting groups and offer information to help you grow. Details on support groups are included in their information packs. They also can advertise your group in their newsletter and on the Internet via their website (www.myeloma-euronet.org), and supply you with a flyer to advertise your meetings in health centres, hospitals and libraries etc.

Where can I learn more?

If you decide to start a group, a more detailed manual is available upon your request. You can also find it on the Myeloma Euronet website at www.myeloma-euronet.org. It will give you help on:

- Choosing a leader
- Roles and responsibilities of a leader
- Controlling the meeting
- Giving your organization a name
- Finances
- Meeting space
- Sample letters; flyers; newsletters